Quality of perinatal care in a multi-ethnic population

© Marianne Alderliesten, Amsterdam 2006
Quality of perinatal care in a multi-ethnic population
PhD thesis; University of Amsterdam – with references – with summary in Dutch

ISBN-10: 90-9020461-X
ISBN-13: 978-90-9020461-1

Keywords: perinatal care, perinatal mortality, perinatal audit, Magnetic Resonance Imaging, ethnicity

Studies published in this thesis were financially supported by a grant from the Health Insurance Fund of the city of Amsterdam, Zon MW, Amsterdam City Counsil, Health Service Amsterdam, Academic Medical Centre, Nutricia Research B.V.

Quality of perinatal care in a multi-ethnic population

Academisch proefschrift

ter verkrijging van de graad van doctor

aan de Universiteit van Amsterdam

op gezag van de Rector Magnificus

Prof. mr. P.F. van der Heijden

ten overstaan van een door het college voor promoties ingestelde

commissie, in het openbaar te verdedigen in de Aula der Universiteit

op

donderdag 20 april 2006, te 14.00 uur

door

Marianne Elisabeth Alderliesten

geboren te Borsele

Promotiecommissie

Promotores:
Prof. dr. O.P. Bleker
Prof. dr. G.J. Bonsel

Co-promotores:
Dr. K. Stronks
Dr. J.M.M. van Lith

Overige leden:
Prof. dr. P.J.E. Bindels
Dr. M. Eskes
Prof. dr. J.G. Nijhuis
Prof. dr. M. Offringa
Prof. dr. E.A.P. Steegers
Prof. dr. J. Stoker

Faculteit der Geneeskunde
This thesis was prepared at the department of Obstetrics/Gynaecology and Public Health, Academic Medical Centre, University of Amsterdam
Meibergdreef 9, H4-205 | 1105 AZ Amsterdam | the Netherlands

( ) *Eris* liet uit haar mouw een glanzend voorwerp glijden en dat rolde over de vloer. Het was een appel, waarop drie fijnbeschreven maar duidelijk te lezen woorden stonden: **voor de mooiste**
Drie godinnen eisten de appel op: *Hera*, de vrouw van Zeus;
Athene, de moederloze dochter van Zeus, geboren uit zijn schedel met het harnas al aan en de speer in de hand en *Afrodite*, de godin van de liefde.
Zeus besliste dat de appel zou worden uitgereikt door een mens, een jonge, onbevooroordeelde onbedorven herder van goede afkomst. Deze herdersjongen die Zeus op het oog had leefde in de Trojaanse bergen en luisterde naar de naam Paris.
Paris wist niet wat hem overkwam toen hij de drie hemelse wezens onder ogen kreeg en hoorde wat er van hem verwacht werd. Hij keek van de ene wondermooie verschijning naar de andere en besefte dat hij voor een zeer moeilijke opgave stond.

(naar: Ilios, Homeros, vertaling Imme Dros)

Et le petit prince revint vers le renard:

- Adieu, dit-il.....
- Adieu, dit le renard. Voici mon secret. Il est très simple: on ne voit bien qu'avec le coeur. L'essentiel est invisible pour les yeux.
- L'essentiel est invisible pour les yeux, répéta le petit prince, afin de se souvenir.
- C'est le temps que tu as perdu pour ta rose qui fait ta rose si importante.
- C'est le temps que j'ai perdu pour ma rose..... fit le petit prince, afin de se souvenir.
- Les hommes ont oublié cette vérité, dit le renard. Mais tu ne dois pas l'oublier. Tu deviens responsable de ta rose.....
- Je suis responsable de ma rose.....répéta le petit prince, afin de se souvenir.

(uit: Le Petit Prince, Antoine de Saint-Exupéry)

voor mijn kinderen

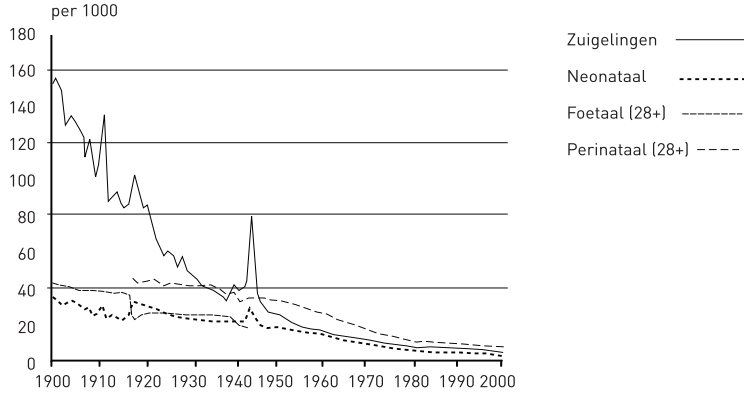
Contents

1

General Introduction

Perinatal mortality

Perinatal mortality, including stillbirths and neonatal deaths, continues to occupy the minds of both policy makers and researchers.[1-5] Since the beginning of the last century, the perinatal mortality rate in the Netherlands declined sharply until 1940. After the Second World War, in 1945, it continued to steadily decline until the eighties, when the downward trend stagnated. After 1990 however, it declined again (see figure 1). [6-8]



The decline of perinatal mortality in the past decades can be explained by a number of factors including improved health status in the general population, the impact of several important medical-technical developments such as the elimination of rhesus antagonism as a major cause of perinatal death, the dissemination and further development of neonatal care in early preterm deliveries,[8] and by improvements in specific other aspects of perinatal care[9].

Any discussion about perinatal mortality in the Netherlands has to take place within the context of the Dutch Perinatal Mortality Rate in comparison to other European countries. In 1980, the Netherlands had one of the lowest perinatal mortality figures in Europe. Currently, the Netherlands has lost its prominent position in the international ranking of countries with favourable perinatal mortality rates.[3] Several factors play a role. The definition of perinatal mortality differs between European countries, making comparisons between countries difficult. Other explanations include an increase of known risk factors on the perinatal mortality rate in the Netherlands, e.g. age of the mother, twin pregnancy rate, and an increase in births among ethnic minority groups.[6]

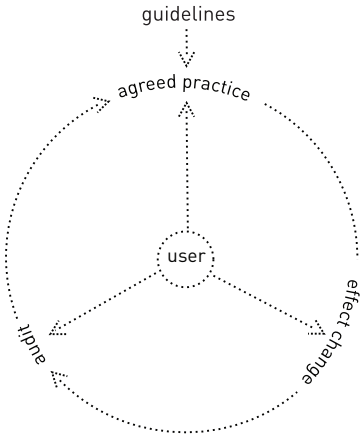
Furthermore, the absence of a standard ultrasound anomaly scan is related to a higher number of undetected congenital anomalies.[10,1,3] Even now, where the Netherlands has a perinatal mortality rate as low as 7 per 1000 births, (> 28 weeks)[11] further improvement of perinatal care with subsequent decrease of this rate should be a target, given levels of perinatal mortality elsewhere. Perinatal mortality is only one of a set of related indicators of the quality of perinatal care. Others are, for example, mode of delivery, the number of preterm births and the timing of the firsts antenatal visit.[12] It can be assumed however, that improvement of perinatal care to decrease perinatal mortality also benefits in terms of other perinatal indicators. This thesis aims to contribute to this improvement. Below, we first describe an important tool that can elicit care factors contributing to perinatal mortality, in particular those associated with care, i.e. the perinatal audit. This may be viewed as the counterpart of epidemiological analysis. While a perinatal audit can often provide a final judgement on the causal pathway in the individual case, it is vulnerable in missing patterns of weaker, yet prevalent factors. Second, we elaborate further on the concept of cause and cause attribution. Standard analysis of causes of death requires both adequate information tools (e.g. post mortem data, lab tests, etc), but also adequate concepts and classifications. Finally we explore ethnicity-related differences in both perinatal mortality as well as accessibility of antenatal care. The role of ethnicity as a general explanatory factor is undisputed, but its specific role may be difficult to determine in particular in the individual case. We describe the possible contribution of ethnicity, and the analytical strategy used to explore whether ethnicity has a role in perinatal mortality, and whether this role can be explained by the existence of specific determinants. The establishment of underlying factors is a key to the development of intervention strategies for example by shedding light on whether risk factors rather than a risk group approach is justified.

Perinatal audit

Measuring the quality of perinatal care is difficult. An important and accepted method of studying the role of perinatal care in perinatal death is the perinatal audit.[13,14] A perinatal audit is defined as 'the systematic, critical analysis of the quality of perinatal care, including the procedures used for diagnosis and treatment, the use of resources and the resultant outcome and quality of life for women and their babies'.[14] An audit may –not necessary- have its starting point in the investigation of perinatal death. The concept of (perinatal) audit requires some elaboration. Audit has a central position in the process of developing and implementing guidelines in healthcare.[15,16] An audit can be applied at every desired level of the care organisation, nationally down to each individual hospital or care provider. Every level will require dedicated

strategies for data collection, judgment and implementations of findings. Regardless the level at stake, involvement of the involved care provider is thereby essential. At any level, an audit will use regional/national/international guidelines as reference and will hopefully contribute to their development and improvement. Subjects that can be included in the audit for example, can be a specific outcome or the complication rate of a standardized surgical procedure. Another starting point can be a specific guideline, or even the emergence of a new intervention which requires systematic evaluation. The resulting information can elicit a review of the guideline, thereby establishing a circle, or impetus for quality improvement (figure 2) [15,16]

Figure 2 Audit circle



A perinatal audit is an example of an 'adverse event' or 'critical incident' audit[17]. Such a perinatal audit does not evaluate one guideline or the application of a specific intervention, and goes beyond a simple complication registry. A perinatal audit should evaluate the presence of conditions and the chain of events that precede a perinatal death, and reviews among the many potential factors specifically whether during the process some aspects of care could be considered 'substandard'. Substandard care is hereby defined as a situation where perinatal care does not meet the defined minimally accepted standards. All the terms used require operational definition, which will be done below. One must be aware that the extent to which trespassing guidelines explains the incidence of perinatal mortality, still needs judgment.
Perinatal audits have been performed at many different levels. Since 1993, the Confidential Enquiries into Stillbirths and Death in Infancy (CESDI) in the UK have been implemented nationwide implying that every year a different sample of all perinatal deaths is reviewed [18,19]
In Scandinavia, perinatal audits have also been performed both

nationwide,[20] restricted to specific regions [21] or research areas.[22] In the Netherlands, several perinatal audits have been performed in a research setting. Where levels of "avoidablity" were the accepted terms to define the degree to which perinatal care failed in preventing a perinatal death in the early perinatal audits,[23,24] this was gradually replaced by the term 'substandard care' in the more recent audits. This emphasized the fact that improvement of perinatal care is at stake rather than a legal judgment of actions taken by an individual hospital or care provider.[25-27] These audits all differ in many ways, but there is one aspect that is common to all the audits mentioned above, i.e. the members of the audit committee do not work in the region where the perinatal deaths originate. Reasons for this are not always made explicit, but most likely, independence is the major concern. Unwillingness of regional care providers to provide information and biased judgment both to the advantage or disadvantage might be the result. However, a regional, or internal audit, so far has not been investigated in a systematic way. As mentioned earlier, the concept of audit has a central position in the process of developing and implementing guidelines in healthcare. Recently, the first results of a nationwide pilot for a Dutch perinatal audit (LPAS) were presented,[5] with the intention that it be implemented in the coming years.[28] This emerging audit actualises the discussion on the best format of such an audit, which should be assessed taking the implementation of quality improvement into account. A recent Cochrane review investigated the merit of perinatal audits, however the reviews reported that no studies were available, on which to base an optimal format.[17] In this thesis we present the design and results of a regional perinatal audit in the city of Amsterdam. These results can be regarded as one of the (urban) pilot studies of a national approach.

Cause of death

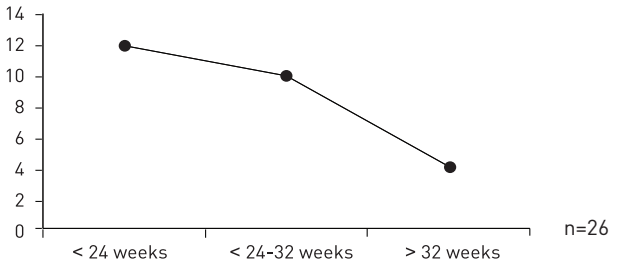
To establish whether substandard care was present in a particular case of perinatal death, at least two requirements have to be satisfied: an adequate classification of (partial) causes, which in turn depends on some etiological model, and an appropriate measurement of the presence of such causes. The two are interrelated: if the etiological model offers space for maternal factors and for care provider factors, then the classification system and the measurement procedures directly or indirectly should be able to cover these factors. Here we expand on these two requirements starting with the etiological model and the associated classification of causes of death.

Gradually the 19th century simple monocausal infectious disease model has been replaced by a non-hierarchical multicausal model, which accepts causal contributions from the mother (genetic, physiological), child (genetic, physiological) and external physical and biological conditions. Classification of death is known to be difficult at the end of life, where there is multiple morbidity. This is also true at the beginning of life

where there is often no clue as to the cause of death, or where several mild risk factors exist, leaving the question to be answered why death occurred in this particular case. The current International Classification of Diseases is unsuitable to address perinatal death.[7] This is especially the case if the aim is evidence-based improvement of the perinatal death rate based on an etiological analysis that distinguishes between factors that are amenable for intervention and those that are not. Many different classification systems for classifying perinatal deaths exist. Classifying causes of perinatal death may bring to light differences, in the occurrence of causes of death. The division of perinatal deaths in a cause of death classification has a long history, starting in 1954 with the Aberdeen Clinicopathological Clasification by Baird et al.[29] Since then, thirty classification systems have been introduced. Until now, there is no international agreement on the use of one or more classification system. The Confidential Enquiries into Stillbirths and Death in Infancy[18] have a long experience in the use of three classification systems, the Extended Wigglesworth,[30] the fetal and infant classification[31] and the modified Aberdeen classification.[29] In the PARIS study we adopted these three classification systems, conform CESDI-protocol.
The presence of an adequate etiological model, classification system and methods to establish the presence of such causes, is a necessary, but not a sufficient condition, for perinatal audit. It is also important to have documentation on conditions (e.g. the care provided, living and work conditions) and biological material available to fulfil the requirements of the classification. One of the building blocks is information from the autopsy on the child.[32,33] A careful and thorough post mortem analysis often rules out many causal factors, frequently establishes one or more risk factors, and thereby (if combined with contextual information), offers sufficient evidence to establish the presence of substandard care. Establishing the cause of death is important on a macro level to observe cause of death patterns in a population, and also individually for the counselling of parents in the coping process as well as in taking decisions in regard to future pregnancies.[34] Surprisingly, as many as 40% of all perinatal deaths are not submitted for autopsy.[32,35,36]

The reason for this is largely unknown. Landers et al identified the parents' socio-economic status and the clinical diagnosis as factors related to consent to neonatal autopsy in 33 cases.[37] We investigated the consent rate to autopsy, in relation to gestational age. This showed that parents were more likely to consent to autopsy, when a perinatal death occurred at a younger gestational age (figure 3, unpublished work).

Figure 3



In view of the high refusal rate, alternative methods of investigation have been explored. A less invasive investigation was considered to be more acceptable for parents, and could hopefully also provide results, comparable to those elicited at an autopsy. One example is Magnetic Resonance Imaging. The first experiences with MRI being used as an alternative to autopsies were reported in the nineties.[38-42] Due to the choice of population in the last two studies mentioned, (i.e. terminated pregnancies for congenital malformations (Woodward) or fetuses recruited from the pathology unit (Brookes)), a very high rate of malformations was found at autopsy in these studies. The value of MRI as an alternative to autopsy however, could not be estimated. In this thesis we investigated the concordance of post-mortem perinatal MRI with autopsy findings in a unselected obstetric population.

Ethnic related differences in perinatal care

Ethnicity-related perinatal mortality differences have attracted much attention over the past years,[43-46] as well as ethnicity related differences in health care accessibility in general.[47] In most European countries perinatal mortality is reported as being higher among ethnic minorities and immigrants than among the native population, in registries as well as in specific studies.[43,45,46,48,49] Moreover, several determinants of perinatal mortality, e.g. maternal age, parity, obstetrical history, maternal education, are known to be related to ethnic background.[45,50,51] Though often put forward as a potential explanation,[52] little is known about the systematic role of antenatal and perinatal substandard care in explaining ethnicity related differences in perinatal mortality. E.g., a Swedish study suggested that substandard care was an important indicator for the higher perinatal mortality among East-African women when compared to native Swedish mothers.[22]

When we focus on ethnic related differences in perinatal mortality and in particular if we compare countries, classification of ethnicity is important, as well as the technical definiton of perinatal mortality. Moreover, there is a known difference between the gestational age at which a perinatal death occurs between ethnic groups.[43]

The definition of ethnicity has changed over the years. Where formerly ethnicity was based on several biological characteristics (Caucasian,

Creoles), this was recently replaced by a registration based on the country of birth of the mother.[53]
As mentioned earlier, the registration of perinatal mortality differs widely between European countries. In the Netherlands, since July 1991, all stillbirths and live births from 24 weeks onwards and children who died within 7 days post-natally are included in the national perinatal death figures and recorded by the Central Statistics Office. The National Obstetric Register reports perinatal death from 16 weeks onward until 7 days after delivery. The WHO-definition of perinatal mortality, according to the 10th revision of the International Classification of Diseases however, defines perinatal mortality as the period commencing at 22 completed weeks of gestation and ending within 7 days post-natally.[54] Many countries, the Netherlands included, use different definitions from the WHO recommendations, which of course has a substantial impact on the published perinatal mortality rates (note that mortality rates decrease during pregnancy which causes considerable effect of a change from e.g. 24 to 23 weeks as lower pregnancy duration limit).
In an important study on ethnic related differences in perinatal mortality in the Netherlands, based on information from the National Obstetric Registry, large differences between the ethnic groups were found between 16 and 24 weeks of gestation (based on the biological definition of ethnicity).[43] Moreover, one might argue that a seven-day limit in neonatal death registration should be replaced with a 28 day threshold, given the rapid improvements in neonatal care in the past years.[7] Moreover, it can be anticipated that care differences during pregnancy and delivery affect the mortality rate beyond seven days. We investigated differences in the perinatal mortality rate between ethnic groups in the city of Amsterdam, defining perinatal death as a fetal death at 16 weeks of gestation until a neonatal death, 28 days after delivery. Moreover, we have used the above-mentioned procedure of perinatal audit to estimate differences in the presence of substandard care factors between the ethnic groups in the city of Amsterdam.

Apart from differences in accessibility to health care in general between ethnic groups, ethnic differences also exist in accessibility of antenatal care [55;56]. Since the use of antenatal care, assessed by means of number of antenatal visits or start date of antenatal care is commonly associated with adverse fetal and maternal outcome of pregnancy, the relationship between ethnicity and the start of antenatal care is important.[9,57-59]
Several other determinants are known to influence a delay on start of antenatal care. Maternal factors related to a late start of antenatal care include a young age,[60,56,61] low level of education,[62,63] unwanted[64] and/or unplanned pregnancy,[61,65,66], poor language proficiency in English,[67] high parity,[55-61] and a high obstetric risk.[55] In this thesis we describe existing differential timing of the first antenatal visit that exists between different ethnic groups. Furthermore, we have explored the contribution of several non-economic determinants, both related and unrelated to ethnicity.

Aim of the thesis

The aim of the present thesis is to address the following questions:

1a What is the feasibility of a regional perinatal audit according to the PARIS -team and the audit members? Can the design and the resulting prevalence of substandard care be compared to that of other, existing perinatal audits?
1b If substandard care is present, in what component and in what level of perinatal care is it located (this includes the possible contribution of the mother)?

2 What is the concordance of post-mortem perinatal Magnetic Resonance Imaging (MRI) with autopsy findings in a non-selected obstetric population? How is the acceptance of MRI, compared to autopsy and how is it implemented in routine obstetric practice?

3a Are ethnic related differences present in the frequency of substandard care in cases of perinatal mortality?
3b Is there a existing differential timing of the first antenatal visit according to ethnicity, which could represent a specific cause of ethnic related substandard care? If so, what is the contribution of known non-economic determinants?

Outline of the thesis

Chapter 2 describes the experiences with the design of a regional perinatal audit in the city of Amsterdam, the Netherlands, including a description of the experiences of the audit members themselves. A random selection of perinatal death cases, reviewed by the regional audit committee, is reviewed by an external audit committee. The design and outcome of the Amsterdam perinatal audit is compared with other perinatal audits. Experiences among audit members are recorded by survey research.

Chapter 3 shows the results of the Amsterdam perinatal audit. Consecutive perinatal death cases are reviewed to establish the cause of death and the presence of substandard care using a standardized procedure. The main outcome measures are the cause of death, classified by the extended Wigglesworth classification and the presence of substandard care (unlikely, possibly, or likely to be related to perinatal death). The secondary outcome measures are the component of care considered to be substandard (detection, therapy, logistics or communication), and the responsible actor (midwife, obstetrician, paediatrician and mother).

Chapter 4 examines the concordance of post-mortem perinatal Magnetic Resonance Imaging (MRI) and autopsy findings in a non-selected obstetric population, and studies MRI with regard to its acceptance and implementation in routine obstetric practice. A consecutive cohort of perinatal deaths in a large teaching hospital is studied. MRI is performed prior to autopsy after full parental consent. Agreement between MRI and autopsy is calculated. The consent rate for both examinations was recorded separately, as well as the time between perinatal death and the MRI.

Chapter 5 compares the perinatal mortality rates between different ethnic groups, and explores their background. Perinatal care is evaluated by an audit procedure to elicit the role of care inadequacies as causal factors including the possible involvement of the mother. The cause of death is classified using the extended Wigglesworth classification; the differences in substandard care between the ethnic groups are calculated and evaluated.

Chapter 6 investigates differences in timing of the first antenatal visit among the ethnic groups in a large prospective cohort of 12,000 pregnant women in the city of Amsterdam. A timely start of antenatal care is

commonly regarded as an essential feature of quality of care, with a negative effect of delay on perinatal and maternal outcome. This paper describes the differences in timing of the first antenatal visit according to ethnicity. We explore the contribution of several non-economic determinants, both related and unrelated to ethnicity.

Chapter 7 and 8 present the summary and conclusions of the present thesis, including recommendations for perinatal care and implications for future research respectively in English (chapter 7) and in Dutch (chapter 8).

Reference List

(1) Hoogendoorn D. [Impressive but still disappointing decline in perinatal mortality in The Netherlands (published erratum appears in Ned Tijdschr Geneeskd 1986 Nov 22;130(47):2160)]. [Dutch]. Ned Tijdschr Geneeskd 1986; 130(32):1436-1440.

(2) Richardus JH, Graafmans WC, van der Pal-de BK, Amelink V, MP, Verloove-Vanhorick SP et al. An European concerted action investigating the validity of perinatal mortality as an outcome indicator for the quality of antenatal and perinatal care. [Review] [46 refs]. J Perinat Med 1997; 25(4):313-324.

(3) Buitendijk S, Zeitlin J, Cuttini M, Langhoff-Roos J, Bottu J. Indicators of fetal and infant health outcomes. Eur J Obstet Gynecol Reprod Biol 2003; 111 Suppl 1:S66-S77.

(4) Achterberg P. Measuring up to the best. International differences in perinatal mortality [in Dutch]. 270032. 2005. The Hague, RIVM.

(5) Eskes M, van Diem M. Nationwide Perinatal Audit Study (LPAS) [in Dutch]. 231. 24-11-2005. Diemen, College voor Zorgverzekeringen.

(6) Achterberg P, Kramers P. A healthy start? perinatal mortality in the Netherlands: trends and causes in international perspective. 271558. 1-3-2001. research for man and environment; national institute of public health and the environment.

(7) Galan-Roosen AEM. Registration, classification of causes of death and risk factors [University of Nijmegen, Thesis; 2002.

(8) Garssen J, Van der Meulen A. Perinatal mortality in the Netherlands;background of a worsening international ranking. Demographic Research 2004; 11(13):357-394.

(9) Villar J, Bergsjo P. Scientific basis for the content of routine antenatal care. I. Philosophy, recent studies, and power to eliminate or alleviate adverse maternal outcomes. Acta Obstet Gynecol Scand 1997; 76(1):1-14.

(10) van der Pal-de Bruin KM, Graafmans W, Biermans MC, Richardus JH, Zijlstra AG, Reefhuis J et al. The influence of prenatal screening and termination of pregnancy on perinatal mortality rates. Prenat Diagn 2002; 22(11):966-972.

(11) Central Statistics Office. Perinatal mortality in 2004. 2004. Voorburg/Heerlen, the Netherlands, CBS Statline.

(12) Wildman K, Blondel B, Nijhuis J, Defoort P, Bakoula C. European indicators of health care during pregnancy, delivery and the postpartum period. Eur J Obstet Gynecol Reprod Biol 2003; 111 Suppl 1:S53-S65.

(13) Bergsjo P, Bakketeig LS, Langhoff-Roos J. The development of perinatal audit: 20 years' experience. Acta Obstet Gynecol Scand 2003; 82(9):780-788.

(14) Dunn PM. Perinatal audit in Europe. Br J Obstet Gynaecol 1997; 104(8):875-876.

(15) Donabedian A. The quality of Medical Care. Science 1978; 200(4344):856-864.

(16) Hearnshaw HM, Harker RM, Cheater FM, Baker RH, Grimshaw GM. Are audits wasting resources by measuring the wrong things? A survey of methods used to select audit review criteria. Qual Saf Health Care 2003; 12(1):24-28.

(17) Pattinson R, Say L, Makin J, Bastos M, Pattinson RC. Critical incident audit and feedback to improve perinatal and maternal mortality and morbidity. Cochrane Database Syst Rev 2005;(4):CD002961.
(18) Maternal and Child Health Research Consortium London. CESDI; Confidential Enquiry Into Stillbirths and Deaths In Infancy. 6th annual report. CESDI-organisation 1998.
(19) Macintosh M (ed). Projwct 27/28: An Enquiry into quality of care and its effects on the survival of babies born at 27-28 weeks. 2003. TSO.
(20) Westergaard HB, Langhoff-Roos J, Larsen S, Borch-Christensen H, Lindmark G. Intrapartum death of nonmalformed fetuses in Denmark and Sweden in 1991. A perinatal audit. Acta Obstet Gynecol Scand 1997; 76(10):959-963.
(21) Langhoff-Roos J, Borch-Christensen H, Larsen S, Lindberg B, Wennergren. Potentially avoidable perinatal deaths in Denmark and Sweden 1991. Acta Obstet Gynecol Scand 1996; 75(9):820-825.
(22) Essén B, Bödker B, Sjöberg NO, Langhoff-Roos J, Greisen G, Gudmundsson S et al. Are some perinatal deaths in immigrant groups linked to suboptimal perinatal care services? BJOG 2002; 109(6):677-682.
(23) P.A.O.M. de Reu, Nijhuis JG, Oosterbaan HP, Eskes TK. Perinatal audit on avoidable mortality in a Dutch rural region: a retrospective study. Eur J Obstet Gynecol Reprod Biol 2000; 88(1):65-69.
(24) Eskes M, van Alten D, Treffers PE. The Wormerveer study; perinatal mortality and non-optimal management in a practice of independent midwives. Eur J Obstet Gynecol Reprod Biol 1993; 51(2):91-95.
(25) Wolleswinkel-van den Bosch JH, Vredevoogd CB, Borkent-Polet M, van Eyck J, Fetter WP, Lagro-Janssen TL et al. Substandard factors in perinatal care in The Netherlands: a regional audit of perinatal deaths. Acta Obstet Gynecol Scand 2002; 81(1):17-24.
(26) Vredevoogd CB, Wolleswinkel-van den Bosch JH, Amelink-Verburg MP, Verloove-Vanhorick SP, Mackenbach JP. [Perinatal mortality assessed: results of a regional audit]. Ned Tijdschr Geneeskd 2001; 145(10):482-487.
(27) Bais JM, Eskes M, Bonsel GJ. [The determinants of the high Dutch perinatal mortality in a complete regional cohort, 1990-1994]. Ned Tijdschr Geneeskd 2004; 148(38):1873-1878.
(28) Eskes M, Diem vM. LPAS, nationwide Dutch perinatal Audit Study; protocol. College voor Zorgverzekeringen, editor. 2003.
(29) Baird D. The causes and prevention of stillbirths and first week deaths. J Obstet Gynaecol Br Empire 1954; 61:433-448.
(30) Settatree RS, Watkinson M. Classifying perinatal death: experience from a regional survey. Br J Obstet Gynaecol 1993; 100(2):110-121.
(31) Butler NR, Bonham DG. Perinatal mortality; the first report of the 1958 British perintatal mortality survey. 1963. Edinburgh, Livingstone.
(32) Saller DNJ, Lesser KB, Harrel U, Rogers BB, Oyer CE. The clinical utility of the perinatal autopsy. JAMA 1995; 273(8):663-665.
(33) Faye-Petersen OM, Guinn DA, Wenstrom KD. Value of perinatal autopsy. Obstet Gynecol 1999; 94(6):915-920.

(34) Chiswick M. Perinatal and infant postmortem examination [editorial; comment] [see comments]. BMJ 1995; 310(6973):141-142.
(35) Craven CM, Dempsey S, Carey JC, Kochenour NK. Evaluation of a perinatal autopsy protocol: influence of the Prenatal Diagnosis Conference Team. Obstet Gynecol 1990; 76(4):684-688.
(36) Cartlidge PH, Dawson AT, Stewart JH, Vujanic GM. Value and quality of perinatal and infant postmortem examinations: cohort analysis of 400 consecutive deaths [see comments]. BMJ 1995; 310(6973):155-158.
(37) Landers S, Kirby R, Harvey B, Langston C. Characteristics of infants who undergo neonatal autopsy. J Perinatol 1994; 14(3):204-207.
(38) Ros PR, Li KC, Vo P, Baer H, Staab EV. Preautopsy magnetic resonance imaging: initial experience. Magn Reson Imaging 1990; 8(3):303-308.
(39) Roberts MD, Lange RC, McCarthy SM. Fetal anatomy with magnetic resonance imaging. Magn Reson Imaging 1995; 13(4):645-649.
(40) Nasu K, Yoshimatsu J, Anai T, Miyakawa I, Komatsu E, Maeda T. Magnetic resonance imaging of fetal autosomal recessive polycystic kidney disease. J Obstet Gynaecol Res 1998; 24(1):33-36.
(41) Woodward PJ, Sohaey R, Harris DP, Jackson GM, Klatt EC, Alexander AL et al. Postmortem fetal MR imaging: comparison with findings at autopsy. AJR Am J Roentgenol 1997; American Journal of Roentgenology. 168(1):41-46.
(42) Brookes JA, Deng J, Wilkinson ID, Lees WR. Three-dimensional imaging of the postmortem fetus by MRI: early experience. Fetal Diagn Ther 1999; 14(3):166-171.
(43) Schulpen TWJr. Mortality differences between migrant and native Dutch children in the Netherlands [in Dutch]. Centre for Migration and Child Health . 1996.
(44) van Enk A, Buitendijk SE, van der Pal KM, van Enk WJ, Schulpen TW. Perinatal death in ethnic minorities in The Netherlands. J Epidemiol Community Health 1998; 52(11):735-739.
(45) Essén B, Hanson BS, Östergren PO, Lindqvist PG, Gudmundsson S. Increased perinatal mortality among sub-Saharan immigrants in a city-population in Sweden. Acta Obstet Gynecol Scand 2000; 79(9):737-743.
(46) Doornbos J, Nordbeck HJ. Perinatal mortality. Obstetric riskfactors in a community of mixed ethnic origin in Amsterdam. Thesis 1985;(Dordrecht, ICG printing, 1985).
(47) Stronks K, Ravelli AC, Reijneveld SA. Immigrants in the Netherlands: equal access for equal needs? J Epidemiol Community Health 2001; 55(10):701-707.
(48) Zeitlin J, Combier E, De CF, Papiernik E. Socio-demographic risk factors for perinatal mortality. A study of perinatal mortality in the French district of Seine-Saint-Denis. Acta Obstet Gynecol Scand 1998; 77(8):826-835.
(49) Macfarlane A, Mugford M. Statistics of pregnancy and childbirth. The stationary Office; 2000.
(50) van Enk WJ, Gorissen WH, van Enk A. [Teenage pregnancy distribution by ethnicity in the Netherlands, 1990-1993]. [Dutch]. Ned Tijdschr Geneeskd 1999; 143(9):465-471.
(51) Knuist M. Pregnancy induced hypertension in a low-risk population. Thesis. Department of Obstetrics and Gynaecology, Academic Medical Center Amsterdam; 1998.

(52) Bonsel G.J., van der Maas PJ. Scenarios for health care concerning human reproduction 1995-2010. 1994.
(53) Centraal Bureau voor de Statistiek. Bevolking per gemeente naar geboorteland, resp. geboorteland ouders; 1 januari 1997. Mndstat Bevolking (CBS) 1997; 12:89-107.
(54) World Health Organisation. International classification of diseases, 10th revision. World Health Organisation, editor. 1992. Geneva, World Health Organisation.
(55) Kupek E, Petrou S, Vause S, Maresh M. Clinical, provider and sociodemographic predictors of late initiation of antenatal care in England and Wales. BJOG 2002; 109(3):265-273.
(56) Rowe RE, Garcia J. Social class, ethnicity and attendance for antenatal care in the United Kingdom: a systematic review. J Public Health Med 2003; 25(2):113-119.
(57) Gortmaker SL. The effects of prenatal care upon the health of the newborn. Am J Public Health 1979; 69(7):653-660.
(58) Ryan GM, Jr., Sweeney PJ, Solola AS. Prenatal care and pregnancy outcome. Am J Obstet Gynecol 1980; 137(8):876-881.
(59) Quick JD, Greenlick MR, Roghmann KJ. Prenatal care and pregnancy outcome in an HMO and general population: a multivariate cohort analysis. Am J Public Health 1981; 71(4):381-390.
(60) Blondel B, Dutilh P, Delour M, Uzan S. Poor antenatal care and pregnancy outcome. Eur J Obstet Gynecol Reprod Biol 1993; 50(3):191-196.
(61) Delvaux T, Buekens P, Godin I, Boutsen M. Barriers to prenatal care in Europe. Am J Prev Med 2001; 21(1):52-59.
(62) McDonald TP, Coburn AF. Predictors of prenatal care utilization. Soc Sci Med 1988; 27(2):167-172.
(63) Essex C, Counsell AM, Geddis DC. The demographic characteristics of early and late attenders for antenatal care. Aust N Z J Obstet Gynaecol 1992; 32(4):306-308.
(64) Pagnini DL, Reichman NE. Psychosocial factors and the timing of prenatal care among women in New Jersey's HealthStart program. Fam Plann Perspect 2000; 32(2):56-64.
(65) Delgado-Rodriguez M, Gomez-Olmedo M, Bueno-Cavanillas A, Galvez-Vargas R. Unplanned pregnancy as a major determinant in inadequate use of prenatal care. Prev Med 1997; 26(6):834-838.
(66) Hulsey TM. Association between early prenatal care and mother's intention of and desire for the pregnancy. J Obstet Gynecol Neonatal Nurs 2001; 30(3):275-282.
(67) Hemingway H, Saunders D, Parsons L. Social class, spoken language and pattern of care as determinants of continuity of carer in maternity services in east London. J Public Health Med 1997; 19(2):156-161.

2

Marianne E Alderliesten [1]
Karien Stronks [2]
Gouke J Bonsel [1,2]
Bert J Smit [4]
Maarten MJ van Campen [3]
Jan MM van Lith [1]
Otto P Bleker [1]

Academic Medical Centre Amsterdam, the Netherlands, Department of Obstetrics and Gynaecology, (1) Department of Public Health, (2) Board AMC (3)
Erasmus MC - Sophia's Children's Hospital, University Medical Centre, Rotterdam, The Netherlands, Department of Neonatology (4)

PARIS - a regional perinatal audit: design and evaluation

Abstract

Objective: to describe the experiences of a regional audit of perinatal deaths, including the experiences of the audit members, to discuss similarities and differences with other, existing perinatal audits and to summarize the implications for future implementation.

Study design: perinatal audit with blinded regional auditors. Consecutive cases of perinatal death were analysed for the presence of substandard care. A random selection of cases was reviewed by an external audit panel. The prevalence of substandard care in the Amsterdam audit was compared with other, existing audits. A survey among audit members was executed.

Results: care providers from all Amsterdam hospitals, as well as general practitioners and independent midwives cooperated. 137 perinatal deaths were reviewed. In 25 % of all perinatal death cases, substandard care factors were present. After 23 completed weeks substandard care factors were present in 35% of cases, and in 52% of intrapartum deaths. These figures are comparable with other, non-regional oriented audits. The review of the external panel was also comparable to the review of the regional audit committee. All audit members felt secure to discuss freely the presence of substandard care.

Conclusion: first systematic experiences with a regional perinatal audit are described. We conclude that a regional perinatal audit is executable. Cooperation of regional care providers is good. Review of substandard care is comparable to other, non-regional oriented perinatal audits.

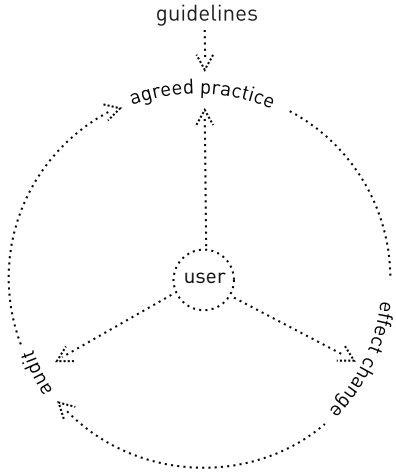
Introduction

Perinatal audit, a process whereby perinatal deaths are investigated for the presence of substandard care factors (SSCFs), is performed at many different levels. Since 1993, the recommendations of the Confidential Enquiry into Stillbirths and Death in Infancy (CESDI) in the UK have been implemented nationwide and every year a different sample of all perinatal deaths is reviewed.[1,2] In the Netherlands, several regional perinatal audits have been performed recently in a research setting.[3-6]

These audits all differ, for example in the cause of death classification used, the composition of the audit committee, or the use of evidence to define the concept of substandard care. There is one aspect, however, that is common to all the audits mentioned above, i.e. the members of the audit committee do not work in the region where the perinatal deaths originate. Reasons for this are not always given, but could include the unwillingness of local health workers to cooperate, or the concern that the investigation might be biased and a more favourable review given.

Audit, nevertheless, has a central position in the process of developing and implementing guidelines in healthcare. Involvement of the involved care provider is therefore essential for its execution. (see figure 1)

Figure 1 Audit circle



As far as we are aware a perinatal audit with regional reviewers has not been performed in a systematic way. The Perinatal Audit, Research and Implementation Study (PARIS) presented here, investigated perinatal mortality in a consecutive cohort of perinatal deaths in Amsterdam. The study conformed to CESDI principles, to which we added available guidelines and evidence-based medicine criteria to define the conception 'substandard'. In this study, obstetricians, paediatricians, midwives and general practitioners reviewed perinatal care in their own region. A random selection of perinatal death cases was reviewed by a second audit panel of professionals from outside the region.

The aim of this paper is to describe experiences with a perinatal audit with regional reviewers, including the experiences of the audit members, to discuss similarities and differences with other, existing perinatal audits and to summarize the implications for future implementation.

Approach

Data collection

All consecutive cases of perinatal mortality, from 16 weeks of gestational age onwards until 28 days after delivery in the city of Amsterdam were included. Deliveries took place in hospital, under an obstetrician's care, as well as at home under the care of the independent midwife.
A structured case record form in questionnaire format was developed, based on published risk factors for perinatal death and based on existing guidelines for perinatal care (1: content of structured CRF [see appendix 3 in Dutch])[7]. Perinatal deaths were reported to the investigator by a fax which contained the information the investigator needed to trace the case of perinatal death (see appendix 2). The investigator filled in the structured CRF on site, in order to minimize the extra work for the care providers. The study group separated the collection of data on all perinatal deaths from the analytical and auditing task, to achieve a maximum level of blinding. To check for data completeness, local sources, e.g. delivery books, yearly reports and data from the National Dutch Perinatal Database were examined. This stage of data collection was finalized by the preparation of an anonymous case summary with minimal changes to prevent recognition of the individual cases. Finally, when data analysis was finished and the audit panels had reached a decision the key to all individual cases of perinatal death was destroyed.

Audit

The audit committee consisted of 16 obstetricians and paediatricians from all Amsterdam hospitals, three independent midwives and two general practioners. All care providers in the city of Amsterdam cooperated in the data collection. At every panel meeting two paediatricians, two obstetricians, a general practitioner and two midwives from the above mentioned pool were present. The committee reviewed all perinatal deaths following a two-month schedule. All audit members were trained during a training session, before starting this study. The case summaries and clinical data (such as CTG's) were distributed three weeks prior to each audit session. The members were allowed to ask for any additional information, if available. Review included an individual judgment of each case, using a structured judgment form (see appendix 4), prior to the session. A collective judgment of the perinatal audit panel followed after discussion during the audit session. An independent chairman (i.e. a GP, professionally trained in quality of care assessments with extensive hospital experience) presided over all sessions. The cause of death was recorded during the panel meetings, using three internationally accepted classification methods. (Extended Wigglesworth classification, modified Aberdeen classification, fetal and infant classification).[8-10]

A substandard care factor (SSCF) was defined as being present, if perinatal care did not meet the defined minimally accepted standards. Accepted sources of evidence were the guidelines of the Dutch Society for Obstetrics and Gynecology (DSOG), the Royal College of Obstetricians and Gynaecologists (RCOG), the American College of Obstetricians and Gynaecologists (ACOG), the Cochrane database, guidelines of the Dutch Society of Midwives (DSM) and the Dutch Society of Pediatrics (DSP). An overall review of the contribution of SSCFs in one case to the occurrence of perinatal death was determined. The following four categories were distinguished: no substandard care present, substandard care present with an unlikely, possible or likely contribution to perinatal death.

The combined judgment of one case was considered to reflect 'consensus' if all reviewers agreed on both the presence and the degree of contribution of SSCFs to perinatal death, or when a maximum of two out of seven members disagreed to only a minor, one-level degree (no-unlikely; unlikely-possible; possible-likely). All cases were discussed except written consensus cases.
Ten cases reviewed by the Amsterdam audit were allocated at random and presented to the external audit committee. This committee consisted of the same professionals as the Amsterdam audit, who were familiar with the process of perinatal audit (midwife, pediatrician, obstetrician and general practitioner). Consensus between these two committees was considered to have been achieved when both the committees agreed on both the presence and the degree of the contribution of SSCFs to perinatal death, or when the contribution of SSCFs was different to only a minor, one-level degree (no-unlikely; unlikely-possible; possible-likely).

Outcome

Main results

In the study period, 137 perinatal deaths were reviewed. There were 61 cases of fetal death, including 10 terminated pregnancies for lethal congenital anomalies; 27 children died during labor and delivery, and 46 children died after birth (12 < 24 hours; 33 > 24 hours). (Of three fetuses, time of death could not be estabilished).

Fifteen perinatal deaths could be reviewed in a two hour session. In 97% of all cases, consensus was reached. In 30% of the cases, consensus had already been reached after the written review. In 50% of the cases, there was a short discussion (< 10 minutes). In 20% of the cases, an extensive discussion (> 10 minutes) was held about the presence and contribution of SSCFs. In 50.4% of the cases no SSCFs were found. In 35 cases, 55

SSCFs were considered to be present. The contribution of substandard care to perinatal death is shown in table 1.

Table 1 Presence of substandard care factors and their contribution to perinatal death, from 16 weeks and 24 weeks of gestation onwards

Substandard care factors	**> 16 weeks**		**> 24 weeks**	
	N	**(%)**	**N**	**(%)**
None	69	(50)	36	(41)
Unlikely contribution to perinatal death	29	(21)	20	(23)
Possible contribution	27	(20)	22	(25)
Likely contribution to perinatal death	8	(6)	7	(8)
Too little information to review case	4	(3)	3	(3)
Total number of patients	**137**	**(100)**	**88**	**(100)**

Perinatal audits in Western Europe after 1990, with a broad inclusion of perinatal deaths were compared in regard to design and outcome (table 2). The range of SSCFs in PARIS (25% for all perinatal deaths, 35% after 23 completed weeks and 52% intrapartum deaths) is comparable to the other perinatal audit processes.[1,3,5,6,11]

Validity

In seven cases (out of 10), the regional and external committee agreed on the presence and contribution of SSCFs. In four of these consensus cases, both panels agreed on no SSCFs, whereas in the other three cases, both panels agreed that SSCFs were present. In two out of three non-consensus cases the regional committee attributed substandard care where the external committee did not. In the other case, the opposite occurred. Guidelines were involved only in one (out of six) cases where SSCFs were attributed. This case was a consensus case.

Experiences of the audit members

A questionnaire was prepared for the members of the Amsterdam audit to investigate their opinion about the audit and their own efforts. This questionnaire consisted of four open and 12 multiple-choice questions. The evaluation was sent to all audit members. Sixteen responded (76%). For all committee members, reviewing cases of perinatal death was a time-consuming process. The mean duration of preparing the cases for the meeting was four hours, with a range of 1½ - 10 hours. All participants felt secure enough to discuss their reviews freely concerning the presence of SSCFs. In 26% of cases a perinatal death was discussed

Table 2

	Composition audit committee	Datacollection	Population	Outcome (grade 2 and 3 substandard care only)
PARIS	Obstetrician (general and teaching hospital), midwife, paediatrician/neonatologist, general practitioner	Structured questionnaire, based on known risk factors for perinatal death. Standardized summary of clinical data **Guidelines**: DSOG, RCOG, ACOG, Cochrane, DSM, DSP evidence	Consecutive cohort of 8 months perinatal deaths in Amsterdam 16 weeks – 28 days pp N= 137	Congenital malformations included > 24 weeks: 35% intrapartum: 52% 25% SSCF [1]
Nedernatal [4]	General practitioner, obstetrician (general and teaching hospital) paediatrician/neonatologist, midwife	Structured questionnaire, based on known risk factors for perinatal death Summary of clinical data **Guidelines**: Explicit, evidence based criteria; Cochrane Pregnancy & Childbirth Database	South-Holland; region of the Netherlands. > 24 weeks N= 342	Congenital malformations included 32% SSCF
De Reu [3]	Midwife, obstetrician, general practitioner, pathologist	Summary of clinical data **Guidelines**: not described	Brabant, a region of the Netherlands.; > 24 weeks, N= 73	Congenital malformations included 55% SSCF
Westergaard[11]	10 senior Danish and Swedish obstetricians	Summary of clinical data, autopsy reports, **Guidelines**: not described	Denmark and Sweden; > 24 weeks N= 50	Intrapartum deaths only SSCF total
CESDI[1]	Obstetrician, midwife, paediatrician/neonatologist, pathologist, general practitioner	Anonimised version of medical reports **Guidelines**: RCOG	´1 in 10' enquiries; random selection of perinatal deaths; > 22 weeks n= 573	population n.a. SSCF: 16%
Bais [6]	3 Obstetricians, paediatrician	Summary of clinical data **Guidelines**: Dutch Society of Midwives, Dutch Society of Obstetricians	Consecutive singleton perinatal deaths > 22 weeks, -28 days after delivery N=92 25% SSCF	Congenital malformations included

[1] smoking important SSCF (10 %)

where the participant him/herself, or a close colleague, was involved (n=4). This involvement slightly hindered two members of the committee in their review of the case. No members were strongly hindered by their involvement. For 86% of the audit members, the audit was an important process for quality of care. They felt that the frequency of a future cooperation in a perinatal audit should be a maximum of four times per year. No audit members felt able to cooperate on a monthly basis. 20% of audit members said they would not cooperate in the future, due to the time-consuming nature of the process which had to be performed in their non-working time.
In a future setting, half of the members agreed on a selection of cases. Propositions concerning a case selection were: to leave out all cases of perinatal death due to congenital malformations or to start at 23 completed weeks of gestation. In both these groups only a few SSCFs were attributed.

Discussion

In 1999, a regional perinatal audit was performed in the city of Amsterdam, the Netherlands. The cooperation of regional care providers in data provision as well as participation in the audit committee was good. The prevalence of substandard care in our regional perinatal audit was comparable to other audits of perinatal care. This suggests that in a regional audit with a structured approach judgement will be neither harsher nor milder than the judgement of a perinatal audit panel not directly involved in care provision. The random allocation of 10 reviewed cases to an external committee supports that opinion.

Experiences of the audit members

Within the given context (i.e. strict rules in regard to privacy) all respondents felt secure in discussing their opinions freely in regard to the presence of substandard care. 80% of all respondents said they would cooperate in a future audit. Despite the fact that practically all data on the perinatal death cases were collected by a research-doctor (MEA), 20% of audit members said they would not cooperate under similar conditions in the future, due to the time-consuming nature of the process. The invested time reflected the preparation of the perinatal audit and the panel meeting itself. Feedback of audit results was given at regional meetings, where the prevalence and content of substandard care was discussed in general terms.
Only a few data are available on the effect of feedback to care providers in audit and feedback,[12] showing that the effect of quality improvement after feedback is difficult to predict; the only factor influencing its effect is a low baseline adherence to recommended practice.
One study states that regional care providers tend to be stricter

concerning their own actions, than an external audit committee.[5] However, this was not systematically investigated.

Considering the composition of the audit committee we experienced the presence of a general practioner, although not directly involved in the delivery of perinatal care in the city of Amsterdam, worthwhile, as he or she is to the patient a central figure in health care delivery. We advise the presence of a pathologist to supplement the audit process, since the cause of death appeared to be of importance for the attribution of substandard care (for example, the presence of a congenital heart defect or asphyxia during delivery).

Implications for practice

A perinatal audit is an important quality process in the review of substandard care in cases of perinatal mortality. This is illustrated by its implementation in the UK and in the near future in the Netherlands.[13] Our experiences indicate that a perinatal audit can be performed as well on a regional basis. Cooperation of doctors and midwives was good. Furthermore, a regional audit appears to produce reviews of perinatal care that are neither harsher nor milder than the judgements of perinatal audit panels comprising members not directly involved in care provision. However, these first experiences should be confirmed in a larger cohort.

Implementation of guidelines and evaluating the changes they propose is a difficult process, which has been an important topic for researchers in the past.[14,15] The effect of audit and feedback is known to be valuable, but the determinants defining its effects are not clear[12]. Moreover, a recently published Cochrane review on the effectivity of a critical incident audit concludes that no sufficient evidence is available that can predict the best way in which such a perinatal audit should be performed.[16]

A nation wide and a regional perinatal audit aim at different goals. The former investigates subsets of perinatal deaths, can trace trends in the presence of substandard care, and has the possibility to review guidelines on a nation wide level. For the participants, such an audit can be regarded safe, but it is also more distant.

In the latter however, man can expect a more direct involvement of the participating care providers. This direct involvement has advantages, as well as disadvantages. The possibility of direct feedback, and therefore an expected good implementation of the results of the audit can be regarded as an advantage. A disadvantage of this direct involvement could be the emotions of care providers involved in a certain perinatal death. For both approaches, the relevance with respect to change of practice is completely dependent whether the disseminated results are effectively discussed within groups of care providers or not.

Acknowledgements

We would like to thank D.J. Bekedam, P.J.E. Bindels, A.B. Dijkman, K.F. Heins, N. Jorna, J.C. Kaandorp, M. Knuist, J.H. Kok, D. Lesscher, G.L.M. Lips, S. Logtenberg, N. Menelik, J.A.M. van der Post, J.I. Puyenbroek, M.K. Sanders, L. van Toledo, A.J. van Veelen, E.M.A. van de Veer, G. van Waveren, M. Wieringa- de Waard, who participated in the Amsterdam perinatal audit. We thank prof. dr. J.P. Holm, prof. Dr. M.P. Springer, P.A.O.M. de Reu, prof. dr. P.J.E. Bindels, prof. dr. L.A.A. Kollée for their cooperation to the external committee.

...

Reference List

(1) Maternal and Child Health Research Consortium London. CESDI; Confidential Enquiry Into Stillbirths and Deaths In Infancy. 6th annual report. CESDI-organisation 1998.

(2) Macintosh M (ed). Project 27/28: An Enquiry into quality of care and its effects on the survival of babies born at 27-28 weeks. 2003. TSO.

(3) Reu P.A.O.M., Nijhuis JG, Oosterbaan HP, Eskes TK. Perinatal audit on avoidable mortality in a Dutch rural region: a retrospective study. Eur J Obstet Gynecol Reprod Biol 2000; 88(1):65-69.

(4) Wolleswinkel-van den Bosch JH, Vredevoogd CB, Borkent-Polet M, van Eyck J, Fetter WP, Lagro-Janssen TL et al. Substandard factors in perinatal care in The Netherlands: a regional audit of perinatal deaths. Acta Obstet Gynecol Scand 2002; 81(1):17-24.

(5) Vredevoogd CB, Wolleswinkel-van den Bosch JH, Amelink-Verburg MP, Verloove-Vanhorick SP, Mackenbach JP. [Perinatal mortality assessed: results of a regional audit]. Ned Tijdschr Geneeskd 2001; 145(10):482-487.

(6) Bais JM, Eskes M, Bonsel GJ. [The determinants of the high Dutch perinatal mortality in a complete regional cohort, 1990-1994]. Ned Tijdschr Geneeskd 2004; 148(38):1873-1878.

(7) Alderliesten ME, Bleker OP, Bonsel GJ, Stronks K, Lith v JMM. PARIS; Perinatal Audit; Research and Implementation Study. research protocol department of Obstetrics/ Public Health, Academic Medical Centre 1998.

(8) Settatree RS, Watkinson M. Classifying perinatal death: experience from a regional survey. Br J Obstet Gynaecol 1993; 100(2):110-121.

(9) Baird D. The causes and prevention of stillbirths and first week deaths. J Obstet Gynaecol Br Empire 1954; 61:433-448.

(10) Butler NR, Bonham DG. Perinatal mortality; the first report of the 1958 British perintatal mortality survey. 1963. Edinburgh, Livingstone.

(11) Westergaard HB, Langhoff-Roos J, Larsen S, Borch-Christensen H, Lindmark G. Intrapartum death of nonmalformed fetuses in Denmark and Sweden in 1991. A perinatal audit. Acta Obstet Gynecol Scand 1997; 76(10):959-963.

(12) Jamtvedt G, Young JM, Kristoffersen DT, Thomson O'Brien MA, Oxman AD. Audit and feedback: effects on professional practice and health care outcomes. Cochrane Database Syst Rev 2003;(3):CD000259.

(13) Eskes M, van Diem M. Nationwide Perinatal Audit Study (LPAS) [in Dutch]. 231. 24-11-2005. Diemen, College voor Zorgverzekeringen.

(14) Grol R, Grimshaw J. From best evidence to best practice: effective implementation of change in patients' care. Lancet 2003; 362(9391):1225-1230.

(15) Grol R. Implementation of evidence and guidelines in clinical practice: a new field of research? Int J Qual Health Care 2000; 12(6):455-456.

(16) Pattinson R, Say L, Makin J, Bastos M, Pattinson RC. Critical incident audit and feedback to improve perinatal and maternal mortality and morbidity. Cochrane Database Syst Rev 2005;(4):CD002961.

3

Marianne E Alderliesten [1]
Gouke J Bonsel [1,2]
Jan MM van Lith [1]
Karien Stronks [2]
Bert J Smit [4]
Maarten MJ van Campen [3]
Otto P Bleker [1]

Academic Medical Centre Amsterdam, The Netherlands, Department of Obstetrics and Gynaecology, (1) Department of Public Health, (2) Board AMC (3)
Erasmus MC - Sophia's Children's Hospital, University Medical Centre, Rotterdam, The Netherlands, Department of Neonatology (4)

Substandard care in consecutive cases of perinatal death; results from the Amsterdam audit

Abstract

Background: 88 consecutive cases of perinatal death were analysed for the presence of substandard care factors (24 weeks gestational age - 28 days after delivery) by means of a perinatal audit with blinded regional auditors in Amsterdam, the Netherlands. The objective was to investigate evidence-based a cohort of cases of perinatal death for the presence of substandard care factors and to suggest recommendations for practice.

Methods: A standardized procedure to establish cause of death and the presence of substandard care by perinatal audit. The main outcome measures were: Cause of death (presented by extended Wigglesworth classification), presence of substandard care factors (unlikely, possibly or likely to be related to perinatal death). Component of care and responsible actor considered to be substandard were noted.

Results: In 33% of perinatal death cases, 48 SSCFs were found with a possible (25%) or likely (eight %) contribution to perinatal death. Twenty three percent of these substandard care factors were attributed to the midwife, 42% to the obstetrician and 29% to the mother. Among the mothers to whom substandard care was assigned there was an overrepresentation of immigrants. SSCFs were present in 59% of intrapartum cases of death. Another important SSCF identified was delayed action after notification of growth retardation in pregnancy (by both midwives and obstetricians).

Conclusions: recommendations for good practice based on the outcome of this study imply prompter action after growth retardation has been identified and the structural evaluation of intrapartum deaths. Even in complicated intrapartum death cases, guidelines or local protocols concerning the SSCFs were present in 88% of cases. There should be more emphasis on providing information to pregnant women, especially those belonging to an ethnic minority group.

Introduction

Perinatal mortality is considered to be an objective indicator of the quality of obstetric and neonatal care.[1] It is associated with many factors, but only a few represent a traditional 'cause'. Some factors are obvious yet difficult to change (e.g. maternal age, twin pregnancies and ethnic background). Others are amenable to intervention such as exposure to infectious agents, misconduct of the patient or obstetric caregiver where there are apparent symptoms, or delayed transportation of pregnant women or newborn babies due to lack of facilities. The perinatal audit is an internationally accepted method of recording risk factors. Audits provide opportunities to analyse the factors at individual level for the presence of substandard care, and to make judgments for improving health care.[2,3]

In the UK and Scandinavia, such audits have been performed routinely. In the UK, since 1993, the recommendations of the Confidential Enquiry into Stillbirths and Death in Infancy (CESDI) have been implemented.[4,5] In Scandinavia, Westergaard and Langhoff-Roos systematically compared perinatal death rates in Denmark and Sweden based on audit data (1997).[6,7] In the Netherlands, unrelated regional studies were carried out in Wormerveer (1979-1982), Den Bosch (1994-1995) and Zuid Holland-Noord (1996-1997), all in a temporary research setting.[8-10]

The first two audits focused on avoidability in absolute and legal terms and provided the aggregated percentage of avoidable perinatal deaths. Such a judgment is artificial however, as few factors are monocausal and there is not a strong relationship between avoidability and causality. Recent studies replaced the judgment on avoidability with a judgment on the presence of 'substandard care factor(s)' (SSCFs). Each SSCF is assigned to a responsible actor and defined component of care and each is judged for its causal contribution to the specific case. The two-step approach separates the process of quality judgment from the preceding probabilistic etiological judgment. The latter judgement is considered to be more valid from a biological, epidemiological and legal point of view. The Perinatal Audit, Research and Implementation Study (PARIS) presented here, investigated perinatal mortality in a consecutive cohort of perinatal deaths, carried out by a regional audit panel. The regional panel consisted of active care providers from different disciplines relating to Amsterdam perinatal care. The audit conformed to CESDI principles but we also formally checked that all available (relevant) guidelines and published evidence were adhered to. We also conducted a rigorous blinding procedure.

Material and methods

A member of the study-group separated the collection of data on all perinatal deaths from the analytical and auditing task to achieve a

maximum level of blinding. Study subjects consisted of a consecutive cohort of cases from the city of Amsterdam. The total number of births in the city of Amsterdam (1999) was 10,225.[11]

Criteria and setting

We included all cases of perinatal mortality from 16 weeks of gestational age onwards until 28 days after delivery (February until October 1999). The analysis for the presence of SSCFs was restricted to all cases over 23 completed weeks of gestation. In the Netherlands, perinatal care is delivered by obstetricians, as well as by independent midwives. Deliveries take place in hospital, as well as at home.
A structured case record form (questionnaire format) was developed, based on published risk factors for perinatal death and on existing guidelines for perinatal care[12] (clinical CRF, see appendix 3). Accepted sources of evidence were the guidelines of the Dutch Society for Obstetrics and Gynecology (DSOG), the Royal College of Obstetricians and Gynaecologists (RCOG), the American College of Obstetricians and Gynaecologists (ACOG), the Cochrane database, guidelines of the Dutch Society of Midwives (DSM) and the Dutch Society of Pediatrics (DSP). The questionnaire included a detailed verification procedure of all the clinical and process data required for the unambiguous diagnostic classification of the perinatal death. This was necessary to minimize the subjective component of data recording.
The following information was collected: gestational age at the time of death and the perinatal setting (primary care only, hospital care after referral by a midwife and hospital care only). Any involvement of a pediatrician was recorded, including the time of call and subsequent arrival. This stage of data collection was finalized by the preparation of an anonymous narrative, with minimal changes to prevent recognition of the individual case.

The audit committee consisted of two paediatricians, two obstetricians, a general practitioner and two midwives; all recruited from Amsterdam hospitals and independent midwifery practices. All audit members (except the chairman) rotated every four months. The committee reviewed all cases of perinatal death following a two-month schedule. All participants received a training session, prior to their participation. The case summaries and clinical data (such as CTG's) were distributed three weeks prior to each session. The members were allowed to request any additional data (if available) prior to the audit session. Review included an individual judgment of each case, prior to the session and a collective judgment of the perinatal audit panel in session. An independent chairman (i.e. a GP, professionally trained in quality of care assessments with extensive hospital experience) presided all meetings.

Substandard care factors (SSCFs)

A SSCF was considered present if perinatal care did not meet the defined minimally accepted standards according to the CESDI protocol (see also table 1).

The collective judgment of a case was considered to reflect 'consensus' if all reviewers agreed on both the presence and the degree of contribution of SSCFS to perinatal death, or when a maximum of two members disagreed to only a minor, one-level degree (no-unlikely; unlikely-possible; possible-likely). Consensus cases were accepted beforehand without discussion but all other cases were discussed. In 97% of cases, final consensus was reached. In the other 3% of cases, the chairman decided on the presence and contribution of SSCFs.
The causes of death were primarily classified using the extended Wigglesworth classification.[13] The component of perinatal care which was judged to be substandard (detection, therapy, logistics or communication) was recorded, as was the responsible care provider. Feedback of audit results was provided during regional meetings, where the SSCFs detected were discussed in general terms as presented in this article. The implications for practice as are enclosed in the discussion section were discussed thoroughly with care providers of all Amsterdam hospitals, so ensuring maximal implementation of the results of this study.

Data analysis

Descriptive and standard cross-tabulations were computed using SPSS 11.5; no missing data imputation was used.

Results

During the study period, 137 consecutive cases of perinatal death over 16 weeks GA were registered and included. All but three deliveries occurred at the hospital under the responsibility of the obstetrician. In one case, the midwife was notified after an unassisted delivery at home. There were 61 cases of fetal death, including 10 terminated pregnancies for unequivocal lethal congenital anomalies; 27 children died during labor and delivery, and 46 children died after birth (12 < 24 hours; 33 > 24 hours)(of three fetuses, time of death could not be established). Median maternal age was 29 years in nulliparous and 33 years in multiparous women. Of all 137 cases, 10 children represented five twin pairs and three were one of a pair of twins. 39 women received primary care until the occurence of the perinatal death, another 44 women were referred to the obstetrician after 20 weeks, and 44 women with high-risk pregnancies received secondary care before 20 weeks of pregnancy. Ten mothers did not receive antenatal care, and were only seen during delivery.

The analysis to investigate the presence of SSCFs was performed only for perinatal death cases above 23 completed weeks gestational age (n=88), since the effect of optimizing perinatal care was considered small below this gestational age. In the discussion section, these early preterm perinatal death cases are discussed briefly.

Substandard care factors (SSCFs)

Of these 88 cases, three were excluded because their clinical data was incomplete. Two of these cases were perinatal deaths at term, where the audit committee considered the case too complicated to be able to reach a decision on the presence of SSCFs. These cases are presented here in detail.

Case I: late neonatal death at term, 24 days after a traumatic delivery with augmentation of labour, intra-uterine infection, difficult ventouse delivery and shoulder dystocia. No clear signs of asphyxia or cerebral bleeding were present after delivery. Cause of death did not become clear, even after rigorous investigations. The audit discussion noted that there had been a long, traumatic delivery, but the relationship between delivery and death could not be satisfactorily explained, so the contribution of perinatal care during delivery and up to the time of death could not be estimated.

Case II: Death during delivery. Performance of an emergency caesarean because of fetal distress. The child had a complex cor vitium, but the baby's prognosis remained unclear, since no parental consent for autopsy was given. The audit panel decided that cause of death was not clear, therefore the contribution of the care given during delivery up to the time of death could not be estimated.

Case III: a sudden early preterm delivery, where insufficient information was available to review the case.

In 36 of 85 cases (41%) no SSCFs were found. In 20 cases (23%) SSCFs were found but it was considered unlikely that they had contributed to perinatal death. In the remaining 29 cases, 48 SSCFs were found. In 22 cases (25%) it was considered possible that SSCFs had contributed to perinatal death while in the remaining seven cases (eight %) it was considered likely that SSCFs had contributed. (Table 1).

Table 1 Presence of substandard care and contribution to perinatal death

Substandard care	**N**	**(%)**
None	36	(41)
Unlikely contribution to perinatal death	20	(23)
Possible contribution to perinatal death	22	(25)
Likely contribution to perinatal death	7	(8)
Too little information to review case	3	(3)
Total	**88**	**(100)**

Cause of death

Table 2 shows the cause of death as classified by the perinatal audit panel, using the extended Wigglesworth classification, related to the presence of SSCFs. Forty percent were judged to be unexplained ante partum fetal deaths (34/85). These cases consisted of 34% growth retarded fetuses (below the fifth percentile). SSCFs were attributed to almost half of the ante partum fetal death cases. In five out of 16 cases (30%) this was because the action of the obstetrician or midwife in relation to detected growth retardation was considered to be inadequate.

Table 2 Causes of perinatal death, related to the presence of substandard care*

Cause of death, extended Wigglesworth classification[13]	**Substandard care; N (%)** No SSCFs/ unlikely contribution	SSCFs possible/ likely contribution	**Total**
Congenital malformation	16 (100)	- -	16 (100)
Unexplained antepartum fetal death	18 (53)	16 (47)	34 (100)
Death from intrapartum asphyxia, anoxia or trauma	7 (41)	10 (59)	17 (100)
Immaturity	5 (71)	2 (29)	7 (100)
Infection	5 (83)	1 (17)	6 (100)
Other specific causes	3 (100)	0 -	3 (100)
Accident or non-intrapartum trauma	0 -	0 -	0 -
Sudden infant death, cause unknown	0 -	0 -	0 -
Unclassifiable	2 (100)	- -	2 (100)
Total	**56** (66)	**29** (34)	**85** (100)

* n=85: 3 cases were left out; too little information was available to review the presence of SSCFs and cause of death

SSCFs with a possible or likely contribution to perinatal death were attributed to 10 out of 17 (59%) of all deaths during delivery, with a total of 17 SSCFs in these 10 cases. Details of these SSCFs are summarized in table 3. In 11 of these 17 SSCFs, the SSCF consisted of non-compliance with a recognized guideline. In three additional SSCFs, clear evidence was present, although no recognized (inter)national guideline was available. In one case, a local protocol was violated. In two SSCFs, no guidelines were present.

Table 3 Details of substandard care, attributed to intrapartum death cases

Case (AD)	Amount of SSCFs	Description of SSCF	Guidelines involved?
A (41 4/7)	1	Inadequate supervision of midwife-trainee by independent midwife during delivery	DSM[1]
B (41 2/7)	1	Amniotomy with a non-engaged head, without impression of the head	-
C (39 3/7)	1	Delay in performance of caesarean for fetal distress in second of twin; due to late arrival of operating team.	DSOG * [2]
D (41 5/7)	3	1. Obese patient: for optimal antenatal fetal surveillance antenatal care should have been in secondary care	DSM
		2. Surveillance of obstetrician during delivery inadequate (no micro-blood sample, administration of prostin with non-observed suboptimal CTG)	DSOG
		3. Paediatrician not called to be present at delivery	RCOG/ ACOG[3]
E (35 4/7)	1	Artificial rupture of membranes with a presenting arm	Evidence
F (40 3/7)	1	Suboptimal CTG during delivery; delay in the performance of a caesarean, despite failure to aquire a micro blood sample	DSOG
G (29 0/7)	2	1. Early preterm delivery in general hospital; no timely NICU place available	DSOG
		2. Artificial respiration equipment not working	DSP[4]
H (42 0/7)	3	1. Traumatic ventouse and forcipal delivery (seven times ventouse, one time forcipal extraction tried, neonate delivered with caesarean)	RCOG/ ACOG
		2. Senior obstetrician arrived too late in hospital	DSOG
		3. Delay in intubation and ventilation	Evidence

Case (AD)	Amount of SSCFs	Description of SSCF	Guidelines involved?
J (36 1/7)	1	Patient had complaints for weeks without adequate diagnosis of obstetrician, finally maternal reanimation for asthma cardiale and caesarean for fetal distress	-
K (38 5/7)	3	1.Obvious symptoms of uterine rupture not recognized	Evidence
		2. Administration of vaginal prostaglandins without prior CTG	DSOG
		3. Inadequate communication obstetrican – (hospital) midwife	Local protocol
Total	**17 SSCFs**		

* the local protocol changed after this perinatal audit meeting, concerning the presence of an operating team during night time.

1 Dutch Society of Midwives

2 Dutch Society of Obstetrics and Gynaecology

3 Royal College of Obstetrics and Gynaecology/ American College of Obstetrics and Gynaecology

4 Dutch Society of Pediatrics

Maternal substandard care

Fourteen SSCFs (29%) were attributed to the pregnant women themselves(Table 4 shows all SSCFs in some detail). Seven women consulted the obstetrician about ruptured membranes or an observed decrease in fetal movements too late. Five women received poor or no antenatal care, and two women deliberately refused essential treatment such as caesarean section in cases of severe fetal distress.

General practitioner substandard care

Only one SSCF out of 48 (two %) was found to be attributable to a general practitioner. A missed diagnosis of manifest preeclampsia was considered to be possibly related to perinatal death.

Midwife substandard care

Eleven SSCFs out of 48, (23%) were found to be attributable to midwives. Eight SSCFs were related to inadequate detection, missed intrauterine growth retardation (n=7), and one missed diagnosis of placental abruption. One SSCF was related to therapy (prolapsed cord following artificial rupture of the membranes with a non-engaged head) and two SSCFs were related to the communication between primary care providers, or between patient and care provider.

Table 4 Components and echelon of substandard care* ¶

	Component of substandard care					
	Detection	Therapy	Logistics	Communication	Total	
Patient	11	2	-	1	14	(29)
General practitioner	1	-	-	-	1	(2)
Midwife	8	1	-	2	11	(23)
Obstetrician	11	7	1	1	20	(42)
Paediatrician	-	2	-	-	2	(4)
Total SSCFs	**31**	**12**	**1**	**4**	**48**	**(100)**

* substandard care with possible or likely contribution to perinatal death only

¶ Cases can prevail more than once in this table, since more than 1 substandard care factor could be attributed to a case.

Obstetrician substandard care

Twenty SSCFs out of 48 (42 %) were found to be attributable to obstetricians. Eleven SSCFs were related to detection. Among these SSCFs were a delay upon notification of growth retardation (n=4) and insufficient quality of antenatal care concerning the detection of maternal or fetal distress (n=4).Two SSCFs were related to care during labour and delivery (missed fetal distress, missed uterine rupture). Seven SSCFs were related to therapy. These SSCFs comprised inadequate antenatal care (n=2) or inadequate care during labour and delivery (n=5). In one case the referral to a tertiary care academic centre was too late to be beneficial.

Paediatrician substandard care

A paediatrician was involved in 28 cases of perinatatal mortality. In these 28 cases two SSCFs were attributed to the paediatrician. These were too late intubation after birth and insufficient support of the newborn baby after caesarean section.

Discussion

In this study of consecutive cases of perinatal death, data were collected through a sensitive two-stage procedure. We also insured a high level of explicit blinding. All cases were subsequently discussed in a structured meeting of a newly installed regional perinatal audit.

Our study shows general consensus (97%) in regard to the presence or absence of SSCFs and the cause of death according to the extended Wigglesworth classification. In 41% of all 85 cases over 23 completed

weeks of gestation, no SSCFs were found. A possible contribution to perinatal death was found in 25% of cases and a likely contribution in eight %, which implies that there is potential for improvement in care in one out of three cases. The most important groups that are predisposed for the presence of SSCFs are the unexplained antepartum fetal deaths and the intrapartum deaths.

In the present study, a regional audit panel reviewed cases of perinatal death. A recent report on perinatal audit that provided feedback to the doctors involved revealed that these doctors tended to be stricter in their attribution of SSCFs then an external audit panel.[14] However, to our knowledge no other reports have been published where a regional audit panel systematically reviewed perinatal death cases.

Forty seven cases of perinatal death before 23 completed weeks were not included for analysis in this study. Within this group, SSCFs were attributed to 13% of cases. This prevalence may be an overestimation as recent data suggest little effect of cervical length measurements and cerclage, which were the only SSCFs attributed below 23 completed weeks.[15,16]
Providing feedback to care providers, about the presence of substandard care is an essential component of (perinatal) audit. Feedback in this study was given in general terms, and by organising several symposia for regional care providers in regard to SSCFs.
The audit process was discussed extensively with all panel members in order to evaluate the process. A random selection of cases of perinatal death was evaluated by an external audit panel. When the prevalence of SSCFs in this study is compared with other perinatal audits in Western Europe, our figures are within the same range.[4,6,7,9,17] Furthermore, we believe that feedback to care providers can be more easily given in a rotating regional audit. The change of a local protocol after the panel meetings is for that an important example. (see table 2)

At the outset of this study, we decided to categorize the smoking behaviour of the mother in pregnancy as a well-known risk factor for perinatal death, such as the use of other drugs, maternal (over)weight and maternal age.[18,19] It was not considered a maternal SSCF, as was done in some other studies. [10,17]

Our study recognized the key role of the mother. 29% of the 48 SSCFs (14 SSCFs in 11 cases) were attributed to the pregnant woman. In 10 out of the 11 cases, the mother belonged to an ethnic minority group. As 50% of all Amsterdam inhabitants are from ethnic minority groups[20] this overrepresentation suggests that the presence of maternal SSCFs is more prevalent among ethnic minorities.

Some of the maternal SSCFs were related to traditional beliefs and cultural differences.These factors are difficult to change. However, most maternal SSCFs were related to communication problems between mother and care provider concerning detection and therapy. (Such as notification of a decrease of fetal movements to the midwife after three days or the refusal to implement a life-saving therapy for the baby). In these cases, many questions remain unanswered. For example, was the information given by the midwife/obstetrician adequate and/or was there a language problem between the woman and the care providers? These questions were beyond the scope of the present study. More research is therefore needed to understand the background of these particular maternal SSCFs.

As a result of our study we suggest the following recommendations be implemented in practice.

Prompt action after notification of growth retardation

Prompt action by both midwives and obstetricians is required when they suspect or receive notification of growth retardation. In this study, very strict criteria were used to assign SSCFs to cases where intra uterine growth retardation was suspected or reported. In general, detection of growth retardation is poor, even if current diagnostic tools are applied under controlled trial conditions.[21] In this study, the audit panel only considered growth retardation as a SSCF if this condition was suspected and notified during pregnancy but there was a delay taking action (e.g. intensive fetal monitoring, ultrasound etc). The importance of growth retardation as a SSCF has been observed previously [9,10,17] but not the specific contribution of delay following notification of growth retardation. Clear diagnostic procedures should be implemented following the notification or suspicion of a growth retarded fetus.

Guidelines in intrapartum death cases

In complicated cases of intrapartum deaths, the majority of SSCFs concern the violation of national or international guidelines, or a local protocol (15/17 SSCFs). These intrapartum deaths should be discussed structurally with the involved care providers, for example hospital-wide. Local or regional protocols should be subject to regular discussion and should be frequently updated and improved if necessary.

The role of the general practitioner

General practitioners do not often provide structural perinatal care and therefore, only one SSCF was attributed to this group. However, pregnant women will consult their general practitioner with symptoms of, for example, pre-eclampsia. Therefore, obstetric problems with possible severe consequences for fetal and maternal outcome should be a priority in the education and (re)training of general practitioners.

Background of maternal substandard care

Antenatal care in the Netherlands is available for all pregnant women at a low threshold. It is therefore of concern that in our small study population at least 14 pregnant women consulted an obstetric care provider too late or acted against their advice, possibly or likely resulting in the death of the fetus or neonate. More women from ethnic minority groups than expected (based on the ethnic composition of the city of Amsterdam), were among this group of women.

The background of maternal SSCFs could not be estimated in this study. This issue should be investigated further however, and midwives and obstetricians should be encouraged to provide pregnant women, (especially from ethnic minority groups), with clear information about when they should contact the care provider during pregnancy or delivery.

In an era where there is an unprecedented level of biochemical and physical diagnostic tools available, perinatal mortality continues to resist causal analysis. This study of perinatal audit however shows that perinatal mortality will only be improved by taking small steps in a number of different areas rather than through a few big leaps. These steps however will at least assist in minimizing the distance between observed substandard care and change.

Acknowledgements

We would like to thank the following people who participated in the Amsterdam perinatal audit: D.J. Bekedam, P.J.E. Bindels, A.B. Dijkman, K.F. Heins, N. Jorna, J.C. Kaandorp, M. Knuist, J.H. Kok, D. Lesscher, G.L.M. Lips, S. Logtenberg, N. Menelik, J.A.M. van der Post, J.I. Puyenbroek, M.K. Sanders, L. van Toledo, A.J. van Veelen,G. van Waveren, E.M.A. van de Veer, M. Wieringa- de Waard.

Reference List

(1) Richardus JH, Graafmans WC, van der Pal-de BK, Amelink V, MP, Verloove-Vanhorick SP et al. An European concerted action investigating the validity of perinatal mortality as an outcome indicator for the quality of antenatal and perinatal care. [Review] [46 refs]. J Perinat Med 1997; 25(4):313-324.

(2) Dunn PM. Perinatal audit in Europe. Br J Obstet Gynaecol 1997; 104(8):875-876.

(3) Pattinson RC, Makin JD. Critical incident audit and feedback to improve perinatal and maternal mortality and morbidity [Protocol for a Cochrane Review]. Cochrane library 2003;(1).

(4) Maternal and Child Health Research Consortium London. CESDI; Confidential Enquiry Into Stillbirths and Deaths In Infancy. 6th annual report. CESDI-organisation 1998.

(5) Macintosh M (ed). Project 27/28: An Enquiry into quality of care and its effects on the survival of babies born at 27-28 weeks. 2003. TSO.

(6) Westergaard HB, Langhoff-Roos J, Larsen S, Borch-Christensen H, Lindmark G. Intrapartum death of nonmalformed fetuses in Denmark and Sweden in 1991. A perinatal audit. Acta Obstet Gynecol Scand 1997; 76(10):959-963.

(7) Langhoff-Roos J, Borch-Christensen H, Larsen S, Lindberg B, Wennergren. Potentially avoidable perinatal deaths in Denmark and Sweden 1991. Acta Obstet Gynecol Scand 1996; 75(9):820-825.

(8) Eskes M, van Alten D, Treffers PE. The Wormerveer study; perinatal mortality and non-optimal management in a practice of independent midwives. Eur J Obstet Gynecol Reprod Biol 1993; 51(2):91-95.

(9) Reu Pd, Nijhuis JG, Oosterbaan HP, Eskes TK. Perinatal audit on avoidable mortality in a Dutch rural region: a retrospective study. Eur J Obstet Gynecol Reprod Biol 2000; 88(1):65-69.

(10) Vredevoogd CB, Wolleswinkel-van den Bosch JH, Amelink-Verburg MP, Verloove-Vanhorick SP, Mackenbach JP. [Perinatal mortality assessed: results of a regional audit]. Ned Tijdschr Geneeskd 2001; 145(10):482-487.

(11) O&S ABoS. The Amsterdam population, birth and death, 1997-2001[in Dutch]. O&S . 2000.

(12) Alderliesten ME, Bleker OP, Bonsel GJ, Stronks K, Lith v JMM. PARIS; Perinatal Audit; Research and Implementation Study. Research protocol department of Obstetrics/ Public Health, Academic Medical Centre 1998.

(13) Cartlidge PH, Dawson AT, Stewart JH, Vujanic GM. Value and quality of perinatal and infant postmortem examinations: cohort analysis of 400 consecutive deaths. BMJ 1995; 310(6973):155-158.

(14) Amelink-Verburg MP, Roosmalen Jv, Roelofsen JM, Wolleswinkel-van den Bosch JH, Verloove-Vanhorick SP. Evaluation and validation of a perinatal death audit by means of feedback to the caregivers. Ned Tijdschr Geneeskd 2003; 147(47):2333-2337.

(15) Harger JH. Cerclage and cervical insufficiency: an evidence-based analysis. Obstet Gynecol 2002; 100(6):1313-1327.
(16) Drakeley AJ, Roberts D, Alfirevic Z. Cervical stitch (cerclage) for preventing pregnancy loss in women (Cochrane Review). Cochrane Database Syst Rev 2003;(1):Cochrane Database 003253.
(17) Wolleswinkel-van den Bosch JH, Vredevoogd CB, Borkent-Polet M, van Eyck J, Fetter WP, Lagro-Janssen TL et al. Substandard factors in perinatal care in The Netherlands: a regional audit of perinatal deaths. Acta Obstet Gynecol Scand 2002; 81(1):17-24.
(18) Rosenberg TJ, Garbers S, Chavkin W, Chiasson MA. Prepregnancy weight and adverse perinatal outcomes in an ethnically diverse population. Obstet Gynecol 2003; 102(5 Pt 1):1022-1027.
(19) Seoud MA, Nassar AH, Usta IM, Melhem Z, Kazma A, Khalil AM. Impact of advanced maternal age on pregnancy outcome. Am J Perinatol 2002; 19(1):1-8.
(20) O&S ABoS. The Amsterdam population, ethnic groups - 1985-1996 [Dutch]. Amsterdam, O&S 1996.
(21) Bais JMJ, Eskes M, Pel M, Bonsel GJ, Bleker OP. Effectiveness of detection of intrauterine growth retardation by abdominal palpation as screeningtest in a low risk population: an observational study. Eur J Obstet Gynecol Reprod Biol 2004; 116(2):164-169.

Marianne E Alderliesten [1,5]
Jan Peringa [2]
Victor PM van der Hulst [2]
Hans LG Blaauwgeers [3]
Jan MM van Lith [1,5]

4

OLVG Hospital Amsterdam, The Netherlands; department of Obstetrics and Gynaecology(1), Radiology (2), and Pathology(3) Academic Medical Centre Amsterdam, The Netherlands; department of Obstetrics and Gynaecology (5)

...

Perinatal mortality; clinical value of post-mortem Magnetic Resonance Imaging compared to autopsy in routine obstetric practice

Abstract

Objective: To compare post-mortem Magnetic Resonance Imaging (MRI) with autopsy in perinatal deaths. To determine the acceptance and feasibility of post-mortem perinatal MRI.

Design: cohort study

Setting: large teaching hospital

Population: Fetuses and neonates from 16 weeks of gestation until 28 days after births, stillbirths as well as neonatal deaths.

Methods: MRI was performed prior to autopsy in a consecutive cohort of perinatal deaths after full parental consent. Agreement between MRI and autopsy was calculated. The consent rate for both examinations was recorded separately, as well as the time between the perinatal death and the MRI.

Main outcome measure: Full agreement between MRI and autopsy.

Results: Of 58 cases, 26 parents consented to both examinations (45%). Autopsy showed 18 major malformations, of which ten were detected with MRI. The positive predictive value of MRI was 80% (4/5) and the negative predictive value was 65% (13/20). Additional consent for MRI was given in eight cases (14%). In 84% the MRI could be performed within 48 hours.

Conclusions: MRI is of value if autopsy is refused, but diagnostic accuracy is insufficient to recommend substitution of full autopsy. The acceptance rate of MRI only is better then that of autopsy.

Introduction

Pregnancies are complicated by perinatal death in about 1%.[1] Establishing the cause of this perinatal death is important for the counselling of parents and in taking decisions for future pregnancies.[2] Several studies have confirmed the diagnostic value of perinatal autopsy in post-mortem examination. [3,4] However, studies in both the United States and Europe indicate that as many as 40% of all perinatal deaths are not submitted for autopsy. [3,5,6] The reason for this high percentage of refusals is largely unknown. Landers et al identified the parents' socio-economic status and the clinical diagnosis as factors related to consent to neonatal autopsy in 33 cases.[7]

In the early nineties, the first experiences with Magnetic Resonance Imaging (MRI) as an alternative for autopsy in post-mortem examinations among both adults, fetuses and neonates were published.[8,9,10]

In 1996 and 1997 Woodward[11] and Brookes[12] systematically compared MRI to autopsy in 26 and 20 cases of perinatal death, respectively. Due to the inclusion process (predominantly terminated pregnancies for congenital malformations in Woodward et al's atudy or fetuses recruited from the pathology unit in Brookes et al's study a very high rate of malformations was found at autopsy in these studies. The value of MRI as an alternative to autopsy in a non-selected obstetric population could not be estimated.

The objective of the present study was to establish the concordance of post-mortem perinatal MRI with autopsy findings in a non-selected obstetric population. The second objective was to determine the acceptance of MRI compared with autopsy and to evaluate its implementation in routine obstetric practice.

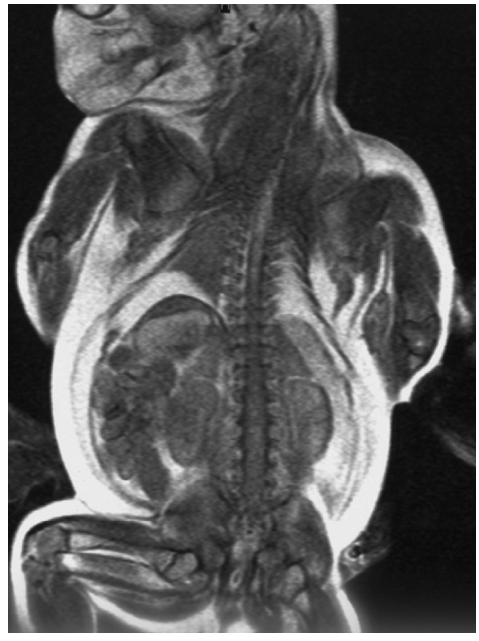
Methods

We scheduled to study a consecutive cohort of perinatal deaths in the OLVG Hospital, a general district hospital with approximately 2000 hospital deliveries and 800 home deliveries a year. The study group consisted of fetuses and neonates, who were born from 16 weeks of gestation and who died intrauterine, during delivery or after delivery, until 28 days after birth. Consent for autopsy was asked of all parents, as part of routine perinatal care. Independent of the consent for autopsy, explicit parental consent for an MRI was asked as part of the study protocol. After consent, MRI was performed as soon as possible. Both the MRI and the autopsy were reported by the same radiologist and pathologist, respectively, in a standardised way. All organs were reviewed and the malformations observed were described. The extremities were not examined as they are easily evaluated by physical examination

and conventional X-rays. The radiologist was not supplied with clinical information and both radiologist and pathologist were blinded for each other's findings. The autopsy findings were compared with those of MRI. Afterwards, the malformations found at autopsy were classified as major or minor malformations, according to Woodward,[11] at a clinical meeting with an obstetrician, pathologist and radiologist. The concordance between MRI and autopsy per case of perinatal death, considering only the major malformations, was calculated.
MRI was performed on a Philips Gyroscan NT 1 Tesla with a powertrak 3000 Gradientsystem. Depending on the size of the child a specific coil was used. Small children up to 500 grams were scanned using a dedicated knee coil. Larger children were scanned with 'wrap-around' surface coils. The imaging protocol of the head consisted of a sagittal and transverse T1 weighted sequence (TR 500 ms, TE 18 ms, matrix 512x512, NSA 2, slicethickness/gap 3mm/0.6) and a transverse T2-dual weighted Turbospin echo sequence (TR 3000, TE1 11, TE2 150, matrix 512x512, NSA 2, slicethickness/gap 3.0mm/0.3). The body was scanned in a coronal and sagittal direction using a T1 weighted sequence in the first 16 cases and using a T2 Turbospin echo sequence in the following 10 cases.
All analyses were performed using SPSS 10.0 statistical program. Approval from the local medical ethics committee was obtained prior to the start of this study.

Results

During the inclusion period , 58 perinatal deaths occurred at the OLVG hospital. Technically, MR images were of good quality. Maceration influences the quality of MRI, as it influences the quality of autopsy; in some cases however, very good images could be obtained even from third degree macerated fetuses (see figure 1).



1. T1-weighted MRI image of a third degree macerated fetus, born after a gestational age of 25 4/7 weeks. Autopsy was performed, but evaluating the presence of malformations was difficult due to the degree of maceration. At MRI no malformations were detected.

One case was excluded from analysis because the quality of the MRI was insufficient for reporting.
In 26 cases, a combined consent for autopsy and MRI could be obtained. The mean gestational age in the 26 cases with combined consent was 25,3 weeks (range: 16-40), with a mean birthweight of 909 g (range 60-3885 g). There was one twin pregnancy and there were 17 male and 9 female fetuses/neonates in the study group.
A total of 18 major and 8 minor malformations were found at autopsy. Fifty-six percent (n=10) of the major malformations were detected with MRI (see Table 1). Umbilical hernia and lung lesions were the minor malformations that were detected with MRI (see Table 2). Multiple small lung lesions were visible on MRI, where at autopsy meconium aspiration was present (lung lesions).

Table 1 Major malformations at autopsy

Case nr.	Major malformations	Detected with MRI	GA (weeks)	Birthweight (grams)
6	omphalocele	-	16	204
7	myelomeningocele	-	21	74
8	omphalocele	+	25	1316
	anal atresia	-		
12	complex cor vitium	-	29	695
	mega ureters	-		
14	hypoplastic lungs	+	36	3885
	dysplastic kidneys	+		
15	complex cor vitium	-	40	3430
17	hydrops	+	32	3505
18	left kidney agenesis	+	18	178
22	tracheo-oesophageal fistula	-	23	430
25	hydroureter	+	22	738
	dysplastic kidney	+		
	aortic coarctation	-		
	distal urethral stenosis and dilatation of the bladder	+		
26	spina bifida occulta	+	21	400
	malformations genital system, secondary to neural tube defect; aplastic/hypoplastic bladder;	+		

Table 2 Minor malformations at autopsy

Case nr.	Minor malformations	Detected with MRI	GA (weeks)	Birthweight (grams)
4	VSD 1-2 mm	-	29	1225
12	horseshoe shaped kidney	-	29	695
	umbilical hernia	+		
18	tumour under left kidney (1.5 cm)(neural tissue)	-	18	178
20	lung lesions	+	39	3400
21	VSD 1-2 mm	-	20	350
22	micrognatia	-	23	430
25	small ASD	-	22	738

Two cases of congenital pneumonia and one case of intra-uterine sepsis were seen at autopsy. On MRI, one of the two cases of congenital pneumonia showed multipele lung lesions that were interpreted as a substrate for the lung infection. (The other case showed no specific findings on MRI). In 14 cases no malformations or only minor malformations were detected at autopsy. In only one of these cases a malformation was suspected on MRI (abdominal wall defect) that was not established at autopsy. Considering only the major malformations, the diagnostic accuracy of MRI was 17/25. Accepting autopsy as gold standard, the positive predictive value (PPV) of MRI for the detection of malformations per case of perinatal death was 80% and the negative predictive value (NPV) was 65% (see Table 3).

Table 3 Full agreement between autopsy and MRI

		Autopsy +	Autopsy § -	Total
MRI*	+	4	1	5
MRI	-	7	13	20
Total		**11**	**14**	**25**

§ Cases in which no major malformations were found at autopsy.

* All major malformations in one case detected with MRI.

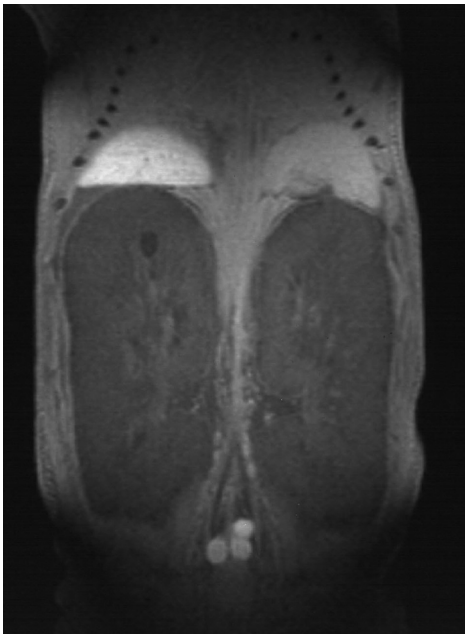
The autopsy rate in the study group was 45% (n=26). MRI was consented to by 59% of all parents (n=34). There were no cases with consent to

autopsy only without consent to MRI. Four pregnancies were electively terminated for congenital malformations. In 39% of cases, the MRI was performed within 24 hours after death or delivery (in case of a stillbirth); in 45%, it was performed between 24 and 48 hours. All scans were performed within 96 hours. In two cases, no consent to MRI was given because the projected time interval between delivery and the scan was considered too long by the parents. In these cases, the scan could have been performed within 48 hours.
A higher acceptance rate for both examinations was seen in the early gestational age group. Before 24 weeks the parents were more likely to consent to both examinations. In the combined consent group more fetuses died before delivery but this difference was not significant (n= 20 versus n= 5).

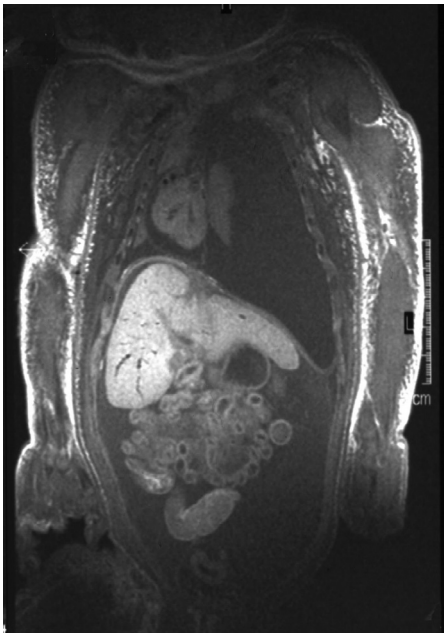
Discussion

From a diagnostic point of view, accuracy of post-mortem MRI in perinatal death was somewhat disappointing even if attention was restricted to major malformations. Several major malformations were clearly visible on MRI (e.g. the presence of dysplastic kidneys in a small fetus) (figure 2). In addition, a hydrops fetalis could be well detected (figure 3). However, several differences were found between the outcome of autopsy and MRI. Some of these differences can be explained by the early gestational age or low birthweight of the child (see Table I), some by the nature of the malformation. Cardiac defects were not detected in this study. The same poor sensitivity for cardiac malformations was found in the studies of Woodward[11] and Brookes.[12] In their studies good results are described in the detection of central nerve system (CNS) malformations; in our study the number of CNS malformations was too small to confirm this conclusion. Obstetricians as well as parents should be aware that a normal MRI does not necessarily equate with a normal baby; even major malformations can be missed.
Only one 'false positive' finding was detected at MRI: a presumed abdominal wall defect. This suspected malformation was present in a fetus of 90 grams, born at a gestational age of 23 weeks who died intrauterine two weeks before delivery and who was third degree macerated. There was a strange configuration of the umbilical cord seen at autopsy, which could explain the possible abdominal wall defect suspected at MRI.
In the present study the radiologist was blinded to the clinical findings and did not see the child himself. At least three malformations were missed at MRI that certainly would have been observed after physical examination of the child (anal atresia, omphalocele, myelomeningocele). In addition, the abdominal wall defect too would not have been detected.

This would improve the PPV to 100% (5/5); and the NPV to 70% (14/20). Our study population consisted of only four cases of electively terminated pregnancies for congenital malformations. This may be the reason why our rate of malformations is low compared with other studies. In the present study a total of 18 major malformations were found, compared with 46 major malformations in the study of Woodward et al[11], where the study group of 26 fetuses included 10 terminations of pregnancy for congenital malformations. Therefore the prevalence, the positive and negative predictive values found in this study, will more accurately reflect an obstetric population in a general district hospital.
In a 13- month cohort of 58 patients consent for routine autopsy could be obtained in about half of cases, which is in conformity with national and international autopsy rates. [3,5,6] Consent for MRI was obtained in an additional 15%, demonstrating a higher acceptance. In 84% of all cases the MRI could be performed within 48 hours after the perinatal death. A faster access to MRI could only have given a slight improvement.
The acceptance rate of 59% for MRI in the study group was not divided



2. Dysplastic kidneys (T1 weighted image)



3. Hydrops fetalis of unknown origin. This child was born at GA 32 weeks with an estimated time of death two days before delivery; the birthweight was 3505 grams. (T1 weighted image) Hydrops can be seen clearly in the thorax; in the stomach, and under the skin.

equally between the different gestational ages at birth. The younger the gestational age at the time of birth, the more likely the parents were to consent to both MRI and autopsy. Especially above 32 weeks, the parental consent to autopsy was low.

No evidence was found in this study for an additional value of MRI when the consent for a full autopsy is obtained. Autopsy remains the gold standard in postmortem examination of perinatal death. Therefore, parents should not be offered MRI scans until it is clear they will not consent to autopsy, except possibly in those cases where an abnormality known to be demonstrable on MRI is suspected.

When offering MRI to parents they should be adequately counselled on the limitations of the MRI technique, preventing the danger of parental disillusionment if they have the impression that MRI is even or nearly as good as autopsy. However, the chance of malformations being false positively detected with MRI is so low that in cases of autopsy refusal MRI examinations may yield important extra information in relation to the perinatal death.

Reference List

1 anonymous, Perinatal mortality in the Netherlands and Amsterdam. 1994-1998. Causes of death statistics Central Bureau of Statistics 1999

2 Chiswick M. Perinatal and infant post-mortem examination [editorial; comment]. BMJ 1995;310:141-142.

3 Saller DNJ, Lesser KB, Harrel U, Rogers BB, Oyer CE. The clinical utility of the perinatal autopsy. JAMA 1995;273:663-665.

4 Faye-Petersen OM, Guinn DA, Wenstrom KD. Value of perinatal autopsy. Obstet. Gynecol. 1999;94:915-920.

5 Craven CM, Dempsey S, Carey JC, Kochenour NK. Evaluation of a perinatal autopsy protocol: influence of the Prenatal Diagnosis Conference Team. Obstet. Gynecol. 1990;76:684-688.

6 Cartlidge PH, Dawson AT, Stewart JH, Vujanic GM. Value and quality of perinatal and infant postmortem examinations: cohort analysis of 400 consecutive deaths. BMJ 1995;310:155-158.

7 Landers S, Kirby R, Harvey B, Langston C. Characteristics of infants who undergo neonatal autopsy. J.Perinatol. 1994;14:204-207.

8 Ros PR, Li KC, Vo P, Baer H, Staab EV. Preautopsy magnetic resonance imaging: initial experience. Magn.Reson.Imaging 1990;8:303-308.

9 Roberts MD, Lange RC, McCarthy SM. Fetal anatomy with magnetic resonance imaging. Magn.Reson.Imaging 1995;13:645-649.

10 Nasu K, Yoshimatsu J, Anai T, Miyakawa I, Komatsu E, Maeda T. Magnetic resonance imaging of fetal autosomal recessive polycystic kidney disease. J.Obstet.Gynaecol.Res. 1998;24:33-36.

11 Woodward PJ, Sohaey R, Harris DP, et al. Postmortem fetal MR imaging: comparison with findings at autopsy. Am.J.Roentgenol. 1997;168:41-46.

12 Brookes JA, Hall-Craggs MA, Sams VR, Lees WR. Non-invasive perinatal necropsy by magnetic resonance imaging. Lancet 1996;348:1139-1141.

Marianne E Alderliesten [1]
Karien Stronks [2]
Jan MM van Lith [1]
Bert J Smit [3]
Marcel F van der Wal [4]
Gouke J Bonsel [1,2]
Otto P Bleker [1]

5

Academic Medical Centre Amsterdam, Department of Obstetrics and Gynaecology, (1) Department of Public Health, (2) ErasmusMC - Sophia Children's Hospital, University Medical Centre Rotterdam, Department of Neonatology (3) Municipal Health Service Amsterdam (4)

Ethnic differences in perinatal mortality. A perinatal audit on the role of substandard care

Abstract

Objectives: to investigate the contribution of substandard care to ethnic inequalities in perinatal mortality.

Design and setting: perinatal audit in Amsterdam, the Netherlands.

Population: 137 consecutive perinatal death cases (16 weeks GA - 28 days after delivery).

Methods: A standardized procedure to establish cause of death and substandard care by perinatal audit.

Main Outcome measures: Perinatal mortality rates in ethnic groups. Cause of death classified by extended Wigglesworth classification. Presence of substandard care: unlikely to be, possibly or likely to be related to perinatal death. Component of care considered to be substandard.

Results: In Surinamese and other 'non-Western mothers' (mainly from Ghana) perinatal mortality, beyond 16 weeks gestational age, was statistically significantly higher than among native Dutch mothers. (4,01%; 2,50% and 1,07% respectively). In Surinamese and Moroccan mothers, we observed a higher rate of early preterm deliveries. The frequency of substandard care differed statistically significant between ethnic groups (p=0,034), being the highest among Surinamese mothers. These differences were especially met in the prevalence of (more) maternal substandard care factors among Surinamese and Moroccan mothers. These factors consisted of a later start date for antenatal care or a later notification of the caregiver about obstetrical problems (e.g., rupture of membranes, decrease of fetal movements).

Conclusions: The higher perinatal mortality in Surinamese and other non-Western groups is mainly due to a higher rate of early preterm deliveries. No differences were observed in care during labour and delivery between ethnic groups. Among Surinamese mothers, however, the results indicate that substandard care with maternal involvement plays a role in explaining their higher perinatal mortality rates.

Introduction

In most European countries perinatal mortality is reported as being higher among ethnic minorities than among the native population, in registries as well as in specific studies. [1 2 3 4 5] The literature reports that several determinants of perinatal mortality, e.g. maternal age, obstetrical history, are related to ethnic background.[3;6;7] Though often put forward as a potential explanation [8] little is known about the systematic role of antenatal and perinatal care in explaining ethnic differences in perinatal mortality. Recently, a Swedish study suggested that substandard care was an important indicator for the higher perinatal mortality among East-African women when compared to native Swedish mothers[9]. This single observation requires confirmation and further elaboration. In addition, more insight should be obtained into the background of substandard care, (such as cause of death, duration of pregnancy) as this might indicate possibilities for improvement.

The present study compares the perinatal death rates among ethnic groups living in the city of Amsterdam, the Netherlands as indicator for perinatal care. We first studied differences in perinatal mortality among ethnic groups. This was followed by an audit procedure to elicit specifically the role of care inadequacies as causal factors, including the possible involvement of the mother.

Methods

We included all consecutive cases of perinatal mortality from 16 weeks of gestational age onwards until 28 days after delivery from February until October 1999. Perinatal deaths were included from 16 weeks of gestation since there is a known difference in the prevalence of very early preterm deliveries between ethnic groups.[1]

Ethnic related perinatal mortality

The ethnic origin of the fetus/newborn was based on the country of birth of the mother and from her parents, using Amsterdam population registry data. The mother was considered a first generation immigrant when she was born abroad; she was considered a second generation immigrant when (one of) her parents were born abroad, but she herself was born in the Netherlands (standard definition of 'ethnicity' of the Central Bureau of Statistics) [10] The following ethnic groups were distinguished: Dutch, other Western, Surinamese, Turkish, Moroccan, other non-Western. The other non-Western group in Amsterdam consists for a large part of Ghanese women. These ethnic groups represent the largest ethnic groups in the city of Amsterdam.[10]

To calculate the perinatal mortality rate, the monthly birth rate divided to ethnic group in the city of Amsterdam in the study period was used as a denominator.

Cause of death

The cause of death was recorded during the panel meetings, using the extended Wigglesworth classification.[11]

Substandard care

A structured case record form in questionnaire format was developed, based on published risk factors for perinatal death and on existing guidelines for perinatal care (structured case record form available from the authors in Dutch). The questionnaire included a detailed verification procedure on all the clinical and process data, required for the unambiguous diagnostic classification.
An anonymous narrative abstract was prepared with minimal changes to prevent recognition of the individual case. A perinatal audit committee was established with regional caregivers as members. The audit members were not told of the ethnic origin of the mother. The audit committee consisted of two paediatricians, two obstetricians, a general practitioner and two midwives who were rotated every two months. All candidates received a training session, prior to their participation. Review included an individual judgment of each case, prior to the session, and a collective judgment by the perinatal audit panel following discussion during a panel committee meeting.
Substandard care was defined as being present if perinatal care did not meet the defined minimally accepted standards. If present, its contribution to perinatal death in the context given was determined. Four ordinal categories were distinguished: no substandard care detected; substandard care detected but unlikely to have contributed to perinatal death; substandard care detected, possibly contributing to perinatatal death; substandard care detected and likely to have contributed to perinatal death. If substandard care was revealed, the audit panel decided whether it was related to detection, ie. recognition of the problem, or therapy, and if there was any maternal involvement in antenatal care or contacting the care provider in case of a problem. For each case we recorded the maternal age at time of delivery, parity and ethnic origin. Women were divided into three categories of socio-economic status based on postal area code, which has sufficient detail to derive a proxy measure for income.

In the Netherlands, ante- and perinatal care is part of the basic insurance system and has therefore a low threshold for all pregnant women. The present pattern of first antenatal visit consists of a booking visit around the 12th week of gestation, at the independent midwife

(low-risk pregnancy) or obstetrician (prior high-risk pregnancy). When risk factors are changing e.g. development of hypertension, the pregnant woman is referred to an obstetrician in a hospital. Referral is also possible during delivery, for example when there is meconium stained fluid. Pregnant women, who receive antenatal care from the independent midwife, can choose to deliver at home, as well as in one of the six Amsterdam hospitals. The duration of pregnancy is calculated using either ultrasound or the first day of the last period. No standard anomaly scan is performed in routine antenatal care in the Netherlands.
All independent midwives in the city of Amsterdam, as well as all six Amsterdam hospitals participated in this study. The completeness of data was thoroughly manually checked in all participating hospitals e.g. by controlling delivery books and other sources. Descriptive and standard cross tabulation were computed using SPSS [11.5]; no missing data imputation was applied. A difference was considered statistically significant if $p < 0,05$.
Ethical approval for the performance of this study was obtained from all participating hospitals.

Results

During the study period, 137 consecutive cases of extended perinatal death were included (beyond 16 weeks of gestational age and including the first four weeks of life). A total of 6922 deliveries occurred during the study period in the city of Amsterdam.[12]
42% of the women were nulliparous. Median maternal age was 31, with no difference between ethnic groups. Only one mother was under 18 years of age. All but three deliveries occurred at the hospital under the responsibility of the obstetrician. In one case, the midwife was notified after an unassisted delivery at home. Median maternal age was 29 years in nulliparous and 33 years in multiparous women. Of all 137 cases, 10 children represented five twin pairs and three were one of a pair of twins.
Parity was divided unevenly between the ethnic groups ($p=0,039$); the highest percentage of primiparae was found among the native Dutch group. Among ethnic minorities, a higher percentage of mothers had a low socio-economic status as compared to the native Dutch mothers. ($p= 0,004$)

Ethnic related perinatal mortality

The ethnic origin of the mother could be elicited with certainty in 135 cases. The majority of mothers included, originated from Surinam, Turkey and Morocco. (see table 1). Of all non-Dutch mothers, 82% were first-generation and 18% second-generation immigrants.
Perinatal mortality from 16 and 24 weeks gestational age as compared to the birth rates in the respective ethnic groups is shown in table I.

Over 16 weeks of gestation, a higher percentage of perinatal death was particularly seen in Surinamese and other non-Western mothers (mainly from Ghana).

Table 1 Perinatal death rates in the study population, n=135*

Ethnic origin	Number of births #	Perinatal mortality >16 weeks GA N	(%; CI)	Perinatal mortality > 24 weeks GA N	(%; CI)
Dutch	3172	34	(1.07; 072-1.43)	27	(0.85; 0.53-1.16)
Surinamese	724	29	(4.01; 2.58-5.44)	16	(2.21; 1.14-3.28)
Turkish	522	14	(2.68; 1.29-4.07)	8	(1.53; 0.48-2.58)
Moroccan	941	21	(2.23; 1.28-3.17)	10	(1.06; 0.41-1.71)
Other non-Western	1037	26	(2.50; 1.55-3.45)	18	(1.74; 0.94-2.54)
Other Western	526	11	(2.09; 0.87-3.31)	8	(1.52; 0.47-2.57)
Total	6922	135	1.95	87	1.26

* n =2: ethnicity of the mother could not be derived from the population registry

Source: O & S, monthly births in the city of Amsterdam, divided to ethnic origin of the mother, 1999

Cause of death

The cause of death in the different ethnic groups is shown in table 2. Surinamese and Moroccan mothers had a high number of immature deliveries, as compared to the other ethnic groups. Overall, one-third of cases remained unexplained antepartum fetal deaths. No perinatal deaths were classified in the categories: 'Accident or non-intrapartum trauma' and 'Sudden infant death, cause unknown.'

Substandard care

In just over half of the cases (52 %) no substandard care factors (SSCFs) were found. In 21 % of cases, SSCFs were found, but it was considered unlikely that these had contributed to perinatal death In the remaining 35 cases, 55 SSCFs were found, possibly contributing to perinatal death (in 27 of cases or 21 %). In 8 cases or 6 %, SSCFs were considered likely to have contributed to perinatal death with a maximum of three SSCFs per case. In 13% of perinatal death cases with a gestational age fewer than 23 completed weeks SSCFs with a possible or likely contribution to perinatal death were attributed. Over 23 completed weeks this number was 34%.

The distribution of substandard care (two categories) among the ethnic groups is shown in table 3. In perinatal death cases, where the mother

Table 2 Causes of death in the study population, classified by extended Wigglesworth classification; n=135*

	Extended Wigglesworth classification N (%)									
	Congenitial defect/ Malformation		Unexplained antepartum fetaldeath		Death from intrapartum anoxia or trauma		Immaturity		Infection	
Dutch	5	(15)	13	(38)	7	(20)	4	(12)	3	(9)
Surinamese	4	(14)	10	(35)	4	(14)	7	(24)	3	(10)
Turkish	1	(7)	5	(36)	1	(7)	1	(7)	2	(14)
Moroccan	2	(9)	6	(29)	1	(5)	7	(34)	2	(9)
Other non-Western	4	(15)	9	(35)	4	(15)	3	(12)	6	(23)
Other Western	5	(46)	2	(18)	2	(18)	1	(9)	0	-
Total (100)	**21**	**(15)**	**45**	**(33)**	**19**	**(14)**	**23**	**(17)**	**16**	**(12)**

* n=2: ethnicity of the mother could not be derived from the population registry

Table 3 Contribution of substandard care to perinatal death cases, divided to ethnic origin; n=131*

	Substandard care; N (%)					
Ethnic origin	No substandard care or with unlikely contribution to perinatal death		Substandard care with possible or likely contribution to perinatal death			
Dutch	23	(68)	11	(32)	34	(100)
Surinamese	15	(54)	13	(46)	28	(100)
Turkish	9	(69)	4	(31)	13	(100)
Moroccan	17	(81)	4	(19)	21	(100)
Other non-Western	21	(88)	3	(12)	24	(100)
Other Western	11	(100)	-	-	11	(100)
Total	**96**		**35**		**131**	**(100)**

Pearson chi-square: 0,034

* n=2: ethnicity of the mother could not be derived from the population registry
n=4: no consensus on the presence of substandard care

other specific causes		Accident or non-intrapartum trauma		Sudden infant death, cause unknown		unclassifiable		Total	
1	(3)	0	-	0	-	1	(3)	34	(100)
0	-	0	-	0	-	1	(3)	29	(100)
3	(22)	0	-	0	-	1	(7)	14	(100)
1	(5)	0	-	0	-	2	(9)	21	(100)
0	-	0	-	0	-	0	-	26	(100)
1	(9)	0	-	0	-	0	-	11	(100)
6	**(5)**	**0**	**-**	**0**	**-**	**5**	**(4)**	**135**	

originated from Surinam, a higher amount of substandard care was found. These differences were observed only in substandard care factors with maternal involvement. In the Moroccan group, 85% of all SSCFs were attributed in this category.
The content of these maternal substandard care factors were: a late start date of antenatal care (first antenatal visit after 17 weeks of gestation) 13 (5 SSCFs) and a late notification of the care provider in case of rupture of membranes or a decrease of fetal movements (> three days) (7 SSCFs). Two SSCFs were assigned for the refusal of an essential treatment (caesarean section in case of severe fetal distress). In the other categories, detection and therapy, the amount of substandard care was equally distributed among the ethnic groups.

Discussion

In line with previous studies, we observed a higher perinatal mortality rate among Surinamese women and women from other non-Western countries, with a similar trend among Turkish and Moroccan mothers. Among Moroccan mothers early preterm deliveries account for all excess perinatal mortality. In Surinamese mothers too, preterm delivery was a major cause of perinatal death. Despite post mortem analysis in about 50% of cases, one-third of cases were unexplained antepartum fetal deaths. Substandard care (all degrees) was common (48%), though not equally distributed among ethnic groups. Surinamese mothers had the highest

rate of substandard care. The 'other non-Western' group did not show more substandard care, despite observed higher perinatal mortality rates. Particularly in Surinamese and Moroccan mothers, we observed a late start date for antenatal care, and a late notification of the caregiver as causes of substandard care. The other components of substandard care (therapy and detection) did not differ between the ethnic groups. In our study, only three deliveries took place at home. In one case, the independent midwife was notified after the birth of an -already deceased- baby. In the other two cases, one substandard care factor was assigned to the midwife. Since the completeness of data was thoroughly checked, we assume that the largest amount of perinatal deaths occur in high-risk pregnancies. When a perinatal death occurs in a low-risk pregnancy, they are referred to secondary care in time.

The following methodological considerations need to be discussed. First, in a non-complete cohort an underestimation as well as an overestimation of the occurrence of substandard care can be found, depending on the types of cases missed. Given the thorough check of data in all participating hospitals, a complete coverage of all perinatal deaths during the study period can safely be assumed. The completeness of the cohort was established by comparing the data to the National Dutch Perinatal Database. The figures on perinatal mortality were comparable. (results not shown)
Second, the audit members were blinded for the ethnic background of the cases. The linkage of the mothers with the population registry Amsterdam was performed after the attribution of substandard care. Ethnic details in the narrative summary were left out when possible. As a consequence, the judgment of substandard care could not be influenced by the ethnic origin of the mother, but concealment was not perfect. Lastly, this clinical explanatory rather then epidemiological study is a small study from an epidemiological point of view. However, our data confirm literature data on several important points, eg differences in perinatal mortality, parity and socio-economic status among ethnic groups. We therefore consider that our results reflect the presence of substandard care factors in the study group.

Ethnic related perinatal mortality

Our data confirm published data on ethnic related perinatal mortality differences that also establish a higher perinatal mortality among women from African and Mediterranean descent.[1,2] The fact that we did not observe differences in quality of the provision of care among the ethnic groups in perinatal death cases, can be understood in the light of the observed cause of death pattern. Especially the higher percentage of early preterm deliveries among Surinamese and other non-Western women represents a cause of death which is hardly attributable to the quality of medical care.

Cause of death

The unexplained antepartum fetal deaths comprised 33 % of all perinatal deaths. Included in this group were all growth-retarded children (below the fifth percentile). We observed no differences in the frequency of growth-retardation between the ethnic groups, although it is known that the incidence differs among ethnic groups.[14;15] Our data concerning early preterm deliveries among Surinamese and Moroccan women, confirm earlier publications on perinatal death and ethnicity.[1]

Substandard care

Our findings suggesting comparable care provision among ethnic groups therefore contrasts with a previous study on this subject, which was performed in Sweden.[9] To the authors' knowledge, the Swedish study is the only study that has been carried out. Unfortunately however, there is little information in the Swedish study regarding cause of death patterns. This makes it difficult to compare the previous results with the results reported here.

Only a small amount of SSCFs were attributed before 23 completed weeks. In the 47 perinatal death cases before 23 completed weeks, only in 13 % of cases SSCFs with a possible or likely contribution to perinatal death were attributed (compared to 34% over 23 completed weeks). The content of these early SSCFs were mainly a neglect to perform cervical length measurements and discuss the possibility of cerclage in case of a very preterm delivery in a prior pregnancy. This prevalence may even be an overestimation as recent data reflect the ongoing discussion on this subject between obstetricians. [16;17]

The content of substandard care in the category 'detection' was different between the Surinamese and the native Dutch group. In the Surinamese group detection failures regarding immature delivery were prominent (6/8). In the native Dutch group detection failures mainly referred to a doctor's or midwife's delay in taking action when notified about growth retardation in pregnancy. Improved detection in the latter group most likely will have a larger impact on perinatal outcome.

The incidence of maternal substandard care differed among ethnic groups. In the Surinamese and Moroccan groups, more substandard care factors with maternal involvement were observed. Description of such a phenomenon requires prudence. Differences in health-seeking behavior between women of different ethnic groups can be attributed to a number of reasons that includes language incompetence which acts as a threshold, lower education, cultural insensitivity by health care providers, or reluctance or unwillingness of the mother herself to seek care or medical advice.

We wish to suggest at least two explanations. Firstly, a difference in health-seeking behaviour can be present in these groups. A recent study has shown an under-use of specialised health care services among several ethnic groups.[18] Perinatal care, as well as midwifery care, is also under-used by different ethnic groups.[13;19] A second explanation could be communication problems between caregiver and patient. In the Moroccan group this could be due to limited knowledge of the Dutch language. The Surinamese group however, speaks the Dutch language fluently, as they originate from a former Dutch colony in South America. From other studies, it is known that language proficiency is an important risk factor for inadequate use of antenatal care. [20] However, our results indicate that communication problems might also be related to other factors that go beyond language, including cultural differences and different explanatory models. The lower socio-economic position of immigrant women did not seem to play a role in explaining communication problems, as no association was observed between the frequency of substandard care and the socio-economic status of the mothers [results not shown].

By providing an in-depth analysis of the contribution of substandard care to ethnic inequalities in perinatal mortality accompanied by a careful audit procedure, this study provides a new outlook on health care and indicates areas for further research.

Since we did not find large differences in care provision, we suggest that future research focuses on different morbidity patterns in different ethnic groups in particular, preparing different risk profiles. Future research should also focus on the background of maternal substandard factors. This will enable the starting points for differentiating health care to be located. We showed that comparing rates of substandard care between countries or ethnic groups is not complete without simultaneously analysing causes of death.
Our results indicate that the care for pregnant women in migrant groups can be improved by improving the communication between caregivers and the women concerned. The importance of using the services of an interpreter, either in person or by telephone, in explaining important information to pregnant women, can not be overemphasized. These measures taken however should not focus on language alone, but also on the learning of skills, and attention should be given to existing explanatory models in the different ethnic groups. Given the increase in deliveries in ethnic minorities in Western European countries we believe that a strategy that is tailored to different ethnic groups might contribute to lower perinatal mortality in general.

Acknowledgements

We would like to thank D.J. Bekedam, P.J.E. Bindels, A.B. Dijkman, K.F. Heins, N. Jorna, J.C. Kaandorp, M. Knuist, J.H. Kok, D. Lesscher, G.L.M. Lips, S. Logtenberg, N. Menelik, J.A.M. van der Post, J.I. Puyenbroek, M.K. Sanders, L. van Toledo, A.J. van Veelen,G. van Waveren, E.M.A. van de Veer, M. Wieringa- de Waard, who participated in the Amsterdam perinatal audit.

Reference List

(1) Schulpen TWJr. Mortality differences between migrant and native Dutch children in the Netherlands [in Dutch]. Centre for Migration and Child Health . 1996.

(2) Doornbos J, Nordbeck HJ. Perinatal mortality. Obstetric riskfactors in a community of mixed ethnic origin in Amsterdam. Thesis 1985;(Dordrecht, ICG printing, 1985).

(3) Essén B, Hanson BS, Östergren PO, Lindqvist PG, Gudmundsson S. Increased perinatal mortality among sub-Saharan immigrants in a city-population in Sweden. Acta Obstet Gynecol Scand 2000; 79(9):737-743.

(4) Zeitlin J, Combier E, De CF, Papiernik E. Socio-demographic risk factors for perinatal mortality. A study of perinatal mortality in the French district of Seine-Saint-Denis. Acta Obstet Gynecol Scand 1998; 77(8):826-835.

(5) Macfarlane A, Mugford M. Statistics of pregnancy and childbirth. The stationary Office; 2000.

(6) van Enk, Gorissen WH, van EA. [Teenage pregnancy distribution by ethnicity in the Netherlands, 1990-1993]. [Dutch]. Ned Tijdschr Geneeskd 1999; 143(9):465-471.

(7) Knuist M. Pregnancy induced hypertension in a low-risk population [Department of Obstetrics and Gynaecology, Academic Medical Centre Amsterdam;Thesis, 1998.

(8) Bonsel G.J., van der Maas PJ. Scenarios for health care concerning human reproduction 1995-2010. 1994.

(9) Essén B, Bödker B, Sjöberg NO, Langhoff-Roos J, Greisen G, Gudmundsson S et al. Are some perinatal deaths in immigrant groups linked to suboptimal perinatal care services? BJOG 2002; 109(6):677-682.

(10) red: Swertz O. Persons by origin in the Netherlands 2003[in Dutch]. Central Bureau of Statistics tN, editor. 2003. Central Bureau of Statistics,the Netherlands.

(11) Cartlidge PH, Dawson AT, Stewart JH, Vujanic GM. Value and quality of perinatal and infant postmortem examinations: cohort analysis of 400 consecutive deaths [see comments]. BMJ 1995; 310(6973):155-158.

(12) O&S The Amsterdam population, birth and death, 1997-2001[in Dutch]. Bureau of Research and Statistics. 2000.

(13) Rowe RE, Garcia J. Social class, ethnicity and attendance for antenatal care in the United Kingdom: a systematic review. J Public Health Med 2003; 25(2):113-119.

(14) Lydakis C, Beevers DG, Beevers M, Lip GY. Obstetric and neonatal outcome following chronic hypertension in pregnancy among different ethnic groups. QJM 1998; 91(12):837-844.

(15) Williams KP, Baldwin V. The effect of ethnicity on the development of small for gestational age infants associated with hypertension in pregnancy. Am J Perinatol 1998; 15(2):125-128.

(16) Harger JH. Cerclage and cervical insufficiency: an evidence-based analysis. Obstet Gynecol 2002; 100(6):1313-1327.

(17) Drakeley AJ, Roberts D, Alfirevic Z. Cervical stitch (cerclage) for preventing pregnancy loss in women (Cochrane Review). Cochrane Database Syst Rev 2003;(1):CD003253.

(18) Stronks K, Ravelli AC, Reijneveld SA. Immigrants in the Netherlands: equal access for equal needs? J Epidemiol Community Health 2001; 55(10):701-707.

(19) Kupek E, Petrou S, Vause S, Maresh M. Clinical, provider and sociodemographic predictors of late initiation of antenatal care in England and Wales. BJOG 2002; 109(3):265-273.

(20) Hemingway H, Saunders D, Parsons L. Social class, spoken language and pattern of care as determinants of continuity of carer in maternity services in east London. J Public Health Med 1997; 19(2):156-161.

Marianne E Alderliesten [1]
Tanja GM Vrijkotte [2]
Marcel F van der Wal [3]
Gouke J Bonsel[2]

6

Academic Medical Centre Amsterdam, Department of Obstetrics and Gynaecology,(1) Department of Public Health,(2) Municipal Health Service Amsterdam,(3)

...

Late start of antenatal care among ethnic minorities in a large cohort of pregnant women

Abstract

Objective: To investigate differential timing of the first antenatal visit between ethnic groups and to explore the contribution of several non-economic risk factors.

Design: Prospective cohort study

Setting and population: Pregnant women from independent midwifery practices in the city of Amsterdam, as well as all 6 Amsterdam hospitals. During 15 months, all women were asked to participate (12381) at the first antenatal visit. Ethnic groups were distinguished by country of birth, i.e. ethnic Dutch, other Westerners, Surinamese, Antillean, Turkish, Moroccan, Ghanaians and other non-Western countries.

Main outcome measure: Gestational age at first visit using a standard screening form.

Methods: Questionnaire data revealed possible risk factors for late start. A cox-proportional hazards model was created with (1) only ethnic group and (2) additional all significant risk factors, both time-fixed and time-dependent.

Results: All non-Dutch ethnic groups were significantly later in starting antenatal care during the whole duration of pregnancy compared to the ethnic Dutch group (Hazard ratio's: other Western 0.83 (0.76-0.90), Surinamese 0.62 (0.56-0.68), Antillean 0.56 (0.45-0.70), Turkish 0.62 (0.55-0.69) Moroccan 0.56 (0.52-0.62) Ghanaians 0.50 (0.43-0.58) Other non-Western 0.61 (0.56-0.67)) The range at which 90% was in care varied between 16 3/7 (Dutch) and 24 4/7 weeks (Ghanaians). These differences disappeared almost totally in the non-Dutch speaking ethnic groups when the following risk factors were added to the model: poor language proficiency, low maternal education, teenage pregnancy, multiparity and unplanned pregnancy. These differences remained in the Dutch-speaking ethnic groups. (Surinamese, hazard ratio 0.69 CI 0.62-0.77; Antillean 0.69 CI 0.56-0.87). Adding time-dependent covariates to the model revealed that the Hazard Ratio's were not constant for age and parity (decreased in time) and language proficiency (increased in time).

Conclusions: We observed a disturbing delay by all non-Dutch ethnic groups in the timing of their first antenatal visit. In women born in non-Dutch speaking, non-Western countries these differences were explained by a higher prevalence of the risk factors: poor language proficiency in Dutch, lower maternal education and more teenage pregnancies. In women born in Dutch speaking, non-Western countries, the disparities cannot be explained by higher prevalence of these risk factors, indicating that cultural factors play a role. This emphasises the need for ethnic-specific health strategies.

Introduction

Timely and adequate antenatal care is generally acknowledged to be an effective method of preventing adverse outcomes in pregnant women and their babies. [1,2,3] Although many different antenatal care practices exist and disagreements remain about the appropriate number and timing of antenatal visits, the benefits of initiating antenatal care during early pregnancy are undisputed.[1] Several studies have demonstrated an association between late gestational age at the initiation of antenatal care and adverse maternal and infant outcomes. [4-6]. Maternal factors related to this late start of antenatal care include young age [7,2, 8], low level of education [9,10], unwanted [11] and/ or unplanned pregnancy [8,12;13], poor language proficiency in English [14], high parity, [8;15] a high obstetric risk[15] or being part of a non-white ethnic group. [15] Since being part of a non-white ethnic group is clearly related to a higher prevalence of adverse outcome in pregnancy (i.e. higher perinatal mortality, growth retardation, and preterm birth) its relationship to the initiation of antenatal care is interesting. [16,17,18,19]

Usually, the relationship between ethnicity and start of antenatal care is difficult to study independently from economic factors.[20-23] As antenatal care is universally accessible in the Netherlands and encouraged for all pregnant women irrespective of income, we have an opportunity to investigate the independent role of non-economic factors in the relationship between ethnicity and start of antenatal visits.
This paper describes existing differential timing of the first antenatal visit according to ethnicity. We will explore the contribution of several non-economic determinants, both related and unrelated to ethnicity. Additionally, we hope to propose ways of preventing such late starts and inadequate care in general if we take timing of the first antenatal visit as a proxy.

Material and methods

Study population

Data from a large prospective cohort of pregnant women in the city of Amsterdam, the Netherlands were used in this study. (Amsterdam Born Children and their Development; ABCD-study). In this cohort, the influence of maternal life style and psychosocial conditions during pregnancy on the outcome of the pregnancy and the baby's health was investigated. Between January 2003 and March 2004, pregnant women were invited to participate by the obstetric caregiver (general practitioners, midwives and hospital gynaecologists) at their first antenatal visit. The current pattern of first antenatal visits in the Netherlands consists of a booking visit around the 12th week of gestation at one of the independent midwifery practices (low-risk pregnancy) or hospital-based obstetricians (prior high-risk pregnancy). In total, 12,381 women were approached. A standard screening form, containing information on gestational age, was completed. All the women who were approached subsequently received a pregnancy questionnaire at their home address two weeks after the fist antenatal visit. This questionnaire contained, among others, questions about maternal life style and obstetric information. Questionnaires and standard screening forms were then linked with a unique serial number. In order to achieve an optimal response rate, all approached women were asked to return the pregnancy questionnaires by prepaid mail. A written reminder was sent two weeks after the initial mailing. The questionnaire was available in Dutch, English, Turkish and Arabic languages. Women who could read neither Dutch nor their mother language were offered the choice of responding to the questionnaire by telephone in their mother language.

Data on outcome

Gestational age at first visit was based on ultrasound or on the first day of their last menstrual period (calculation by the obstetric care provider), and noted on the standard screening form. We considered two time ancres to be if importance for the start date of antenatal care: 18 and 24 weeks of gestation. Eighteen weeks (late start[15,2]) marks the end of the window for standard first trimester screening, while 24 weeks (very late start) is the gestational age in the Netherlands at which the fetus becomes a legal person after birth. A start date of antenatal care after this gestational age gives the care provider no possibilities to intervene in any obstetric or other risk factor before that day.

Data on determinants

Information on determinants was obtained from self-reported questionnaires. The following ethnic groups were distinguished: ethnic Dutch, other Westerners, Surinamese, Antillean, Turkish, Moroccan,

Ghanaians and other non-Westerners. These ethnic groups represent the largest ethnic groups in the city of Amsterdam [24]. The following factors were considered to be potential determinants for the date of the first antenatal visit: maternal age (<20 years; 20-36 years; >36 years); language proficiency in Dutch (poor/ fair / good proficiency in Dutch); parity (primiparae vs multiparae); whether the pregnancy was wanted (yes/no); whether the pregnancy was planned (yes/no); risk awareness (stillbirth, miscarriage or severe congenital anomaly in the past) maternal education level (years of education after primary school, defined according to 3 categories: < 5 years; 5-10 years; > 10 years).

Statistical analysis

Survival analysis was performed because the time till event variable, gestational age at first antenatal visit, was of primary interest. Descriptive life tables were used to calculate the percentage of women not in care at 18 weeks gestational age 24 weeks gestational age. The full data set was used for these descriptive analyses. For the explanatory analysis, we restricted our data to all women who entered antenatal care after 9 completed weeks. Given the research objective, data were censored for those whose first visit was after 27 completed weeks of gestation. Ethnic-specific first-visit curves were computed by the Kaplan-Meier method. A univariate survival analysis was used to analyse all determinants.

A multivariate survival analysis was performed with the Cox proportional hazards model with forward stepwise inclusion of ethnic group and all determinants that showed a univariate significant effect (Model 1). In Model 2, some determinants were intentionally added as time-dependent covariates, to investigate whether these risk factors acted differently over time. Finally, risk factors for late start were considered to be those determinants with a univariate significant effect on the first antenatal visit. For each subject, the total number of risk factors was calculated. This variable was used to indicate high risk groups for late start. Data were analysed using SPSS 12.0. In all analysis, the significance level was set at 0.05. Missing values were not imputed.

Ethical approval for this study was obtained from the medical ethical committees of all Amsterdam hospitals and the Registration Committee of Amsterdam. All participating women gave written consent.

Results

8267 women returned the questionnaire (average response rate 67%). The descriptive analysis included 8238 women from whom all data were available on the day of the first antenatal visit. (data on the first antenatal visit was not available for 29 women). The response rate ranged from

41.5% in the Moroccan group to 77.2 % in the ethnic Dutch group. The number of pregnant women with gestational age less than 9 completed weeks at their first visit was 773 (9,4%). They were excluded from the explanatory survival analysis. From the remaining 7488 women 132 (1.8%) were censored at 28 weeks because their gestational age was more then 27 completed weeks at first visit.
Table 1 shows the prevalence of all determinants according to ethnic group. Overall, the 'other-western' group resembled the ethnic Dutch group most closely. Large differences can be seen in Dutch language proficiency among the ethnic groups, showing the highest prevalence of poor language proficiency among Ghanaian (46.3%) and Turkish (43.1%) women. Apart from the ethnic Dutch group, poor language proficiency was almost absent in the Surinamese and Antillean groups as Dutch is the native language of these groups in their home country. Less than five years education after primary school was common in all non-Dutch ethnic groups, except the 'other Western' group. Multiparity was more common in the Surinamese (60.1%), Turkish (63.2%) and Ghanaian (62.6%) groups. Teenage pregnancy was much more prevalent in the Antillean group (14.7%), compared to the ethnic Dutch group (1.9%).

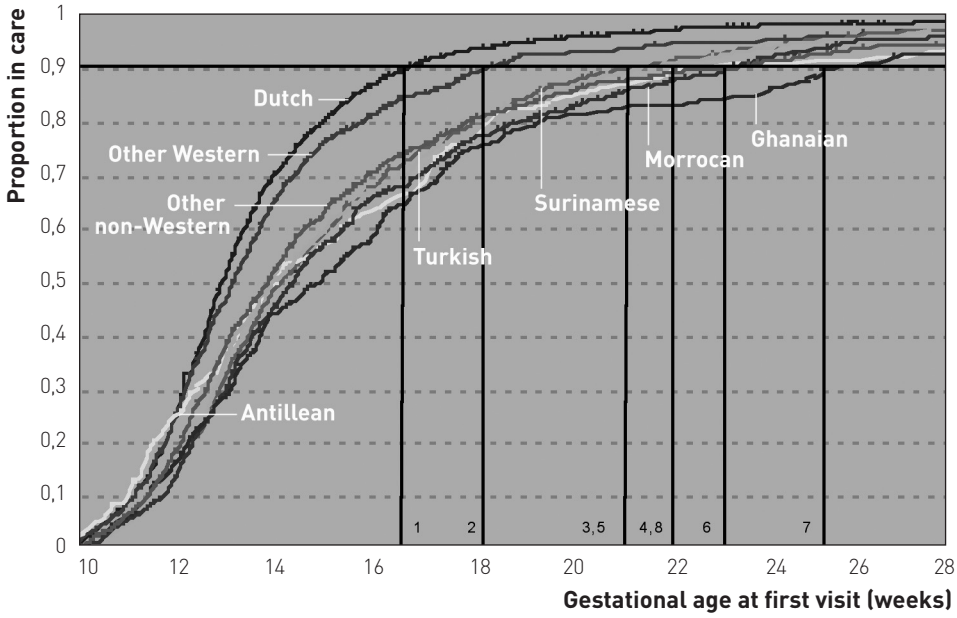
Table 1 Description of cohort; prevalence of determinants

Ethnic background		**Maternal age < 20**	**Multiparity**	**Pregnancy unwanted**	**Risk awareness**	**Low maternal education**	**Poor language proficiency in Dutch**	**Unplanned pregnancy**
	N	%	%	%	%	%	%	%
Dutch	5071	1.9	39.7	0.6	21.3	11.4	0.1	5.0
Other Western	698	0,9	35.3	0.6	20.1	16.5	23.2	5.6
Surinamese	458	3.1	60.1	1.1	25.3	43.0	1.1	15.3
Antillean	95	14.7	38.9	1.1	26.3	42.6	1.1	12.9
Turkish	342	5.3	63.2	5.0	22.2	64.3	43.1	19.4
Morrocan	604	3.6	59.9	2.5	24.1	60.9	34.2	8.9
Ghanaian	203	2.0	62.6	2.0	31.0	56.1	46.3	14.1
Other non-Western	767	3.8	51.8	1.7	21.9	39.5	37.9	12.1
Total	8238	2.5	55.4	1.1	22.0	23.3	11.1	7.4

Figure 1 shows the Kaplan-Meier curves for gestational age at the first antenatal visit in the ethnic groups. In these curves the 9th decile shows a distinct difference between ethnic groups, where the date at which at

least 90% had their first antenatal visit ranges from 16 3/7 weeks (Dutch) to 24 4/7 week Ghanaians.

Figure 1 Ethnic specific survival curves for gestational age at first visit



Vertical lines represent gestational age when 90% is in care

Dutch	16.6
Other Western	18.1
Surinamese	20.9
Turkish	21.1
Antillean	21.9
Other non-Western	22.3
Moroccan	23.0
Ghanaian	25.0

Table 2 shows the percentage of women who did not arrive for antenatal care at 18 and 24 weeks of gestation for all determinants. At 18 weeks of gestation, a clear difference between the ethnic groups was visible. Of all ethnic Dutch mothers, 5.4% were not in care at 18 weeks. Of the Antillean and Ghanaian groups, these percentages were 22.3% and 22.7% respectively. Of ethnic groups who did not turn up for the first antenatal visit at 24 weeks, the largest percentages were seen in the Ghanaian group (12.3%) followed by the Antillean (8.5%) and other non-Western groups (7.4%). At 18 weeks, large differences existed for the determinant 'language proficiency in Dutch' (27.4% vs 7.0%), unplanned/planned pregnancy (23.3% vs 8.7%), maternal education < 5 years (19.5% vs 5.1%) and maternal age under 20 years (32.5% vs 9.5%). At 24 weeks, the pattern was similar.

Table 2 Percentage of pregnant women not in care at 18 and 24 weeks of gestational age

Factor	No. Of Patients	Gestational age < 18 weeks %	< 24 weeks %
Ethnic background			
Dutch	5051	5.4	1.3
Non-Dutch	3158	17.2	6.4
Ethnic background			
Dutch	5051	5.4	1.3
Other Western	695	9.1	3.9
Surinamese	457	18.8	5.3
Antillean	94	22.3	8.5
Turkish	340	18.3	5.3
Moroccan	603	21.9	7.1
Ghanaian	203	22.7	12.3
Other non-Western	766	17.4	7.4
Age			
≥ 20 yr	8035	9.4	3.0
< 20 yr	203	32.5	6.5
Language proficiency in Dutch			
Good	6634	7.0	1.8
Fair	660	15.0	5.3
Poor	915	27.4	5.9
Maternal education			
> 10 yr	3135	5.1	1.3
5 – 10 yr	3106	8.6	2.7
< 5 yr	1903	19.5	7.3
Parity			
Nulli partity	4550	8.5	3.1
Multi parity	3676	11,8	3.5
Happy with pregnancy			
Yes	8112	9.6	3.1
No	86	31.4	15.1
Planned pregnancy			
Yes	7514	8.7	2.7
No	606	23.3	9.4
Risk awareness			
Low	6412	7.9	3.3
High	1823	10.3	3.0
Number of risk factors †			
0	3295	4.5	1.2
1	3163	8.4	2.2
2	1211	19.1	7.1
≥ 3	569	30.6	12.8

† Maximum number of risk factors was 6. Considered risk factors were: age < 20 yr, poor language proficiency in Dutch, maternal education < 5 year, multi parity, not happy with pregnancy, not planned pregnancy.

Table 3 Cox-proportional hazard analysis, data censored after 28 weeks of pregnancy.

	Univariate	**Model 1 Multivariate**	**Model 2 Multivariate + Time dependent covariates**
Ethnic background	Hazard ratio (95% CI)	Hazard ratio (95% CI)	Hazard ratio (95% CI)
Dutch	1		
Non-Dutch	0.63 (0.60-0.66)		
Ethnic background			
Dutch	1	1	1
Other Western	0.83 (0.76-0.90)	1.00 (0.91-1.09)	1.00 (0.91-1.10)
Surinamese	0.62 (0.56-0.68)	0.69 (0.62-0.77)	0.69 (0.62-0.77)
Antillean	0.56 (0.45-0.70)	0.69 (0.55-0.86)	0.69 (0.56-0.87)
Turkish	0.62 (0.55-0.69)	1.00 (0.87-1.14)	1.00 (0.88-1.16)
Moroccan	0.56 (0.52-0.62)	0.82 (0.73-0.91)	0.81 (0.73 0.90)
Ghanaian	0.50 (0.43-0.58)	0.88 (0.80-0.98)	0.78 (0.66-0.93)
Other non-Western	0.61 (0.56-0.67)	0.57 (0.48-0.66)	0.88 (0.80-0.97)
Time dependency	---	---	NS
Age			
≥ 20 yr	1	1	1
< 20 yr	0.53 (0.46-0.62)	0.57 (0.48-0.66)	0.18 (0.10-0.34)
Time dependency	---	---	1.08 (1.04-1.12)
Language proficiency in Dutch			
Good	1	1	1
Fair	0.70 (0.64-0.76)	0.80 (0.71-0.88)	0.75 (0.67-0.84)
Poor	0.52 (0.48-0.56)	0.59 (0.54-0.65)	0,52 (0.45-0.60)
Time dependency	---	---	0.99 (0.98-1.00)
Maternal education			
> 10 yr	1	1	1
5 – 10 yr	0.85 (0.80-0.89)	0.94 (0.90-0.99)	0.94 (0.89-1.00)
< 5 yr	0.59 (0.55-0.62)	0.83 (0.77-0.89)	0.83 (0.77-0.89)
Time dependency	---	---	NS
Parity			
Nulli partity	1	1	1
Multi parity	0.87 (0.83-0.91)	0.90 (0.86-0.95)	0.81 (0.75-0.88)
Time dependency	---	---	1.03 (1.01-1.05)
Happy with pregnancy			
Yes	1	NS	---
No	0.53 (0.42-0.68)	NS	---
Time dependency	---	---	---
Planned pregnancy			
Yes	1	1	1
No	0.64 (0.59-0.70)	0.73 (0.67-0.80)	0.72 (0.66-0.79)
Time dependency	---	---	NS
Risk awareness			
Low	1	---	---
High	0.97 (0.92-1.03)	---	---
Time dependency	---	---	---

NS: not significant

Table 3 describes the univariate and multivariate survival analysis. Taking the ethnic Dutch group as a reference, a statistically significant difference is shown in the univariate analysis for all other ethnic groups. In the multivariate analysis, the difference with the ethnic Dutch group disappears in the other-Western and Turkish groups, and is almost annihilated in the Moroccan, Ghanaian and other non-Western groups. However, the difference remains when the ethnic Dutch group is compared to the Surinamese and Antillean groups.

From the multivariate analysis, less then five years education after primary school and unplanned pregnancy emerged as time-fixed significant determinants, whereas the effect of maternal age under 20 years, parity and Dutch language proficiency were time-dependent. Overall, the improvement of the time dependent model was considerable. The time dependent covariates for age (1.05 CI:1.02-1.08)) and parity (1.03 CI:1.01-1.05) showed that their influence was more pronounced at the beginning of pregnancy, but the difference was still present at 28 weeks. The importance of language proficiency for care increased in time (0.99, CI: 0.98-1.00).
The univariate analysis revealed six risk factors for late start, which were: age < 20 years, poor language proficiency in Dutch, maternal education < 5 years, multi-parity, unplanned pregnancy and not happy with pregnancy. The average number of risk factors and the percentage of women with three or more risk factors are shown in Table 4. This was the highest in the Turkish group with < 5 years maternal education, poor language proficiency in Dutch and unplanned pregnancy as the most prevalent risk factors.

Table 4 Average number of risk factors, and > 3 risk factors, divided to ethnic group

	Average number of risk factors X ± SD	**≥ 3 Risk factors %**
Ethnic background		
Dutch	0.6 ± 0.7	1.5
Other-Western	0.8 ± 0.8	4.4
Surinamese	1.2 ± 0.9	7.9
Antillean	1.1 ± 0.9	6.3
Turkish	2.0 ± 1.1	32.7
Moroccan	1.7 ± 1.1	23.3
Ghanaian	1.8 ± 1.0	23.3
Other non-Western	1.4 ± 1.0	15.3

Discussion

In this study, we observed a disturbing delay by all non-Dutch groups in the timing of their first antenatal visit, despite antenatal care being universally accessible in the Netherlands. This implies major disadvantages in the first trimester of pregnancy for these groups. We observed three different patterns among ethnic groups. First, the 'other-Western' group, consisting mainly of women from other Western-European countries, closely resembled the ethnic Dutch group and showed a small difference in the start date of antenatal care. Second, in the non-Dutch speaking non-Western group, the higher prevalence of selected risk factors explained all (Turkish) or at least an important part of the substantial delay (Moroccan, Ghanaian and other non-Westerners). Third, in the Dutch-speaking group who were not ethnic Dutch (i.e. Surinamese and Antillean women), common risk factors did not explain the substantial delay.
A comparably large study by Kupek et al [15] based on retrospective data from case records of 20771 women in Northern England and Wales showed late initiation of antenatal care in Pakistani, Indian and other non-Western (non-specified) women , independent from a set of specific risk factors. Our results on the Dutch-speaking group who were not ethnic Dutch (a similar group of post colonial immigrants with high native language proficiency) – are similar. From the proposed explanatory variables (language and cultural barriers) our study rules out a role for language. Cultural factors apparently are present despite the fact that this ethnic group contains third (or more) generation members. LaVeist in the US[25], showed no differences in initiation of antenatal care among black immigrants, but more inadequate prenatal care in general; however initiation of antenatal care in the US is later, and dominated by financial incentives.

A major strength of the present study is the mode of data collection (a prospective pregnancy questionnaire in addition to routine prenatal screen information) combined with the large unselected cohort, that provided detailed information on ethnicity, timing differences and specific determinants, e.g. language proficiency. Our study confirmed the contribution of a set of determinants related to the start of antenatal care; e.g. unplanned and/or unwanted pregnancy, teenage pregnancy and a low maternal education.[2;15] There are some limitations nevertheless. Despite our multilingual efforts resulting in an unusually high response rate even among non-Dutch speaking ethnic groups, response among non-Dutch speaking groups was lower, and it is to be expected that the non-responders probably include ethnic people who are illiterate. However, it seems likely, that a complete response rate would intensify our results.
In general, all major studies have reported the risk factors for delay

which can be routinely collected focusing on sociological and/or economic explanations. Few studies to date have offered explanations about the potential causal effect of language proficiency among groups where both culture and language and their interaction are important. Only Hemingway et al demonstrated that a poor native (English) language proficiency hampered continuity of maternity carer, but they did not investigate late initiation of antenatal care.[14] In a larger context, accessibility of health care is known to be hampered by poor English proficiency. [26] This is not known for Dutch proficiency, although the effects can be assumed to be similar.

We suggest that poor proficiency in Dutch can lead to disadvantages in acquiring essential passive as well active information, for example from general practitioners, laymen and other pregnant women (e.g. exchange of experience). Dutch proficiency can also influence the care process itself and communication with the care provider. However, this communication alone cannot explain the found differences in our cohort. Only group-specific research may disentangle the role of language issues (in the non-Dutch speaking group) and cultural factors (in the Dutch speaking group). As effective interventions probably differ according to different groups, our explanatory model offers a major advantage in the analysis of ethnically-related inadequate care.

Teenage pregnancy, another major determinant of timing differences in this cohort, occurred mainly in the Antillean group. (Table 1). However, even after correction for risk factors, Antillean pregnant women continued to arrive later for antenatal care, implying that a large cultural or unknown component is present in this specific group.

Lessons

We propose two different strategies for intervention. First, in the non-Dutch speaking ethnic groups, we emphasise the role of Dutch proficiency in antenatal care timing differences. The learning of the Dutch language should be promoted as a major health advantage (among others) and should be encouraged.

Several health strategies have already been developed for non-Dutch speaking ethnic minorities. In the infant welfare centres good results have been established with the implementation of a consulting hour that routinely uses an interpreter.[27] In a larger context, the "Amsterdam declaration" [28]has been established. This is a European initiative to encourage policy makers and hospitals/care providers to acknowledge the specific health problems of migrants, and to develop appropriate health strategies, also in regard to mother and child care.[29] On the other hand, this declaration advocates that migrants should learn the language of their new host country, and provides structures for health education.[29]

Additionally, the provision of information concerning early attendance of antenatal care should have an important role.
The second strategy for intervention should be preceded by more research into Dutch-speaking ethnic groups, where a late start of antenatal care cannot be explained by a higher prevalence of risk factors. It might be that cultural differences or a different organisation of health care in their home country play a role in explaining these differences. More insight into their reasons for a late start is urgently required to formulate the necessary tools for intervention.
Another important question still to be answered is whether the late start of antenatal care is related to adverse outcome in pregnancy in this particular study. At the current time, this is out of the scope of the present paper, but this analysis will be performed in the near future. The perinatal death cases in this cohort of pregnant women, their causes and the presence of substandard care will be assessed by means of a perinatal audit.
In this study we have observed severe antenatal care disadvantages for all ethnic groups. It emphasises the fact that acculturation is more than merely language proficiency. In future, with the possible introduction of preconception screening, the disparities that already exist will only increase, calling for urgent measures.

Reference List

(1) Villar J, Bergsjo P. Scientific basis for the content of routine antenatal care. I. Philosophy, recent studies, and power to eliminate or alleviate adverse maternal outcomes. Acta Obstet Gynecol Scand 1997; 76(1):1-14.

(2) Rowe RE, Garcia J. Social class, ethnicity and attendance for antenatal care in the United Kingdom: a systematic review. J Public Health Med 2003; 25(2):113-119.

(3) Petrou S, Kupek E, Vause S, Maresh M. Clinical, provider and sociodemographic determinants of the number of antenatal visits in England and Wales. Soc Sci Med 2001; 52(7):1123-1134.

(4) Villar J, Bergsjo P. Scientific basis for the content of routine antenatal care. I. Philosophy, recent studies, and power to eliminate or alleviate adverse maternal outcomes. Acta Obstet Gynecol Scand 1997; 76(1):1-14.

(5) Gortmaker SL. The effects of prenatal care upon the health of the newborn. Am J Public Health 1979; 69(7):653-660.

(6) Ryan GM, Jr., Sweeney PJ, Solola AS. Prenatal care and pregnancy outcome. Am J Obstet Gynecol 1980; 137(8):876-881.

(7) Quick JD, Greenlick MR, Roghmann KJ. Prenatal care and pregnancy outcome in an HMO and general population: a multivariate cohort analysis. Am J Public Health 1981; 71(4):381-390.

(8) Blondel B, Dutilh P, Delour M, Uzan S. Poor antenatal care and pregnancy outcome. Eur J Obstet Gynecol Reprod Biol 1993; 50(3):191-196.

(9) Rowe RE, Garcia J. Social class, ethnicity and attendance for antenatal care in the United Kingdom: a systematic review. J Public Health Med 2003; 25(2):113-119.

(10) Delvaux T, Buekens P, Godin I, Boutsen M. Barriers to prenatal care in Europe. Am J Prev Med 2001; 21(1):52-59.

(11) McDonald TP, Coburn AF. Predictors of prenatal care utilization. Soc Sci Med 1988; 27(2):167-172.

(12) Essex C, Counsell AM, Geddis DC. The demographic characteristics of early and late attenders for antenatal care. Aust N Z J Obstet Gynaecol 1992; 32(4):306-308.

(13) Pagnini DL, Reichman NE. Psychosocial factors and the timing of prenatal care among women in New Jersey's HealthStart program. Fam Plann Perspect 2000; 32(2):56-64.

(14) Delvaux T, Buekens P, Godin I, Boutsen M. Barriers to prenatal care in Europe. Am J Prev Med 2001; 21(1):52-59.

(15) Delgado-Rodriguez M, Gomez-Olmedo M, Bueno-Cavanillas A, Galvez-Vargas R. Unplanned pregnancy as a major determinant in inadequate use of prenatal care. Prev Med 1997; 26(6):834-838.

(16) Hulsey TM. Association between early prenatal care and mother's intention of and desire for the pregnancy. J Obstet Gynecol Neonatal Nurs 2001; 30(3):275-282.

(17) Hemingway H, Saunders D, Parsons L. Social class, spoken language and pattern of care as determinants of continuity of carer in maternity services in east London. J Public Health Med 1997; 19(2):156-161.
(18) Delvaux T, Buekens P, Godin I, Boutsen M. Barriers to prenatal care in Europe. Am J Prev Med 2001; 21(1):52-59.
(19) Kupek E, Petrou S, Vause S, Maresh M. Clinical, provider and sociodemographic predictors of late initiation of antenatal care in England and Wales. BJOG 2002; 109(3):265-273.
(20) Kupek E, Petrou S, Vause S, Maresh M. Clinical, provider and sociodemographic predictors of late initiation of antenatal care in England and Wales. BJOG 2002; 109(3):265-273.
(21) Kupek E, Petrou S, Vause S, Maresh M. Clinical, provider and sociodemographic predictors of late initiation of antenatal care in England and Wales. BJOG 2002; 109(3):265-273.
(22) Zeitlin J, Bucourt M, Rivera L, Topuz B, Papiernik E. Preterm birth and maternal country of birth in a French district with a multiethnic population. BJOG 2004; 111(8):849-855.
(23) Schulpen TWJr. Mortality differences between migrant and native Dutch children in the Netherlands [in Dutch]. Centre for Migration and Child Health . 1996.
(24) van EA, Buitendijk SE, van der Pal KM, van Enk WJ, Schulpen TW. Perinatal death in ethnic minorities in The Netherlands. J Epidemiol Community Health 1998; 52(11):735-739.
(25) Knuist M. Pregnancy induced hypertension in a low-risk population [Department of Obstetrics and Gynaecology, Academic Medical Center Amsterdam; 1998.
(26) Johnson AA, El-Khorazaty MN, Hatcher BJ, Wingrove BK, Milligan R, Harris C et al. Determinants of late prenatal care initiation by African American women in Washington, DC. Matern Child Health J 2003; 7(2):103-114.
(27) Sarnoff R, Adams E. Racial and ethnic disparities in the discordance between women's assessment of the timing of their prenatal care entry and the first trimester standard. Matern Child Health J 2001; 5(3):179-187.
(28) Meikle SF, Orleans M, Leff M, Shain R, Gibbs RS. Women's reasons for not seeking prenatal care: racial and ethnic factors. Birth 1995; 22(2):81-86.
(29) Kogan MD, Alexander GR, Mor JM, Kieffer EC. Ethnic-specific predictors of prenatal care utilisation in Hawaii. Paediatr Perinat Epidemiol 1998; 12(2):152-162.
(30) Kupek E, Petrou S, Vause S, Maresh M. Clinical, provider and sociodemographic predictors of late initiation of antenatal care in England and Wales. BJOG 2002; 109(3):265-273.
(31) Rowe RE, Garcia J. Social class, ethnicity and attendance for antenatal care in the United Kingdom: a systematic review. J Public Health Med 2003; 25(2):113-119.
(32) Kupek E, Petrou S, Vause S, Maresh M. Clinical, provider and sociodemographic predictors of late initiation of antenatal care in England and Wales. BJOG 2002; 109(3):265-273.
(33) LaVeist TA, Keith VM, Gutierrez ML. Black/white differences in prenatal care utilization: an assessment of predisposing and enabling factors. Health Serv Res 1995; 30(1):43-58.

(34) Kupek E, Petrou S, Vause S, Maresh M. Clinical, provider and sociodemographic predictors of late initiation of antenatal care in England and Wales. BJOG 2002; 109(3):265-273.
(35) Rowe RE, Garcia J. Social class, ethnicity and attendance for antenatal care in the United Kingdom: a systematic review. J Public Health Med 2003; 25(2):113-119.
(36) Hemingway H, Saunders D, Parsons L. Social class, spoken language and pattern of care as determinants of continuity of carer in maternity services in east London. J Public Health Med 1997; 19(2):156-161.
(37) Fiscella K, Franks P, Doescher MP, Saver BG. Disparities in health care by race, ethnicity, and language among the insured: findings from a national sample. Med Care 2002; 40(1):52-59.
(38) Van Bekkem-van Vliet W. The infant welfare centre for Turkish and Moroccan children in Delft [in Dutch]. 1985. Scriptie vervolgopleiding Sociale Gezondheidszorg, Leiden, Holland, NIPG-TNO. Ref Type: Report
(39) Ludwig Bolzmann Institute for the Sociology of Health and Medicine. The Amsterdam Declaration. Towards Migrant-friendly hospitals in an Etno-Culturally Diverse Europe. 2005. WHO Collaborating Centre for Health Promotion in Hospitals and Health Care.
(40) Trummer U, Novak-Zezula S, Schulze B, Krajic K, Pelikan J. Subproject B: Migrant-friendly information and training in mother and child care. 2005. Vienna, Ludzwig Boltzmann institute for the Sociology of Health and Medicine, WHO Collaborating Centre for Health Promotion in Hospitals and Health Care. Ref Type: Report

7

Summary, implications for future research and recommendations for perinatal care

Summary

Perinatal mortality has strongly declined since the beginning of the last century, and has continued to decline steadily during the second half of the century. Care provided during pregnancy, during and after delivery has improved during this long period. Apart from primary prevention and overall improvement of health, further improvement of perinatal care may further lower the already low perinatal mortality rate. Since perinatal mortality is only one of the indicators of perinatal care, improvement of care in cases of perinatal death might impact favourably on other perinatal indicators. This thesis contributes to this debate in three different ways.

First, we described the design and performance of a regional perinatal audit. A perinatal audit is an important method of reviewing perinatal care to determine the presence of "substandard care" (care that does not meet the defined minimally accepted standards, as stated in (inter)national guidelines, and regional and local protocols). Audit also has a central role in the developing and implementing of guidelines. Several perinatal audits have been performed internationally as well as nationally. Some of these were permanent and nationwide, others were performed in a small region and in a research setting. In these audits, doctors and midwives did not review perinatal death cases in their own region for obvious reasons. However, as the implementation of guidelines is at the core of the audit process, an active role in the audit for the care providers involved offers an extra opportunity for more direct feedback. We performed a regional perinatal audit in Amsterdam. An audit panel of regional obstetricians, paediatricians, midwives and general practitioners reviewed consecutive cases of perinatal death for the presence of substandard care.

Second, it is of great importance that the cause of death of the fetus or neonate is established to decide whether substandard care is present. Autopsy has, as the accepted gold standard, an important role to play in the perinatal post-mortem investigation. Many parents however, refuse permission for an autopsy, probably due to its invasive character. Therefore more non-invasive and more acceptable forms of post-

mortem investigations have been explored with a view to replacing the autopsy, such as MRI. In early studies, Magnetic Resonance Imaging (MRI) has demonstrated good first results in establishing the presence of congenital malformations. However, the value of an MRI in the common obstetric population could not be estimated. We performed a head-to-head comparative study of MRI and autopsy (gold standard) in an unselected obstetric sample of perinatal deaths.

Third, ethnic differences are known to be present in the prevalence and background of several adverse outcomes of pregnancy (higher perinatal mortality rates, more preterm births and a higher rate of intrauterine growth retardation). By means of a perinatal audit, we compared the presence of substandard care in all ethnic groups in the city of Amsterdam. Ethnicity-related differences in the quality of perinatal care, in particular differential access, have been put forward as one of the explanations. We therefore additionally compared the start date of antenatal care between ethnic groups in a large cohort of women, and we explored the contribution of a selected set of determinants to this differential delay.

Chapter 1 describes the background and aim of the thesis.

Chapters 2 and 3 addressed the first question:

> What is the feasibility of a regional perinatal audit, following the PARIS format, according to the PARIS -team and the audit members? Can the design and the resulting prevalence of substandard care be compared to that of other, existing perinatal audits?
> If substandard care is present, in what component and in what level of perinatal care is it located (this includes the possible contribution of the mother)?

To address these questions, we designed a regional perinatal audit, including a description of the experiences of the audit members.
A random selection of cases of perinatal death was reviewed by an external audit committee. The outcome of the Amsterdam perinatal audit was compared with other perinatal audits. The range of substandard care factors in the present study was comparable with other, non-regionally oriented audits. In 7 cases (out of 10), the regional and external committee agreed on the presence and contribution of SSCFs. In two out of three non-consensus cases, the regional panel attributed SSCFs where the external panel did not. For all audit members, the audit was a time-consuming procedure, even in a situation were a research

doctor collected all data (mean 4 hrs, range 1 ½ - 10). All participants felt sufficiently confident to discuss their reviews freely concerning the presence of SSCFs. Feedback of audit results was given at regional meetings, where the content of substandard care was discussed in general terms. We concluded that the cooperation of regional care providers in providing data and participating in the audit committee was good. The frequency of substandard care in our regional perinatal audit was comparable to other audits of perinatal care. Regional involvement on its own may improve quality of care. Furthermore it may facilitate implementation processes.

Eighty eight cases of perinatal death, after 23 completed weeks of gestation, were reviewed to establish the cause of death and the presence of substandard care, using a standardized procedure. The cause of death was presented by the extended Wigglesworth classification. All cases were reviewed for the presence of substandard care, and its contribution to perinatal death determined (unlikely, possible or likely to be related to perinatal death. In 33% of perinatal death cases, 48 SSCFs were found with a possible (25%) or likely (8%) contribution to perinatal death. Twenty three percent of these SSCFs were attributed to the midwife, 42% to the obstetrician and 29% to the mother. Among these mothers to whom substandard care was attributed there was an over-representation of immigrants. SSCFs were present in 59% of intrapartum cases of death. Another important SSCF identified was delayed action after notification of growth retardation in pregnancy (by both midwives and obstetricians). Recommendations for practice based on the outcome of this study imply prompter action after growth retardation has been identified, and the structural evaluation of all intrapartum deaths. Even in complicated intrapartum death cases, guidelines or local protocols concerning the SSCFs were present in 88% of cases.

Chapter 4 focused on the question:

> What is the concordance of post-mortem perinatal Magnetic Resonance Imaging (MRI) with autopsy findings in a non-selected obstetric population? How is the acceptance of MRI, compared to autopsy and how is it implemented in routine obstetric practice?

To answer this question a prospective cohort study of consecutive perinatal deaths from a general teaching hospital was initiated. The study group consisted of fetuses and neonates, who were born from 16 weeks of gestation and who died intra-uterine, during delivery or after delivery, until 28 days after birth. MRI was performed prior to autopsy

after full parental consent. Agreement between MRI and autopsy was established. The same radiologist and pathologist reported both the MRI and the autopsy in a standardised way. All organs were reviewed and the malformations observed were described. The radiologist was not supplied with clinical information, and both radiologist and pathologist were blinded for the mutual findings. The concordance between MRI and autopsy per case of perinatal death, considering only the major malformations, was calculated.
58 perinatal deaths occurred in the study period. Fifty nine percent of all parents consented to MRI compared to a consent rate of 45% for autopsy, (all part of the MRI group). In 84% the MRI was performed within 48 hours. Autopsy showed 18 major malformations, of which 10 were detected by MRI. The positive predictive value of MRI for the detection of malformations per case of perinatal death was 80% (4/5) and the negative predictive value was 65% (13/20). Consent for routine autopsy could be obtained in about half of cases, similar to national and international autopsy rates. Consent for MRI was obtained in an additional 15%.
We concluded that MRI was of value if autopsy was refused, but the procedure's diagnostic accuracy was insufficient to recommend substitution. No evidence was found in this study for an additional value of MRI when the consent for a full autopsy was obtained. Therefore our recommendation would be that parents should not be offered MRI scans until it is clear they will not consent to autopsy.

Chapter 5 and 6 focus on the third question:

> Are ethnic related differences present in the frequency of substandard care in cases of perinatal mortality? Is there an existing differential timing of the first antenatal visit according to ethnicity, which could represent a specific cause of ethnic related substandard care? If so, what is the contribution of known non-economic determinants?

First, the frequency of ethnic related substandard care difference in perinatal death cases was described. Perinatal care was evaluated by the above-mentioned audit procedure to elicit the role of care inadequacies including the possible involvement of the mother. The ethnic origin of the fetus/newborn was based on the country of birth of the mother and of her parents using Amsterdam population registry data. The cause of death and the differences in substandard care between the ethnic groups were calculated and evaluated.

Beyond 16 weeks of gestation in Surinamese and 'other non-Western mothers' (mainly from Ghana) perinatal mortality was higher than among ethnic Dutch mothers. In Surinamese and Moroccan mothers, we observed a higher rate of early preterm deliveries. Among Moroccan mothers early preterm deliveries accounted for all excess perinatal mortality. In Surinamese mothers too, preterm delivery was a major cause of perinatal death.
The percentage of substandard care differed between the ethnic groups (p=0,034), with the highest percentage among Surinamese mothers. However, the differences were small and located only in the occurence of more substandard care factors with maternal involvement among Surinamese and Moroccan mothers (a late start date for antenatal care, a late notification of the care provider). The other components of substandard care (therapy/detection/communication) did not differ between the ethnic groups. The 'other non-Western' group did not show more substandard care despite observed higher perinatal mortality rates. We concluded that the higher perinatal mortality in Surinamese and other non-Western groups was mainly due to a higher rate of early preterm deliveries. Among Surinamese mothers, however, the results indicated that substandard care with maternal involvement might also play a role in explaining their higher perinatal mortality rates. Possible explanations for these small substandard care differences were formulated, and included differences in health-seeking behavior between women of different ethnic groups and communication problems.

Second, the differential timing of the first antenatal visit between ethnic groups was investigated and the contribution of several non-economic risk factors explored, in a large prospective cohort of pregnant women in the city of Amsterdam. During 15 months, all pregnant women were asked to participate (12.381) at the first antenatal visit (with an independent midwife, hospital-based obstetrician). Ethnic groups were distinguished by country of birth - Dutch, other Western, Surinamese, Antillean, Turkish, Moroccan, Ghanaian and other non-Western women. Gestational age at first visit was derived from a standard screening form. A pregnancy questionnaire revealed possible risk factors for a late start. A cox-proportional hazards model was then created with (1) only ethnic group and (2) additional all significant risk factors, both time-fixed and time-dependent. 8267 women responded.(response rate 67%)
All non-Dutch ethnic groups were significantly later in seeking care during the whole range of pregnancy duration compared to the Dutch group. The range at which 90% were in care varied between 16.6 (Dutch) and 25.0 weeks (Ghanaians). When we added the following risk factors: poor language proficiency, low maternal education, teenage pregnancy, multiparity and unplanned pregnancy to the model, these differences disappeared almost totally in the non-Dutch speaking ethnic groups. In

the Dutch speaking ethnic groups, these differences remained present. Adding time-dependent covariates revealed that the Hazard Ratio's were not constant for age and parity (decreased in time) and language proficiency (increased in time).
We concluded that there was a disturbing delay by all ethnic groups in the timing of the first antenatal visit. In women born in non-Dutch speaking, non-Western countries these differences were explained by a higher prevalence of the risk factors: poor language proficiency in Dutch, lower maternal education and more teenage pregnancies. In women born in Dutch-speaking, non-western countries, the disparities cannot be explained by higher prevalence of these risk factors, indicating that cultural factors play a larger role.

Implications for future research and recommendations for perinatal care

Perinatal audit

The PARIS-study described our systematic approach to a perinatal audit with regional care providers. Considering the anticipated concerns in executing a perinatal audit with regional care providers (biased judgment, difficulties with information provision) we can conclude that we did not observe any of these. The cooperation of regional care providers was good, and judgments were comparable to those of other audits. However, the anticipated better implementation of guidelines needs empirical support. More generally, more research and a longer time horizon is needed to confirm our results.

Substandard care with a possible contribution to perinatal death was found in 25% of cases and a likely contribution in 8%, which implies that there is potential for improvement in care in one out of three cases. The following recommendations can be made. First, prompt action by both midwives and obstetricians is essential when they suspect or receive notification of growth retardation. In this study, the audit panel only considered growth retardation as a SSCF if this condition was suspected and notified during pregnancy, but there was a delay taking action (e.g. intensive fetal monitoring, ultrasound etc). Clear diagnostic procedures should be implemented following the notification or suspicion of a growth retarded fetus. We are aware that at this stage the concept of better detection still requires evidence as to the benefit on the outcome level.
Second, in complicated cases of intrapartum deaths, the majority of SSCFs concern the violation of national or international guidelines, or a regional protocol (15/17 SSCFs). Here the evidence-base is present. All intrapartum deaths should be discussed structurally with the involved care providers hospital-wide. Local or regional protocols should be subject to regular discussion and should be frequently updated and improved if necessary.

A disadvantage of a critical incident audit, of which a perinatal audit is an example, is that the adverse outcome is known to the panel members in advance. This might influence the review of perinatal care. In the 27/28 project of the Confidential Enquiries of Stillbirths and Death in Infancy, a group of children with a good outcome were also reviewed by an audit panel [1] without the panel members knowing the outcome. The authors concluded that a significantly larger frequency of suboptimal care was found in the babies that died. In contrast with this study, a study by Andersen et al showed no difference in the presence of substandard care between neonates with a good and an adverse outcome.[2] Recently, a study was published where the antenatal and perinatal care of a group of live born neonates was reviewed for the presence of substandard care.[3] In this study, almost all investigated cases contained substandard care factors. These studies show that establishing the causal contribution of substandard care is difficult in most instances: existing guidelines have sometimes a weak evidence base or concern weak risk factors. For this reason, more research is needed to compare substandard care between fetuses and neonates with a good, as well as with a bad outcome (for example in term pregnancies). The relative importance of substandard care to the occurrence of a perinatal death can then be estimated. Recently, a report was published which reports a relatively high share of obstetricians in liability lawsuits.[4] This is probably due to two items ; first, the motive of such liability lawsuits are mainly (perinatal) deaths. Second, as mentioned above, the causal contribution of the care provided to the death is difficult to establish. In general, it can be stated that perinatal audit and epidemiological investigations are complementary, both with its own limitations and strengths. Where epidemiologic research can detect patterns at large and investigate causal relations, it is limitated in establishing the role of care in individual cases. An audit, however, can elicit care inadequacies, but cannot establish causal relations.

International evidence on the effectiveness of a critical incident audit is difficult to estimate, since a recently published Cochrane review concluded that there were no studies of sufficiently good quality to establish the best way to perform a critical incident audit on perinatal mortality.[5] Even if such studies do exist the typical Dutch context, where substandard care contains inadequate referral processes between three lines, will require translation. Two items regarding a critical incident audit were undisputed, however: a systematic discussion of all perinatal deaths and the fact that feedback should be given to the relevant persons. These two subjects are of course of importance, but are at the same time vague: who can be regarded as 'the relevant persons' and what should be the content of such a 'systematic discussion'?
The recent presentation of the first results of a nationwide perinatal audit actualises the answers to these questions. What is the optimal

approach to a nation wide audit; and how should this approach be a valid complement to a regional audit? In an ideal situation, it can be stated that a nationwide perinatal audit and a regional perinatal audit are complementary, since their goals are not the same.
A nationwide audit investigates a subset of perinatal deaths, and explores perinatal care structurally, and advises on the development or review of perinatal guidelines. A regional audit investigates more in depth all perinatal deaths in a specific hospital or region and is of critical importance for the review of local protocols. Moreover, with the involvement of active care providers, the process of audit in itself might improve perinatal care. However, for the panel members, the time investment in the perinatal audit is already large, even though we tried to alleviate the burden of data collection for doctors and midwives by gathering it ourselves. Several measures could be implemented to encourage the performance of regional audits alongside a nationwide approach. One example could be that information collected on perinatal death cases for the nationwide audit, can be made available for a regional audit as well.

In considering the composition of the audit committee, we found it beneficial to include a general practioner as one of the panel members, although general practitioners are not directly involved in the delivery of perinatal care in Amsterdam. General practitioners have a central role in health care delivery and are particularly well-suited to judge referral procedures between primary and secondary care. Further, we would advise the presence of a pathologist to supplement the audit process, since we sometimes experienced difficulties in establishing the cause of death. Providing feedback to care providers about the presence of substandard care is an essential component of (perinatal) audit. Feedback in this study was given in general terms, and by organising several meetings for regional care providers in regard to SSCFs. For privacy reasons, feedback to individual hospitals or care providers, will be a difficult process.

In this study, we have chosen the term 'substandard care with maternal involvement.' However, from the medical records it is difficult to determine whether the information provided was sufficient, for example regarding the rupture of membranes or a decrease in movement. We have described these delay factors to the mother, but when communication problems are at stake, the origin of the SSCF can difficultly be determined. However, when a late start of antenatal care was considered a SSCF, this cannot be considered a communication problem.

Cause of death

In the PARIS study, we have used three different cause of death classification, conform CESDI protocol. These three classifications

did not totally fulfil their purpose, As placental pathology,(constituting a substantial part of all antepartum deaths), could not be classified according to any of these classifications. A systematic comparison of these three classifications was out of the scope of the present thesis. Important work has been performed on this subject by De Galan-Roosen [6] and Erwich et al [7] who proposed and investigated a new classification system for perinatal deaths. This 'tulip classification system' has in the past years been tested and used in the nationwide perinatal audit (LPAS). An international consensus on a cause of death classification is to be expected in the near future.
Magnetic Resonance Imaging (MRI) has a modest place in post-mortem investigations in perinatal death cases. Currently, too little evidence is present for a definitive choice between MRI and autopsy, because this raises expectations that cannot yet be fulfilled. The national perinatal autopsy rate remains stable at around 50%, a relatively low percentage. As an important goal for future research, the parental reasons for the refusal of an autopsy should be investigated. In any event, parents could be provided with more adequate information. Concerning the MRI, its value in detecting CNS malformations should be expanded to a common obstetric population. In studies by Brookes and Woodward, MRI was found to be good at detecting CNS malformations. Our study was too small to confirm this finding.

Ethnic differences in perinatal care

In the studies concerning ethnic differences in perinatal care, we have confirmed differences in perinatal mortality rates among ethnic groups, and differences in the start date of antenatal care as one of the potential contributing factors. Ethnic differences in the prevalence of substandard care in perinatal death cases were small, and were situated only in substandard care with maternal involvement.
A late start date of antenatal care in the literature is related to an adverse outcome of pregnancy. In chapter 5 we reviewed a late start of antenatal care several times as a substandard care factor, mainly in ethnic minorities. However, due to the process of audit (only perinatal deaths included) it is difficult to estimate its relative importance. In the present cohort of pregnant women, we will be able to answer the question to what extent the delay found between ethnic groups, influences the outcome of pregnancy. This analysis will be performed in the near future. Moreover, all cases of perinatal death in this cohort will be assessed for cause of death, as well as for the presence of substandard care, conforming to PARIS principles. In this way, unique information concerning a large cohort of pregnant women, their lifestyle, ethnic background and the outcome of pregnancy will come available.
A late start date for antenatal care in the Dutch-speaking, non-Western ethnic groups could not be explained by a higher prevalence of risk

factors. A late start of antenatal care was also established as a one of the substandard care factors with maternal involvement in the Surinamese group. Before strategies for intervention are formulated, more insight is needed into the reasons for such a late start.

By establishing a set of risk factors for a late start date of antenatal care in the ethnic groups, tools for intervention can be identified and put into practice. Language proficiency in Dutch was, among others, a risk factor that strongly influenced the found differences between ethnic groups. This is important evidence for recommendations for perinatal care. The learning of the Dutch language should be promoted as a major health advantage (among others) and should be encouraged.
Next to that, the use of interpreters should be advocated to improve communication between care providers and patients, once in care.
We regard it important that it should be thoroughly checked, whether provided information considering decrease of fetal movements or the rupturing of membranes is fully understood. In a larger context, a European declaration - 'the Amsterdam declaration[8] is an important development that advocates that care providers as well as policy makers should acknowledge the specific health problems of migrants. This declaration, combined with several working documents on, for example, mother and child care, provides practical tools for a larger cultural competence of health care workers while simultaneously advocating the 'empowerment' of migrants themselves.

Perinatal death is a rare, however most severe event. Some cases may be to some extent preventable. Audits may help to reflect on the possibility of prevention of perinatal death. Commitment, reflection and willingness to implement new insights are essential elements to make an important step forward.

Reference List

(1) Macintosh M (ed). Project 27/28: An Enquiry into quality of care and its effects on the survival of babies born at 27-28 weeks. 2003. TSO.

(2) Andersen KV, Hermann N, Gjorp T. Perinatal audit. Are experts biased by knowledge of outcome? Dan Med Bull 1992; 39: 197-9

(3) Aaldriks AA, Wolleswinkel-van den Bosch JH, Mackenbach JP. [Sub-standard factors in primary obstetric care]. Ned Tijdschr Geneeskd 2005; 149(24):1334-1338.

(4) Hubben Je. Gynaecoloog in tuchtrecht. 2005. Den Haag, NVOG, SDU. Ref Type: Report

(5) Pattinson R, Say L, Makin J, Bastos M, Pattinson RC. Critical incident audit and feedback to improve perinatal and maternal mortality and morbidity. Cochrane Database Syst Rev 2005;(4):CD002961.

(6) Galan-Roosen AEM. Registration, classification of causes of death and risk factors [University of Nijmegen] Thesis; 2002.

(7) Eskes M, van Diem M. Nationwide Perinatal Audit Study (LPAS) [in Dutch]. 231. 24-11-2005. Diemen, College voor Zorgverzekeringen.

(8) Ludwig Bolzmann Institute for the Sociology of Health and Medicine. The Amsterdam Declaration. Towards Migrant-friendly hospitals in an Etno-Culturally Diverse Europe. 2005. WHO Collaborating Centre for Health Promotion in Hospitals and Health Care.

8

Samenvatting, richtlijnen voor toekomstig onderzoek en aanbevelingen voor perinatale zorg

Samenvatting

De perinatale sterfte is in het begin van de vorige eeuw sterk afgenomen, een daling die zich in de tweede helft van de vorige eeuw gestaag heeft voortgezet. De antenatale zorg, evenals de peripartum zorg en neonatale zorg zijn in deze lange periode sterk verbeterd. Hieraan heeft zowel primaire preventie als een algehele verbetering van de gezondheidszorg bijgedragen, naast een verbetering van de perinatale zorg. Een verdere verbetering van de perinatale zorg heeft de mogelijkheid het perinatale sterftecijfer verder te doen dalen. Omdat perinatale sterfte slechts één van de indicatoren van perinatale zorg is, zal een verbetering van de perinatale zorg ook een positieve invloed hebben op de andere perinatale indicatoren. In dit proefschrift worden drie bijdragen aan een dergelijke verbetering beschreven.
Ten eerste wordt de opzet en uitvoering van een regionaal georiënteerde perinatal audit beschreven. Een perinatal audit is een belangrijke methode perinatale zorg te beoordelen, door de aanwezigheid te bepalen van 'substandaard zorg'. (gedefinieerd als zorg die niet voldoet aan de geaccepteerde standaarden, zoals vastgelegd in (inter)-nationale richtlijnen, regionale en lokale protocollen).
Het begrip 'audit' heeft ook een centrale rol in de ontwikkeling en implementatie van richtlijnen. Er zijn de afgelopen jaren zowel nationaal als internationaal verschillende perinatal audits uitgevoerd, sommige permanent en landelijk, andere uitgevoerd in een kleine regio, in een onderzoekssetting. In al deze audits hebben regionale dokters en verloskundigen om op zich begrijpelijke redenen niet de perinatale sterftes in de eigen regio beoordeeld. Echter, omdat de implementatie van richtlijnen de kern is van een audit, biedt een actieve rol van regionale dokters en verloskundigen een extra mogelijkheid voor directere feedback van de resultaten. Wij voerden een regionale perinatal audit uit in Amsterdam, (PARIS; Perinatal Audit, Research and Implementation Study) waarbij een auditpanel bestaande uit regionale gynaecologen, kinderartsen, huisartsen en verloskundigen opéénvolgende perinatale sterftecasus beoordeelden voor wat betreft de aanwezigheid van substandaard zorg.

Om te bepalen of substandaard zorg aanwezig is, is het van groot belang dat de doodsoorzaak van een foetus of neonaat goed is vastgelegd. Obductie heeft, als gouden standaard in het postmortale onderzoek,

een belangrijke rol in het vaststellen van de doodsoorzaak. Veel ouders echter weigeren toestemming voor het verrichten van een obductie, waarschijnlijk door het invasieve karakter van het onderzoek. Daarom is de afgelopen jaren gezocht naar andere vormen van postmortaal onderzoek, met het oog op een mogelijke vervanging van obductie. Een voorbeeld van een dergelijk onderzoek is de Magnetic Resonance Imaging, de MRI. In de eerste studies heeft MRI goede eerste resultaten laten zien in het vaststellen van congenitale afwijkingen. Echter, door de keuze van de onderzoekspopulatie kon de waarde van MRI in een gewone obstetrische populatie niet worden vastgesteld. Wij voerden een vergelijkende studie uit tussen MRI en de gouden standaard, obductie, in een niet geselecteerde groep foetussen en neonaten.

Ook is bekend dat ethnische verschillen aanwezig zijn in prevalentie en achtergrond van verschillende negatieve zwangerschapsuitkomsten (hogere perinatale sterfte, meer preterme partus, en een hogere prevalentie van intra-uteriene groeivertraging). Door middel van een perinatal audit hebben we de aanwezigheid van substandaard zorg in perinatale sterftecasus in de grootste etnische groepen in Amsterdam onderzocht en vergeleken. Etniciteits-gerelateerde verschillen in de kwaliteit van perinatale zorg, in het bijzonder van een latere start, is genoemd als één van de verklaringen. Daarom vergeleken we ook de start datum van de antenatale controles in een groot zwangeren cohort, tussen de verschillende etnische groepen, en we onderzochten de bijdrage van een aantal bekende determinanten aan deze verschillen.

Hoofdstuk 1 beschrijft achtergrond en doelstellingen van dit proefschrift.

Hoofdstuk 2 en 3 behandelen de eerste vraag:

> Wat is de uitvoerbaarheid van een regionale perinatal audit, volgens het PARIS-team en het auditpanel? Kan de opzet en de resultante, prevalentie van substandaard zorg, worden vergeleken met andere, bestaande audits?
> Als substandaard zorg aanwezig is, in welke component en welk niveau van perinatale zorg is dit gelegen? (Hierbij wordt ook de mogelijke rol van de moeder meegenomen)

Om deze vragen te kunnen beantwoorden hebben wij een regionale perinatal audit opgezet in de gemeente Amsterdam, waarbij ook aandacht is besteed aan de ervaring van de auditleden. Een steekproef van de perinatale sterftecasus, reeds beoordeeld door het regionale panel, werd opnieuw beoordeeld door een extern auditpanel.

De aanwezigheid van substandaard zorg in de PARIS-studie werd vergeleken met andere perinatal audits. Hierbij was het percentage substandaard zorg in de huidige studie vergelijkbaar met andere, niet-regionaal georiënteerde perinatal audits.
In zeven casus (van de tien) hadden de regionale en externe commissie dezelfde beoordeling van de aanwezigheid van substandaard zorg. In twee van de drie casus waar de beide panels een andere mening hadden, kende het regionale panel substandaard zorg toe, waar het externe panel dit niet deed. Voor alle auditleden was de audit een tijdrovende bezigheid, zelfs in een situatie waar een onderzoeker alle data betreffende de perinatale sterfte verzamelde. (gemiddeld 4 uur, met een range van anderhalf tot tien uur voorbereiding per zitting). Alle auditleden voelden zich veilig genoeg om vrijelijk hun beoordelingen ten aanzien van de aanwezigheid van substandaard zorg te geven. Feedback van de resultaten van de audit werd gegeven op regionale bijeenkomsten waar de prevalentie en inhoud van de substandaard zorg werd besproken in algemene zin. (niet herleidbaar naar individuele dokter/patiënt). Wat betreft de opzet van de audit concludeerden we dat de medewerking van regionale dokters en verloskundigen goed was, zowel in het verstrekken van de gegevens, als in de participatie van het auditpanel. De hoeveelheid substandaard zorg in deze regionale perinatal audit was vergelijkbaar met andere perinatal audits. Regionale betrokkenheid op zichzelf kan de kwaliteit van de perinatale zorg verbeteren, en het kan het implementatieproces vergemakkelijken.

88 perinatale sterftecasus na 24 weken amenorrhoeduur werden beoordeeld wat betreft de doodsoorzaak en de aanwezigheid van substandaard zorg, volgens een gestandaardiseerde procedure. De doodsoorzaak werd vastgelegd aan de hand van de extended Wigglesworth doodsoorzakenclassificatie. De aanwezigheid van substandaard zorg werd vastgesteld, en indien aanwezig, de bijdrage ervan aan de perinatale sterfte (onwaarschijnlijk, mogelijk, waarschijnlijk gerelateerd aan het optreden van de perinatale sterfte). In 33% van alle perinatale sterftes werden 48 substandaard zorgfactoren gevonden met een mogelijke (25%) of waarschijnlijke (8%) bijdrage aan de perinatale sterfte. 23 % van deze substandaard zorgfactoren waren gelegen bij de verloskundige, 42% bij de gynaecoloog en 29% bij de moeder. Een belangrijke substandaard zorgfactor betrof een late reactie van verloskundige en gynaecoloog na de constatering dat er (mogelijk) een groeiretardatie in het spel was. De maternale factoren betroffen met name een late start van de prenatale zorg, en een late reactie op gebroken vliezen en/of verminderde foetale bewegingen. Onder de moeders aan wie substandaard zorg werd toegewezen waren relatief veel allochtone vrouwen.
Substandaard zorgfactoren waren aanwezig in 59% van alle intrapartum sterftes. Aanbevelingen, gebaseerd op de uitkomst van deze studie, houden in een snelle actie na de constatering van een groeivertraging,

en een structurele evaluatie van alle intrapartum sterftes. Zelfs in gecompliceerde intrapartum sterftes, betrof de substandaard zorgfactor het niet naleven van een richtlijn of protocol in 88% van deze sterftes.

Hoofdstuk 4 richt zich op de vraag:

> Wat is de overeenkomst tussen post mortem Magnetic Resonance Imaging (MRI) en obductie in een ongeselecteerde obstetrische populatie? Hoe is de acceptatie van MRI vergeleken met obductie en hoe is de implementatie in de routine obstetrische praktijk?

Om deze vraag te beantwoorden hebben we een prospectieve cohortstudie opgezet in een algemeen ziekenhuis. De studiegroep bestond uit foetussen en neonaten, geboren na 16 weken amenorrhoeduur, tot en met 28 dagen postpartum. Na toestemming van de ouders werd de MRI uitgevoerd voorafgaand aan de obductie, waarbij de overeenkomst tussen beide onderzoeken werd vastgelegd. Dezelfde radioloog en patholoog beoordeelden gestandaardiseerd respectievelijk de MRI en de obductie. Alle organen werden beoordeeld en de aanwezige afwijkingen beschreven. De radioloog kreeg geen klinische informatie, en radioloog en patholoog waren blind voor elkaars bevindingen.Tijdens de studieperiode traden 58 perinatale sterftes op. 59% van alle ouders gaf toestemming voor het verrichten van een MRI, en 45% voor het verrichten van een obductie. In 84% kon deze MRI binnen 48 uur worden verricht. Obductie liet 18 grote afwijkingen zien, waarvan tien werden gedetecteerd door de MRI. De positief voorspellende waarde van MRI voor de detectie van afwijkingen per casus was 80% (4/5) en de negatief voorspellende waarde was 65% (13/20). We concludeerden dat MRI van waarde is als obductie wordt geweigerd, maar dat de accuraatheid in het detecteren van afwijkingen onvoldoende is om vervanging ervan voor te stellen. In deze studie is geen bewijs gevonden voor het verrichten van een MRI als de toestemming voor een volledige obductie is verkregen. Daarom is het advies dat een MRI pas aan ouders zou moeten worden aangeboden als duidelijk is dat ze niet instemmen met het verrichten van een obductie.

Hoofdstuk 5 en 6 hebben betrekking op de derde vraag:

> Zijn etnische verschillen aanwezig in het vóórkomen van substandaard zorg in gevallen van perinatale sterfte? Is er een verschil in de startdatum van de eerste prenatale controles in de verschillende etnische groepen, als specifieke oorzaak van etniciteitsgerelateerde substandaard zorg? Als dat zo is, wat is de bijdrage van bekende niet-economische determinanten aan dit verschil?

Allereerst wordt het vóórkomen van etniciteitsgerelateerde substandaard zorg verschillen bij perinatale sterftes beschreven. Perinatale zorg werd geëvalueerd middels de hierboven genoemde auditprocedure om substandaard zorg op te sporen, inclusief de rol van de moeder hierbij. De ethnische afkomst van de moeder werd gebaseerd op haar geboorteland en van haar ouders, middels data van het Register Amsterdam. De doodsoorzaak en verschillen in substandaard zorg tussen de etnische groepen werden vastgelegd en geëvalueerd.
Gerekend vanaf een zwangerschapsduur van 16 weken was de perinatale sterfte hoger bij Surinaamse en andere niet-Westerse moeders (met name uit Ghana), vergeleken met de Nederlandse moeders. Onder de Surinaamse en Marokkaanse moeders zagen we een hoger percentage immature partus. Onder de Marokkaanse moeders verklaarde dit hoge percentage immature bevallingen volledig de hogere perinatale sterfte. Ook bij de Surinaamse moeders was vroeggeboorte een belangrijke doodsoorzaak. Het percentage substandaard zorg verschilde in de etnische groepen (p=0.034) met het hoogste percentage onder Surinaamse moeders. Echter, deze verschillen waren klein en alleen gelegen in het vóórkomen van meer substandaard factoren met maternale betrokkenheid, in de Surinaamse en Marokkaanse groepen (late start prenatale zorg, late waarschuwing hulpverlener bij problemen). De andere substandaard zorgcomponenten (therapie/detectie/communicatie) verschilden niet tussen de etnische groepen. In de 'overig niet-Westerse groep' werd niet meer substandaard zorg gevonden, ondanks het hogere perinatale sterftecijfer.
We concludeerden dat de hogere perinatale sterfte in de Surinaamse en de 'overig niet-Westerse groep' bijna volledig kon worden verklaard door het vóórkomen van meer immature partus. Onder de Surinaamse moeders echter, lieten de resultaten ook aanwijzingen zien dat substandaard zorg met maternale betrokkenheid ook een rol zou kunnen spelen in het verklaren van de hogere perinatale sterfte. Mogelijke verklaringen voor deze kleine substandaard zorgverschillen zijn opgesteld, hierbij hoorden verschillen in hulpzoekgedrag tussen vrouwen uit de verschillende etnische groepen, en communicatieproblemen.
Vervolgens werden verschillen in de start van de eerste prenatale controle tussen de etnische groepen onderzocht in een groot prospectief cohort van zwangere vrouwen in Amsterdam. Gedurende 15 maanden werd aan alle zwangere vrouwen bij de eerste prenatale controle gevraagd aan dit onderzoek te participeren (12.381 vrouwen werden benaderd, zowel bij de verloskundige als bij de gynaecoloog). Ethnische groepen werden onderscheiden op basis van geboorteland – Nederlands, overig-Westers, Surinaams, Antilliaans, Turks, Marokkaans, Ghanees en overig niet-Westers. De amenorrhoeduur op de eerste prenatale controle werd verkregen van een standaard screeningsformulier. Een cox-proportional hazard model werd vervolgens vervaardigd met (1) alleen etnische groep en (2) hieraan toegevoegd alle significante risicofactoren,

zowel tijdsafhankelijk, als tijdsonafhankelijk.
8267 vrouwen beantwoordden de vragenlijst (respons 67%). Alle niet-Nederlandse etnische groepen verschenen significant later voor de eerste prenatale controle gedurende de hele zwangerschapsduur, vergeleken met de Nederlandse groep. Het tijdstip waarop 90% van de vrouwen voor de eerste prenatale controle was geweest varieerde van 16,6 weken amenorrhoe in de Nederlandse groep tot 25,0 weken amenorrhoe in de Ghanese groep. Als we de volgende risicofactoren aan het model toevoegden; slechte beheersing van de Nederlandse taal, lage maternale opleiding, tienerzwangerschap, multipariteit en ongeplande zwangerschap, dan verdwenen die verschillen vrijwel totaal in de niet-Nederlands sprekende allochtone groepen. In de hoofdzakelijk Nederlands sprekende etnische groepen bleven deze verschillen bestaan. Het toevoegen van tijdsafhankelijke covariaten liet zien dat de hazardratio's van drie risicofactoren niet constant waren over de tijd; de hazardratio's van maternale leeftijd en pariteit werden in de loop van de zwangerschap minder, terwijl de hazardratio van de risciofactor taalbeheersing in de loop van de zwangerschap groter werd.
Concluderend hebben we in deze studie een verontrustend uitstel van alle niet-Nederlandse etnische groepen gevonden van de start van de prenatale controles. Bij vrouwen die geboren zijn in niet-Nederlands sprekende, niet-Westerse landen konden deze verschillen worden verklaard door een hogere prevalentie van de volgende risicofactoren: slechte beheersing van de Nederlandse taal, lage maternale opleiding en tienerzwangerschappen. Bij vrouwen geboren in Nederlands sprekende niet-Westerse landen konden deze verschillen niet worden verklaard door een hogere prevalentie van deze risicofactoren. Mogelijk spelen in deze groepen culturele factoren een belangrijke rol.

Richtlijnen voor toekomstig onderzoek en aanbevelingen voor perinatale zorg

Perinatal audit

De PARIS-studie beschrijft onze systematische aanpak van een perinatal audit met regionale dokters en verloskundigen. Ten aanzien van de verwachte problemen met het uitvoeren van een regionale perinatal audit met de medewerking van hulpverleners uit diezelfde regio (een bias in de beoordeling, problemen met het verkrijgen van informatie) kunnen we concluderen dat wij deze problemen niet hebben ervaren. De medewerking van regionale hulpverleners was goed, en de beoordelingen waren vergelijkbaar met die van andere, niet regionaal georiënteerde perinatal audits. Als kanttekening moeten we hierbij plaatsen dat de te verwachten betere implementatie van de aanbevelingen van de audit meer onderzoek behoeft. Meer in het algemeen is er verder onderzoek en een grotere tijdsspanne nodig om onze resultaten te bevestigen.

Substandaard zorg met een mogelijke bijdrage aan de perinatale sterfte werd gevonden in 25% van de gevallen, met een waarschijnlijke bijdrage in 8%. Dit impliceert dat er een mogelijkheid voor verbetering van de perinatale zorg is bij perinatale sterftes in één van de drie gevallen. De volgende aanbevelingen, gebaseerd op de uitkomsten van de audit kunnen worden gedaan. Ten eerste: een spoedige reactie van zowel gynaecologen als verloskundigen na het opsporen of de verdenking van groeivertraging is essentieel. In de PARIS studie beoordeelde het audit panel alleen die gevallen van groeivertraging als substandaard, wanneer dit was vermoed of bevestigd tijdens de zwangerschap, maar er een vertraging was in de daarop volgende actie. (bv intensieve foetale monitoring, het verrichten van een groei-echo). De aanwezigheid van duidelijke diagnostische procedures zou een stap kunnen zijn, na het constateren of vermoeden van een groeivertraging. We zijn ons ervan bewust, dat een adequate follow up van groeivertraging nog steeds meer evidence behoeft, wanneer het de uitkomst van de zwangerschap betreft. Ten tweede: ook in gecompliceerde intrapartum sterftes, betrof toch de meerderheid van de substandaard zorgfactoren het niet naleven van een nationale of internationale richtlijn, of een regionaal protocol. (15/17 substandaard zorgfactoren). Alle intrapartum sterftes zouden structureel moeten worden besproken met de betrokken hulpverleners, bijvoorbeeld ziekenhuisbreed. Lokale en regionale protocollen moeten regelmatig onderwerp zijn van discussie, en zouden regelmatig moeten worden bijgesteld en verbeterd indien noodzakelijk.

Een nadeel van een 'critical incident audit', waarvan een perinatal audit een voorbeeld is, is dat de slechte uitkomst van tevoren bekend is. Dit kan de beoordeling van de perinatale zorg beïnvloeden. In het '27/28 project' van de 'Confidential Enquiries of Stillbirths and Death in Infancy', werd ook de zorg voor een groep overlevende kinderen, naast een cohort perinatale sterftes met een amenorrhoeduur van 27/28 weken beoordeeld,[1] zonder dat de uitkomst bekend was bij de panel leden. De auteurs concludeerden dat er een significant grotere hoeveelheid substandaard zorg werd gevonden in de groep met kinderen die was overleden. Een eerder verschenen studie door Andersen et al liet juist geen verschil zien in de substandaard zorg in een groep wel en niet overleden kinderen.[2] Recent is in Nederland een studie gepubliceerd waarin de antenatale en perinatale zorg werd beoordeeld van een groep levend geboren, gezonde neonaten op de aanwezigheid van substandaard zorg. In bijna 100% van de gevallen werd substandaard zorg aangetroffen.[3] Deze studies laten zien dat het erg lastig is de oorzakelijke bijdrage van substandaard zorg aan het optreden van het overlijden vast te stellen; bestaande richtlijnen hebben niet in alle gevallen een stevige wetenschappelijke basis, of betreffen matige risicofactoren. Daarom is in de toekomst meer onderzoek noodzakelijk in

een groep neonaten met een goede en een slechte uitkomst, waarbij de aanwezigheid van substandaard zorg dan wordt vastgesteld, bijvoorbeeld bij a terme neonaten. De relatieve bijdrage van substandaard zorg aan het optreden van een perinatale sterfte kan dan worden vastgelegd.
In de afgelopen maanden werd een rapport gepubliceerd waarin wordt beschreven dat er een relatief hoog aandeel is van gynaecologen in het aantal tuchtzaken in Nederland.[4] Dit heeft waarschijnlijk te maken met de volgende twee zaken: ten eerste is de reden voor een tuchtzaak vaak een sterfte, waarmee de gynaecoloog relatief vaak te maken heeft. Ten tweede, zoals hierboven beschreven, is de oorzakelijke bijdrage van de geleverde zorg aan het optreden van de sterfte vaak lastig vast te stellen. In het algemeen kan worden gesteld dat perinatal audit en epidemiologisch onderzoek complementair zijn, allebei met zijn eigen beperkingen en kracht. Epidemiologisch onderzoek kan patronen onthullen en causale verbanden onderzoeken, maar is beperkt in het bekijken van de rol van de geleverde zorg in een individuele casus. Een audit daarentegen, kan substandaard zorg vastleggen, maar geen causale relaties blootleggen.

Het aanwezige bewijs over de effectiviteit van een critical incident audit is lastig in te schatten, nu in een recent gepubliceerd Cochrane review is geconcludeerd dat er geen studies zijn van voldoende kwaliteit om de beste manier te bepalen waarop een dergelijke audit zou moeten worden uitgevoerd.[5] Zelfs als een dergelijke studie wel zou bestaan, dan zou die aanpassing behoeven aan de Nederlandse situatie, die uniek is wat betreft de organisatie van de verloskundige zorg in drie lijnen. Twee zaken ten aanzien van een critical incident audit werden in deze studie niet betwist: de waarde van een systematische discussie over alle perinatale sterftes, en de waarde van het verstrekken van feedback aan de 'relevante personen' . Natuurlijk zijn deze twee zaken van belang, maar als conclusie zijn ze tegelijk ook vaag: wie kunnen worden beschouwd als deze relevante personen, en wat zou de inhoud moeten zijn van een dergelijke systematische discussie?
De recente presentatie van de eerste resultaten van de landelijke perinatal audit in Nederland actualiseert de antwoorden op deze vragen. Wat zou de optimale benadering moeten zijn van een landelijke perinatal audit, en hoe kan deze aanpak een goede tegenhanger zijn van een regionale perinatal audit? In een ideale situatie kan gesteld worden dat een landelijke en een regionale audit complementair zijn, omdat zij niet hetzelfde doel nastreven. Een landelijke audit onderzoekt een subgroep van perinatale sterftes en onderzoekt structureel de perinatale zorg; zij adviseert daarbij over de ontwikkeling en herziening van perinatale richtlijnen. Een regionale audit daarentegen, onderzoekt diepgravender alle perinatale sterfte in een specifiek ziekenhuis of regio, en is zeer belangrijk voor de herziening van lokale protocollen. Meer nog zou

kunnen worden verwacht dat met de betrokkenheid van regionale dokters en verloskundigen het audit proces op zich zelf de perinatale zorg verbetert. Voor de panelleden echter, was de tijdsinvestering in één perinatal audit al groot, terwijl we in het PARIS-onderzoek hebben geprobeerd zoveel mogelijk data zelf te verzamelen.
Een aantal maatregelen zou kunnen worden genomen om naast een landelijke aanpak, de ontwikkeling en uitvoering van regionale audits te stimuleren. Eén voorbeeld hiervan zou kunnen zijn dat de informatie die verzameld wordt ten behoeve van de landelijke audit, op verzoek ter beschikking kan worden gesteld voor de uitvoering van een regionale audit.

Wat betreft de samenstelling van het auditpanel, vonden wij de aanwezigheid van een huisarts als deel van het panel belangrijk, alhoewel in Amsterdam huisartsen niet rechtstreeks betrokken zijn bij het leveren van de perinatale zorg. Ze hebben echter wel een centrale rol in de gezondheidszorg rondom een specifieke patiënt en kunnen verwijsprocedures tussen de eerste en tweede lijn goed beoordelen. Verder zouden we de aanwezigheid van een patholoog adviseren, in bijvoorbeeld een adviserende rol, ten aanzien van het vaststellen van de doodsoorzaak, omdat dit soms erg lastig bleek.
De terugkoppeling van de vastgestelde substandaard zorg is een essentieel onderdeel van een perinatal audit. In het PARIS-onderzoek werd deze terugkoppeling verstrekt in algemene termen en door het organiseren van verschillende bijeenkomsten voor regionale dokters en verloskundigen ten aanzien van de uitkomsten. Om privacyredenen zal een terugkoppeling naar individuele ziekenhuizen of hulpverleners een lastig proces zijn.

In deze studie hebben we gekozen voor de term 'substandaard zorg met maternale betrokkenheid'. Het was echter soms uit de medische status niet duidelijk of de verstrekte informatie aan de patient duidelijk genoeg was geweest en de patient te laat, of dat de informatie onduidelijk was en er sprake was van een interactie probleem tussen moeder en hulpverlener. Echter, wanneer een late start van de prenatale zorg het onderwerp was van de substandaard zorg, kan hier geen sprake zijn van een communicatieprobleem.

Doodsoorzaak

In het PARIS-onderzoek hebben we drie verschillende doodsoorzaken-classificaties gebruikt, zoals in de Confidential Enquiries. Deze drie classificaties voldeden allemaal niet volledig aan hun doel, omdat placentapathologie, wat een belangrijk deel is van de antepartum sterftes in geen van deze drie classificaties kon worden vastgelegd. Een systematische vergelijking van deze doodsoorzakenclassificaties viel buiten de scoop van het huidige proefschrift. Belangrijk werk is in de afgelopen jaren verricht door De Galan-Roosen [6] en Erwich

et al [7] , die een nieuw classificatiesysteem voor perinatale sterftes introduceerden en onderzochten. Dit 'Tulip classification system' is in het afgelopen jaar gebruikt en getest in de pilot van de landelijke perinatal audit. Een internationale consensus over het gebruik van een doodsoorzakenclassificatie wordt in de nabije toekomst verwacht.
MRI heeft een bescheiden plaats verworven in het postmortale onderzoek betreffende perinatale sterftes. Op dit moment is er te weinig wetenschappelijk bewijs om een definitieve keuze te maken tussen MRI en obductie, omdat dit verwachtingen wekt die nog niet kunnen worden vervuld. Het nationale obductiepercentage blijft stabiel rond de 50%, wat relatief laag is. Een belangrijk doel voor toekomstig onderzoek zou dan ook moeten zijn meer inzicht te krijgen in de redenen van ouders om obductie te weigeren, en zo deze ouders van adequatere informatie te kunnen voorzien. Betreffende de MRI, zou meer onderzoek nodig zijn naar het opsporen van centraal zenuwstelsel afwijkingen in een algemene obstetrische populatie. In de studies van Brookes en Woodward was de MRI goed in het detecteren van zentraal zenuwstelsel afwijkingen; onze studie was echter te klein om dit te kunnen bevestigen.

Ethnische verschillen in perinatale zorg

In de twee studies opgenomen in dit proefschrift betreffende ethnische verschillen in perinatale zorg, hebben we verschillen gevonden in het perinatale sterftecijfer in de ethnische groepen, en verschillen in de startdatum van de antenatale controles als een van de mogelijk bijdragende factoren. Ethnische verschillen in de prevalentie van substandaard zorg waren klein en alleen gelegen in de aanwezigheid van substandaard zorg met maternale betrokkenheid.
Een late start van de antenatale controles is in de literatuur gerelateerd aan een vaker voorkomen van een slechte zwangerschapsuitkomst.
In hoofdstuk 5 werd een late start van de antenatale controles een aantal maal beoordeeld als een substandaard zorg factor, met name bij allochtone vrouwen. Door het auditproces, waarbij alleen perinatale sterftes werden beoordeeld, was het moeilijk de relatieve bijdrage hiervan in te schatten.
In het cohort zwangere vrouwen, waarin we hebben gekeken naar de start van de antenatale controles, zullen we de vraag kunnen beantwoorden in welke mate de vertraging, gevonden tussen de etnische groepen, de uitkomst van de zwangerschap beïnvloedt. Deze analyse zal in de nabije toekomst worden gedaan. Ook zullen alle perinatale sterftes in dit cohort worden beoordeeld wat betreft de doodsoorzaak en de aanwezigheid van substandaard zorg, conform het PARIS-format. Op deze manier zal er unieke informatie over een groot cohort zwangeren beschikbaar komen, hun leefstijl, ethnische achtergrond en de uitkomst van de zwangerschap.
De late start van de antenatale controles in de Nederlands sprekende, niet-Westerse ethnische groepen kon niet worden verklaard door een

hogere prevalentie van de bestudeerde risicofactoren. Een late start van de antenatale zorg was ook beoordeeld als één van de substandaard zorgfactoren onder Surinaamse moeders. Voordat een interventie strategie kan worden ontwikkeld, is allereerst meer inzicht nodig in de redenen voor deze late start in deze ethnische groepen.

Door het bevestigen van een aantal risicofactoren voor een late start van de antenatale controles in de verschillende ethnische groepen, kunnen handvatten voor interventie worden geïdentificeerd en in de praktijk worden gebracht. Een slechte beheersing van de Nederlandse taal was, onder andere, een risico factor die de verschillen tussen de ethnische groepen sterk beïnvloedde. Dit is belangrijke informatie voor aanbevelingen voor de perinatale zorg. Het leren van de Nederlandse taal dient te worden gepromoot als onder andere een belangrijk gezondheidsvoordeel en moet worden aangemoedigd.
Behalve dit, zou ook het gebruik van tolken moeten worden vergemakkelijkt om de communicatie tussen hulpverleners en patienten te verbeteren als ze eenmaal in zorg zijn. In een groter verband is een belangrijke ontwikkeling het uitbrengen van de 'Amsterdam declaration' [8], een Europese verklaring, die aandacht vraagt voor de specifieke gezondheidsproblemen van migranten, bij zowel politici als hulpverleners. Deze verklaring, gecombineerd met verschillende werkdocumenten betreffende, bijvoorbeeld moeder-en-kindzorg, biedt praktische handvatten voor een grotere culturele competentie van gezondheidswerkers, en stimuleert tegelijk een 'empowerment'van de migranten zelf.

Perinatale sterfte is een zeldzame maar ernstige gebeurtenis. Sommige gevallen zijn mogelijk tot op zekere hoogte te voorkomen. Audits kunnen helpen om te reflecteren op de mogelijkheid van preventie van een perinatale sterfte. Betrokkenheid, reflectie en de wil om nieuwe inzichten te implementeren zijn essentiële elementen om een belangrijke stap voorwaarts te maken.

Reference List

(1) Macintosh M (ed). Project 27/28: An Enquiry into quality of care and its effects on the survival of babies born at 27-28 weeks. 2003. TSO.

(2) Andersen KV, Hermann N, Gjorp T. Perinatal audit. Are experts biased by knowledge of outcome? Dan Med Bull 1992; 39: 197-9

(3) Aaldriks AA, Wolleswinkel-van den Bosch JH, Mackenbach JP. [Sub-standard factors in primary obstetric care]. Ned Tijdschr Geneeskd 2005; 149(24):1334-1338.

(4) Hubben Je. Gynaecoloog in tuchtrecht. 2005. Den Haag, NVOG, SDU. Ref Type: Report

(5) Pattinson R, Say L, Makin J, Bastos M, Pattinson RC. Critical incident audit and feedback to improve perinatal and maternal mortality and morbidity. Cochrane Database Syst Rev 2005;(4):CD002961.

(6) Galan-Roosen AEM. Registration, classification of causes of death and risk factors [University of Nijmegen] Thesis; 2002.

(7) Eskes M, van Diem M. Nationwide Perinatal Audit Study (LPAS) [in Dutch]. 231. 24-11-2005. Diemen, College voor Zorgverzekeringen.

(8) Ludwig Bolzmann Institute for the Sociology of Health and Medicine. The Amsterdam Declaration. Towards Migrant-friendly hospitals in an Etno-Culturally Diverse Europe. 2005. WHO Collaborating Centre for Health Promotion in Hospitals and Health Care.

Appendices

Extended Wigglesworth classification

Appendix 1

Category 1
Congenital defect/malformation (lethal or severe): Only lethal or potentially lethal congenital malformation should be included here. Serious biochemical abnormalities such as Tay Sach's disease and any known single gene defects known to have a high risk of death should be included.

Category 2
Unexplained antepartum fetal death: Most late fetal losses should be coded here. Where a live-born baby dies due to problems during the antepartum period: code this as 'other specific causes' (category 6).

Category 3
Death from intrapartum 'asphyxia', 'anoxia' or 'trauma': This category covers any baby who would have survived but for some catastrophe occuring during labour. These babies will tend to be normally formed, stillborn or with poor Apgar scores, possible meconium aspiration, or evidence of acidosis. Very premature infants (those less then 24 weeks' gestation) may be asphyxiated at birth, but should not be entered in this category as a rule.

Category 4
Immaturity: This applies to live births only, who subsequently die from structural pulmonary immaturity, surfactant deficiency, intra ventricular haemorrhage, or their late consequences – including chronic lung damage.

Category 5
Infection: this applies where there is clear microbiological evidence of infection that could have caused death, e.g. maternal infection with Group B streptococci, rubella, parvovirus, syphilis etc.; or in the case of a baby dying with overwhelming sepsis.

Category 6
Other specific causes: Use this if there is a specific recognisable fetal, neonatal or paediatric condition not covered under the earlier categories. Examples include:
1) **fetal** conditions: twin-to-twin transfusion and hydrops fetalis;
2) **neonatal** conditions; pulmonary haemorrhage, pulmonary hypoplasia due to prolonged loss of liquor (primary hypoplasia being classed as a malformation), persistent transitional circulation (in the absence of infection, aspiration or surfactant deficiency), blood loss unassociated

with trauma (e.g. vasa praevia).
3) **paediatric conditions;** malignancy and acute abdominal catastrophe (such as volvulus without antecedent congenital malrotation).

Category 7
Accident or non-intrapartum trauma: confirmed non-accidental injury should be coded here. If only suspected code as a sudden infant death cause unknown (category 8)

Category 8
Sudden infant death, cause unknown: This will include all infants in whom the cause is unknown or unsuspected at the time of death. Modification due to postmortem information should be notified later.

Category 9
Unclassifiable. To be used as a last resort. Details must be given if this option is ticked.

Rapid Case Record Form

Appendix 2

Uitsluitend in te vullen door direct verantwoordelijke zorgverlener

PARIS **Rapid Case Record Form**
formulier 1

studienummer ☐☐☐☐
Ziekenhuis

1 Registratienummer moeder ☐

2 Postcode (zonder lettercombinatie) ☐☐☐☐

3 Geboorteland moeder
- ☐ Nederland
- ☐ Anders, nl. ☐

4 Indien Suriname, welke bevolkingsgroep
- ☐ Creools
- ☐ Hindoestaans/Javaans
- ☐ Anders, nl. ☐

5 Geboorteland biologische vader kind
- ☐ Nederland
- ☐ Anders, nl. ☐

6 Indien Suriname, welke bevolkingsgroep
- ☐ Creools
- ☐ Hindoestaans/Javaans
- ☐ Anders, nl. ☐

7 amenorroeduur tijdens partus ☐

8 partusdatum ☐☐☐☐ ☐☐☐☐ dd mm jaar

9 Tijdstip van overlijden kind
- ☐ antepartum
- ☐ durante partum
- ☐ postpartum ☐ binnen 24 uur
  ☐ na 24 uur

10 Klinisch beeld/diagnose waaronder kind overleden is ☐

FAX DEZE ZIJDE NAAR ONDERZOEKER (ORIGINEEL NIET IN STATUS BEWAREN!)

Rapid CRF **PARIS** © AMC

Clinical Case Record Form (content)

Appendix 3

Deel 1

A Demografie

1. Studienummer
2 moeder gehuwd (ja/nee/onbekend)
3 heeft moeder een vaste partner (ja/nee/onbekend)
4 hoe is haar woonsituatie? (alleen/ alleen met kinderen/met partner zonder kinderen/ met partner en kinderen/ anders/onbekend)
5 aantal inwonende kinderen
6 wat is de legale status van moeder (legaal/illegaal/onbekend)
7 heeft moeder een betaalde baan (ja/nee/onbekend)
8 baan moeder
9 heeft partner een betaalde baan (ja/nee/onbekend)
10 baan partner
11 verzekering moeder
12 hoe was de communicatie met moeder (goed/matig, tolk nodig/slecht/onbekend)
13 was de partner bij de partus aanwezig (ja/nee/onbekend)
14 geboorteland moeder
15 geboorteland vader
16 postcode moeder ten tijde van partus

B Details moeder

17 leeftijd moeder bij partus
18 lengte moeder
19 gewicht moeder voor graviteit of bij eerste prenatale controle
20 rhesus moeder (pos/neg /onbekend)
21 duur graviditeit aan de hand van (ELM/vroege US/onbekend)
22 a terme datum

C Details perinatale sterfte

23 partus bij AD in AD
24 partusdatum
25 tijdstip perinatale sterfte in relatie tot partus (antepartum/durante partu/postpartum/ onzeker/onbekend)
26 indien sterfte AP of DP, hoe was de situatie? (voor aankomst in ZH, niet in partu/voor aankomst in ZH, wel in partu/voor aankomst in ZH, wrsch. in partu/na aankomst in ZH, niet in partu/na aankomst, in partu/nvt/onbekend)
27 waar is de sterfte waarschijnlijk opgetreden? (voor eerste contact met eerste

hulpverlener/na contact eerste hulpverlener, maar niet in ZH/in ZH op VK/in ZH op OK/in ZH op couveuse of NICU/in ZH op paediatrie/onbekend)

28 hoe lang voor de eerste diagnose wordt gedacht dat het kind is overleden? (onder observatie/0-6 uur/7-23 uur/24 uur-6dgn./7 dagen/onbekend)

29 observaties aan kind bij geboorte (hoorbare schreeuw/spontane ademhalingspoging of actieve beweging na de geboorte/alleen HA na postpartum/geen teken van leven, geen maceratie/eerste- of tweede graads maceratie/derde graadsmaceratie/onbekend)

30. geboortedatum kind
31. geboortetijdstip kind
32. geboortegewicht
33. geboortegewicht of percentiel
34. begeleiding t.t.v. sterfte (verloskundige/huisarts/2e lijn gynaecoloog/2e lijn kinderarts/3e lijn gynaecoloog/3e lijn neonatoloog/anders/onbekend)
35. sexe kind (man/vrouw/niet goed vast te stellen/onbekend)
36. bij geboorte macroscopische afwijkingen zichtbaar (ja/nee/onbekend)
37. beschrijf macroscopische afwijkingen kind
38. waren er macroscopische afwijkingen zichtbaar aan de placenta (ja/nee/onbekend)
39. beschrijf macroscopische afwijkingen aan placenta
40. placenta ingestuurd voor macroscopisch onderzoek? (ja/nee/onbekend)
41. indien afwijkingen aan placenta infectie? (ja/nee/onbekend)
42. indien afwijkingen aan placenta onrijpheid? (ja/nee/onbekend)
43. indien afwijkingen aan placenta schaemie? (ja/nee/onbekend)
44. indien afwijkingen aan placenta solutio? (ja/nee/onbekend)
45. indien afwijkingen aan placenta anders (ja/nee/onbekend)
46. beschrijf afwijkingen placenta bij PA-onderzoek
47. gewicht placenta
48. is obductie toegestaan? (ja/nee/onbekend)
49. indien afwijkingen bij obductie; infectie? (ja/nee/onbekend)
50. indien afwijkingen bij obductie; perinatale asfyxie? (ja/nee/onbekend)
51. indien afwijkingen bij obductie; cong. afwijkingen? (ja/nee/onbekend)
52. indien afwijkingen bij obductie; anders (ja/nee/onbekend)
53. beschrijf afwijkingen bij obductie
54. bloed afgenomen bij moeder voor TORCH ? (nee/ja, geen bijzonderheden(alles negatief of alleen lgG positief/ja, afwijkend (1 of>dan 1xlgM pos)/nog geen uitslag/onbekend)
55. is een spierfasciebiopt afgenomen bij het kind voor karyotypering? (nee/ja, geen bijzonderheden/ ja, afwijkend/nog geen uitslag/onbekend)
56. is ander chromosomaal onderzoek bij het kind ingezet? (nee/ja, geen bijzonderheden/ja, afwijkend/nog geen uitslag/onbekend)
57. indien vermoeden op een congenitale afwijking, wat was de klinische diagnose
58. komen er congenitale afwijkingen in de familie van vader of moeder voor? (ja/nee/onbekend)
59. indien congenitale afwijkingen in familie, beschrijf
60. zijn vader en moeder bloedverwant? (nee/ja, namelijk neef-nicht/ja, anders/onbekend
61. is het kind postpartum een oorkweek afgenomen? nee/ja, niet afwijkend/ja, afwijkend/onbekend
62. is het kind pp een nasopharynxkweek afgenomen?
63. is bij het kind pp een bloedkweek afgenomen?

64. is bij het kind pp een liquorkweek afgenomen?
65. is bij het kind een navelkweek afgenomen?
66. is bij het kind pp een rectumkweek afgenomen?
67. is bij het kind een introituskweek afgenomen?
68. is bij moeder een cervixkweek afgenomen?
69. is bij moeder een bloedkweek afgenomen?
70. is bij moeder een urinekweek afgenomen?

D Algemeen medische voorgeschiedenis (incl. gynaecologie en fertiliteit)

71. pre-existente hypertensie (ja/nee/onbekend)
72. conisatie/portio-amputatie (ja/nee/onbekend)
73. uterus myomatosus (ja/nee/onbekend)
74. congenitale uterusafwijkingen (ja/nee/onbekend)
75. subfertiliteit (ja/nee/onbekend)
76. schildklierproblematiek (ja/nee/onbekend)
77. vitum cordis moeder (ja/nee/onbekend)
78. HNP/orthopedische afwijkingen bekken/wervelkolom (ja/nee/onbekend)
79. epile[sie (ja/nee/onbekend)
80. overige neurologische afwijkingen (ja/nee/onbekend)
81. psychopathologie (ja/nee/onbekend)
82. sociale problematiek (ja/nee/onbekend)
83. verhoogd thromboserisico (ja/nee/onbekend)
84. stollingsdeficiënties (ja/nee/onbekend)
85. diabetes mellitus (ja/nee/onbekend)
86. A en B thalassemie (ja/nee/onbekend)
87. sikkelcelziekte en –trait (ja/nee/onbekend)

E Screening

88. rubella-screening (screening niet verricht/screening verricht, niet afwijkend/screening verricht, afwijkend/onbekend)
89. hepatitis B-screening (screening niet verricht/screening verricht, niet afwijkend/ screening verricht, afwijkend/onbekend)
90. HIV-screening (screening niet verricht/screening verricht, niet afwijkend/screening verricht, afwijkend/onbekend)
91. Lues-screening (VDRL) (screening niet verricht/screening verricht, niet afwijkend/ screening verricht, afwijkend/onbekend)
92. Lues-screening (TPHA) (screening niet verricht/screening verricht, niet afwijkend/ screening verricht, afwijkend/onbekend)
93. irregulaire antistoffen 12 weken (screening niet verricht/screening verricht, niet afwijkend/screening verricht, afwijkend/onbekend)
94. irregulaire antistoffen 32 weken (screening niet verricht/screening verricht, niet afwijkend/screening verricht, afwijkend/onbekend)

F Infecties

95. maakte moeder een herpes simplexinfectie door in deze graviditeit? (ja/nee/onbekend)
96. diagnose AIDS gesteld, voor/in graviditeit? (ja/nee/onbekend)
97. maakte patiënte een gonorroe-infectie door in deze graviditeit? (ja/nee/onbekend)
98. maakte patiënte in deze graviditeit een chlamydia-infectie door? (ja/nee/onbekend)
99. maakte patiënte in deze graviditeit een parvo-virusinfectie door? (ja/nee/onbekend)
100. maakte patiënte in deze graviditeit een cytomegalie-infectie door? (ja/nee/onbekend)
101. maakte patiënte in deze graviditeit een malaria-infectie door? (ja/nee/onbekend)
102. maakte patiënte in deze graviditeit een toxoplasmose-infectie door? (ja/nee/onbekend)
103. urineweginfectie in deze graviditeit? (nee/cystitis/pyelitis/pyelonefritis/urosepsis/onbekend)
104. ontwikkelde moeder in de graviditeit koorts waarvoor geen focus kon worden gevonden? (ja/nee/onbekend)
105. mediactiegebruik moeder (tekst)
106. is dit kind één van een tweeling? (ja/nee/onbekend)

Deel 2

A Obstetrische voorgeschiedenis

107. obstetrische voorgeschiedenis blanco? (nee/ja|)
108. mevrouw is gravida
109. mevrouw is para (alles > 16 weken)
110. aantal spontane abortus
111. aantal APLA (sociaal/medisch)
112. aantal EUG

Kind 1,2,3,4,5

113. jaartal geboorte kind ()
114. geboortegewicht kind ()
115. kind () geboren bij AD (weken AD/onbekend)
116. kind () meerling? (nee/ja/onbekend)
117. kind () congenitale afwijkingen (ICD 9) (nvt (geen congenitale afwijkingen)/nog niet bekend (wel congenitale afwijkingen)/ICD-code nog niet bekend
118. geboortemechanisme kind () (spontaan/FE/VE/SC primair (electief)/SC,secundair/ onbekend)
119. geslacht kind () (jongen/meisje/onbekend)
120. uitkomst kind () (gezond bij 7 dgn./niet gezond bij 7 dgn./neonatale sterfte/IUVD/onbekend)
121. in VG preeclampsie/HELLP/zwangerschapshypertensie? (nee/ja/onbekend)
122. in VG solutio placentae? (nee/ja/onbekend)
123. in VG placentapathologie? (nee/ja/onbekend)
124. eerder dysmatuur kind? (nee/ja/onbekend)
125. eerder rhesusantagonisme? (nee/ja/onbekend)

B Prenatale zorg en conceptie

126. foliumzuur gebruikt preconceptioneel of in eerste trimester? (nee/ja/onbekend)
127. wijze van conceptie (spontaan/ovulatie-inductie/IUI zonder ovulatie-inductie/IUI met ovulatie-inductie/IVF/ICSI/KID/onbekend)

128. datum eerste prenatale controle (dagen AD)
129. datum eerste prenatale controle (datum)
130. aantal bezoeken per twee weken
131. prenatale zorg alleen in eerste lijn? (nee/ja/onbekend)
132. start PNC eerste lijn, overname tweede lijn? (nee/ja/nvt, geen PNZ of alleen 1e lijn/onbekend)
133. indien overname, wanneer? (dagen AD)
134. indien overname, indicatie? (groeivertraging/hypertensie-preeclampsie/bloedverlies eerste helft/bloedverlies tweede helft/placenta praevia/afwijkende ligging/meerlinggraviditeit/ dreigende partus immaturus/dreigende partus prematurus/anders/nvt/onbekend)
135. PNC eerste lijn; consult gynaecoloog tijdens graviditeit? (nee/ja/nvt: geen PNZ of alleen eerste lijn/onbekend)
136. zo ja, aantal consulten? (onbekend)
137. datum (dagen AD) eerste consult
138. indicatie eerste consult? (minder of geen leven voelen/verdenking groeivertraging/ hypertensie//preeclampsie/bloedverlies 1e helft/bloedverlies 2e helft/verdenking liggingsafwijking: ook na versie retour eerste lijn/dreigende partus immaturus/dreigende partus prematurus/anders/nvt/onbekend)
139. datum (dagen AD) tweede consult (minder of geen leven voelen/verdenking groeivertraging/hypertensie//preeclampsie/bloedverlies 1e helft/bloedverlies 2e helft/verdenking liggingsafwijking: ook na versie retour eerste lijn/dreigende partus immaturus/dreigende partus prematurus/anders/nvt/onbekend)
140. indicatie tweede consult (minder of geen leven voelen/verdenking groeivertraging/ hypertensie//preeclampsie/bloedverlies 1e helft/bloedverlies 2e helft/verdenking liggingsafwijking: ook na versie retour eerste lijn/dreigende partus immaturus/dreigende partus prematurus/anders/nvt/onbekend)
141. datum (dagen AD) derde consult
142. indicatie derde consult (minder of geen leven voelen/verdenking groeivertraging/ hypertensie//preeclampsie/bloedverlies 1e helft/bloedverlies 2e helft/verdenking liggingsafwijking: ook na versie retour eerste lijn/dreigende partus immaturus/dreigende partus prematurus/anders/nvt/onbekend)
143. PNC primair bij gynaecoloog? (nee/ja/nvt: geen PNZ of alleen eerste lijn/onbekend)
144. indien ja, medische indicatie? (preexistente hypertensie/conisatie//portio-amputatie/ uterusmyomatosus/congenitale uterusafwijkingen/subfertiliteit/schildklierproblematiek/ vitum cordis moeder/HNP-orthopedische afwijkingen aan bekken of WK/epilepsie/ overige neurologische afwijkingen/psychopathologie/sociale problematiek/verhoogd thromboserisica/stollingsdeficientie/diabetus mellitus/A en B thalassemie/ sikkelcelziekte/Rhesusantagonisme vorige graviditeit/IUVD in VG/partus immaturus in VGpartus prematurus in VG/zwangerschapshypertensie (pre)eclampsie in VG/ diabetes gravidarum in VG/SC in VG/meconiumhoudend vruchtwater in VG/fluxus pp vorige graviditeit/ MPV in VG/reanimatie vorige graviditeit/neonatale mortaliteit/anders/nvt/onbekend)

C Onderzoeken deze graviditeit

145. is in deze graviditeit een structuurecho verricht? (nee/ja, niet afwijkend/ja, afwijkend/onbekend)
146. indien structuurecho afwijkend, beschrijf
147. is een NT-meting verricht? (nee/ja, geen verhoogd risico/ja, wel verhoogd risico/onbekend)

148. is in deze graviditeit een tripletest vericht? (nee/ja, geen verhoogd risico/ja, wel verhoogd risico/onbekend)
149. is in deze graviditeit een amnionpunctie verricht? (nee/ja, niet afwijkend/ja, afwijkend/onbekend)
150. is in deze graviditeit een chorionbiopsie verricht? (nee/ja, niet afwijkend/ja, afwijkend/onbekend)
151. foetale biometrie verricht in deze graviditeit? (nee/ja/onbekend)
152. biometrie; data (dagen AD)
153. biometrie; echo's conform percentiel?
154. is in deze graviditeit een echo doppier verricht? (nee/ja/onbekend)
155. echo doppler-metingen (dagen AD)
156. echo doppler-metingen, PI art.umbilicalis

D Intoxicaties

157. hoeveel rookte moeder in graviditeit? (aantal sig.dd/nee/onbekend)
158. advies gegeven over roken? (nee/ja/onbekend)
159. alcoholgebruik moeder in graviditeit? (EH alcohol dd/nee/onbekend)
160. advies gegeven over alcoholgebruik (nee/ja/onbekend)
161. softdrugsgebruik moeder in graviditeit? (joints o i d/nee/onbekend)
162. indien softdrugs, welke?
163. harddrugsgebruik in graviditeit? (EH dd/nee/onbekend)
164. indien harddrugs, welke?
165. is er een advies gegeven over drugsgebruik? (niet vermeld/ja, zelf/ja, doorverwezen/nvt; geen soft- of harddrugsgebruik/onbekend)

Deel 3

A Complicaties deze graviditeit

166. was er een cervixinsufficientie? (nee/ja/onbekend)
167. dreigende partus prematurus/immaturus? (nee/ja/onbekend)
168. preeclampsie?HELLP/eclampsie/zwangerschapshypertensie? (nee/ zwangerschapshypertensie/preeclampsie/HELLP/eclampsie/onbekend)
169. negatieve dyscongruentie? (nee/ja/onbekend)
170. diabetes gravidarum? (nee/ja/onbekend)
171. bloedverlies? (nee/ja/onbekend)
172. afwijkende ligging (derde trimester)? (nee/ja/onbekend)
173. serotiniteit? (nee/ja/onbekend)
174. solutio placentae? (nee/ja/onbekend)
175. was er antepartum een overplaatsing? (nee/ja/onbekend)
176. indien ja, bij welke AD? (dagen AD/onbekend)
177. indien overplaatsing, reden overplaatsing? (nee/ 2e naar 3e lijn; zorg/2e naar 3e lijn -plaatsgebrek/3e naar 2e lijn - abstineren/3e naar 2e lijn - kind goed/3e naar 3e lijn plaatsgebrek/onbekend)
178. indien overplaatsing, waar naartoe? (binnen Amsterdam/buiten Amsterdam, maar binnen de regio/buiten de regio (regio=Noord Holland, Kennemerland, Flevopolder en Gooi)/onbekend)
179. abstinerend beleid antepartum (nee/ja/onbekend)
180. geen IUVD, geen afbreking (nee/ja)

181. geen IUVD, wel afbreking (nee/ja)
182. wel IUVD, geen afbreking (nee/ja)
183. wel IUVD, wel afbreking (nee/ja)
184. indien afbreking, op welke manier? (nee/dilapan/dilapan+nalador/nalador/oxytocine/anders/nvt/onbekend)
185. tijdsduur start afbreking – start weeënactiviteit? (uur/onbekend)
186. tijdsduur start inleiding – geboorte kind (uur/onbekend)

C Deze graviditeit – peripartus

187. plaats partus (thuis, voor aankomst verloskundige/thuis. na aankomst verloskundige/tijdens transport/verloskamer ziekenhuis/operatiekamer ziekenhuis/anders/onbekend)
188. aspect vruchtwater? (helder/meconium/onbekend)
189. duur weeënactiviteit? (uur/nvt; primaire SC/onbekend)
190. duur uitdrijving (uur/onbekend)
191. CTG verricht na breken vliezen? (nee/ja, intermitterend/ja, continue/onbekend)
192. zijn MBO's verricht? (nee/nvt/onbekend)
193. is de baring ingeleid? (nee/ja, wegens serotiniteit, overigens normaal/ja, wegens gebroken vliezen zonder weeën, overigens normaal/ja, wegens groeiachterstand/ja, wegens verdenking matige foetale conditie/i v m vorderende baring/nvt/onbekend)
194. inleiding door middel van (dilapan/dilapan en oxytocine/prostaglandinegel/prostaglandinegel en oxytocine/dilapan en prostaglandinegel/nvt (geen inleiding)/onbekend)
195. foetale hartslag < 100 tijdens ontsluiting of uitdrijving? (nee/ja, maar korter dan 1 minuut/ja > 1 minuut maar < 5 minuten/ja, langer dan 5 minuten/nvt, primaire sectio/onbekend/niet geregistreerd)
196. baringsmechanisme (spontaan/vacuum, secundair/forceps, secundair/vacuum en forceps/secundaire sectio zonder vacuum of forceps/secundaire sectio met voorafgaande vacuum en forceps/primaire sectio/onbekend)
197. indien kunstverlossing/sectio, indicatie (niet vorderende ontsluiting/niet vorderende uitdrijving/foetale nood/dysproportie/maternale indicatie/anders/nvt/onbekend)
198. presentatie bij partus (achterhoofdsligging achterhoofd voor/achterhoofdsligging achterhoofd achter/andere hoofdligging/onvolkomen stuitligging/volkomen stuitligging/dwarsligging/onbekend)
199. partus gedaan door (huisarts/verloskundige/assistent gynaecoloog/gynaecoloog tweede lijn/gynaecoloog derde lijn/anders/ onbekend
200. durante partu overdracht van eerste naar tweede lijn? (nee/nabreken vliezen/tijdens ontsluiting/tijdens uitdrijving/nvt. geen start partus in eerste lijn/onbekend)
201. indien ja, indicatie verwijzing (cortonenpathologie-aanwijzingen foetale nood/afwijkende ligging/gebroken vliezen zonder weeën/meer dan 24 uur gebroken vliezen/NVO/NVU/meconiumhoudend vruchtwater/partus immaturus/partus prematurus/anders/nvt/onbekend)
202. indien begin partus in tweede lijn, durante partu overdracht naar derde lijn? (nee/ja/nvt, geen start partus tweede lijn/onbekend)
203. indien ja, indicatie verwijzing (tekst)
204. ontwikkelde moeder koorts durante partu? (nee/ja/onbekend)
205. zo ja, hoeveel uur voor partus temperatuursverhoging? (xxx uur/nvt geen koorts/onbekend)
206. is het kind durante partu overleden? (kind levenloos geboren; geen IUVD) (nee/ja)

D Neonatale en verlengd neonatale zorg

207. leeftijd kind bij overlijden (dagen)
208. apgar score 1 minuut
209. apgar score 5 minuut
210. apgar score 10 minuten
211. consult kinderarts aangevraagd? (nee/ja/onbekend)
212. door wie is dit consult aangevraagd? (assistent gynaecoloog/verloskundige/gynaecoloog/onbekend)
213. wanneer consult aangevraagd? (antepartum/durante partu/postpartum/nvt/onbekend)
214. hoeveel uur voor geboorte is het consult aangevraagd? (xx uur/onbekend)
215. was kinderarts aanwezig bij bevalling? (nee/ja/onbekend)
216. indien niet aanwezig, hoeveel later KA gearriveerd? (xx minuten/onbekend)
217. interventie (circulatoir/respiratoir) na geboorte? (nee/zuurstof/IPD (intermittent positive pressure)/intubatie/hartmassage/medicatie/onbekend)
218. arteriele navelstreng PH bepaald ? (ja/nee/onbekend)
219. veneuze navelstreng PH bepaald? (ja/nee/onbekend)
220. is het kind postpartum opgenomen? (nee, kind te slecht voor opname/nee, kind te goed voor opname/observatie kraam-zuigelingenafdeling/opname couveuseafdeling (tweede lijn)opname medium care afdeling (derde lijn)/opname Neonatal Intensive Care Unit (derde lijn/onbekend)
221. bij opname infectie? (nee/ja/onbekend)
222. bij opname congenitale afwijkingen? (nee/ja/onbekend)
223. bij opname perinatale asfyxie? (nee/ja/onbekend)
224. bij opname prematuriteit? (nee/ja/onbekend)
225. bij opname dysmaturiteit? (nee/ja/onbekend)
226. bij opname ander onderliggend lijden? (nee/ja/onbekend)
227. diagnose hyaliene membranenziekte gesteld? (nee/ja/onbekend)
228. is respiratoire ondersteuning gegeven? (nee/CPAP, nasaal/endotracheale beademing/nvt, geen opname neo of couveuse/onbekend)
229. duur respiratoire ondersteuning? (aantal dagen/onbekend)
230. is surfactant gegeven? (aantal maal/nee/onbekend)
231. is circulatoire ondersteuning gegeven? (nee/ja/onbekend)
232. is de diagnose sepsis gesteld? (nee/ja/onbekend)
233. is de diagnose necrotiserende enterocolitis gesteld? (nee/ja/onbekend)
234. is de diagnose cerebrale bloeding gesteld? (nee/ja/onbekend)

Review of substandard care; Case Record Form

Appendix 4

PARIS **Beoordeling Case Record Form**

studienummer					
nummer beoordelaar					

1. Doodsoorzaak

a. Wat is de voornaamste ziekte of aandoening bij kind/ foetus?

b. Andere ziektes of aandoeningen bij kind/ foetus

c. Belangrijkste maternale ziekte of aandoening, die kind of foetus beïnvloedde

d. Andere maternale ziekte(s) of aandoeningen die kind of foetus beïnvloedden

e. Andere relevante oorzaken

2. Classificaties

a. Extended Wigglesworth classificatie ☐ (hier categorie-nummer vermelden volgens bijlage A)

b. 'Fetal and Infant classification' ☐☐

c. Obstetrische classificatie ☐☐
(Modified Aberdeen classificatie)

3.Zijn er, naar uw oordeel, substandaard factoren aanwezig in deze casus?

- ☐ Nee (0) vervolg met de algemene vragen zie vraag 12 →
- ☐ Één of meer, maar het is onwaarschijnlijk dat deze tot perinataal overlijden hebben geleid.
- ☐ Één of meer, en deze hebben mogelijk tot perinataal overlijden geleid.
- ☐ Één of meer, en deze hebben waarschijnlijk tot perinataal overlijden geleid. Hierbij is er één factor aan te wijzen die een dominante rol heeft gespeeld
- ☐ Één of meer, en deze hebben waarschijnlijk tot perinataal overlijden geleid. Hierbij heeft met name de combinatie van factoren ertoe geleid dat de sterfte is opgetreden. Er is niet één dominante factor aan te wijzen.

Beoordelings CRF **PARIS** © AMC

4. Beschrijf de eerste substandaard factor

5. In welk echelon is deze substandaard factor gelegen?
(Slechts één hokje aankruisen; indien meerdere van toepassing; benoem deze als een aparte substandaard factor)

- ☐ maternaal/sociaal
- ☐ huisarts
- ☐ verloskundige
- ☐ gynaecoloog 2e lijn
- ☐ gynaecoloog 3e lijn
- ☐ kinderarts 2e lijn
- ☐ neonatoloog (3e lijn)

Aanvullende opmerkingen:

6. In welk traject van zorg is deze factor gelegen?
(Slechts één hokje aankruisen; indien meerdere van toepassing; benoem deze als een aparte substandaard factor)

- ☐ transport/wachtlijstproblematiek
- ☐ signalerende perinatale zorg
- ☐ diagnose
- ☐ therapie, ingesteld door behandelaar
- ☐ therapietrouw patiënt
- ☐ niet van toepassing

Aanvullende opmerkingen:

8. Was er sprake van een tweede substandaard factor?

- ☐ ja ga verder met vraag 9 →
- ☐ nee vervolg met de algemene vragen zie vraag 12 →

9. Beschrijf de tweede substandaard factor

10. In welk echelon is deze substandaard factor gelegen?
(Slechts één hokje aankruisen; indien meerdere van toepassing; benoem deze als een aparte substandaard factor)

- ☐ maternaal/sociaal
- ☐ huisarts
- ☐ verloskundige
- ☐ gynaecoloog 2e lijn
- ☐ gynaecoloog 3e lijn
- ☐ kinderarts 2e lijn
- ☐ neonatoloog (3e lijn)

Aanvullende opmerkingen:

11. In welk traject van zorg is deze factor gelegen?
(Slechts één hokje aankruisen; indien meerdere van toepassing; benoem deze als een aparte substandaard factor)

- ☐ transport/wachtlijstproblematiek
- ☐ signalerende perinatale zorg
- ☐ diagnose
- ☐ therapie, ingesteld door behandelaar
- ☐ therapietrouw patiënt
- ☐ niet van toepassing

Aanvullende opmerkingen:

Algemene vragen betreffende deze casus

12. Zijn er, naar uw mening, richtlijnen, protocollen en/of evidence omtrent het onderwerp van deze casus aanwezig?

☐ ja, te weten:
- Lokaal protocol ☐
- NVOG richtlijn ☐
- KNOV richtlijn ☐
- Evidence uit Cochrane Data Base ☐
- Anders, namelijk ☐

☐ nee, beschrijf welke richtlijn aanbevelenswaardig zou zijn:

13. Is er essentiële informatie die u miste in deze casus - zonder welke het erg moeilijk was - de doodsoorzaak vast te stellen,

- ☐ nee
- ☐ ja, beschrijf welke essentiële gegevens u miste:

14. Miste er essentiële informatie, zonder welke het erg moeilijk was de zorg, voorafgaand aan de sterfte te beoordelen?

- ☐ nee
- ☐ ja, beschrijf welke essentiële gegevens u miste:

15. Welke (aanvullende) informatie zou u nog graag beschikbaar hebben voor de bespreking van deze casus in de auditcommissie?

16. Heeft u, naar aanleiding van deze casus, nog opmerkingen die u hierboven nog niet heeft genoteerd, maar die u toch niet onvermeld wilt laten?

List of abbreviations

ABCD	Amsterdam Born Children and their Development
CESDI	Confidential Enquiry into Stillbirths and Deaths in Infancy
CRF	Case Record Form
MRI	Magnetic Resonance Imaging
PARIS	Perinatal Audit; Research and Implementation Study
SSC	Substandard Care
SSCFs	Substandard Care Factor(s)

...

Dankwoord

Promoveren doe je samen met veel andere mensen, en het is een voorrecht deze mensen hierbij allemaal te kunnen bedanken.

Mijn onderzoekspad is niet altijd over rozen gegaan. De grote subsidie, die BIJNA binnen was op het moment dat ik aan het onderzoek begon, is er helaas nooit gekomen, en dat vergde aanpassingen in studie opzet en -uitvoer. Aan de andere kant heeft het me ook de gelegenheid gegeven om andere delen van het onderzoek uit te voeren die ik anders waarschijnlijk niet had gedaan; de MRI studie en de mogelijkheid te participeren in een klein deel van de ABCD-studie, een groot en belangrijk cohort onderzoek naar voedings- en leefgewoonten onder zwangeren in de gemeente Amsterdam.

In dit proefschrift hebben we op verschillende manieren naar de perinatale sterfte 'casus' gekeken, met als doel een verbetering van zorg. Het spreken over 'casus' kan misschien een beetje clean lijken, toch realiseer ik me heel goed dat achter elk cijfer in de perinatale sterfte statistieken een persoonlijke familietragedie schuilgaat. Alle ouders die in een moeilijke situatie toestemming hebben gegeven voor het verrichten van een MRI onderzoek, wil ik hiervoor hartelijk bedanken.
Ook alle zwangere vrouwen die hun medewerking hebben verleend aan de ABCD studie wil ik hiervoor bedanken.

Alle auditleden, D.J. Bekedam, P.J.E. Bindels, A.B. Dijkman, K.F. Heins, N. Jorna, J.C. Kaandorp, M. Knuist, J.H. Kok, D. Lesscher, G.L.M. Lips, S. Logtenberg, N. Menelik, J.A.M. van der Post, J.I. Puyenbroek, M.K. Sanders, L. van Toledo, A.J. van Veelen, E.M.A. van de Veer, G.van Waveren en M. Wieringa- de Waard, die veel tijd en energie geïnvesteerd hebben in het beoordelen van de perinatale sterfte casus, en in de audit zittingen zelf, wil ik hiervoor hartelijk bedanken.
Het beoordelen van perinatale sterftes uit de eigen regio vergt moed en zorgvuldigheid. Jullie openheid tijdens de auditzittingen en ook bij het verstrekken van alle informatie heeft veel indruk op mij gemaakt. Zonder jullie inzet had dit onderzoek niet uitgevoerd kunnen worden.
Ook wil ik alle verloskundigen, neonatologen, gynaecologen en natuurlijk de betreffende arts-assistenten in Amsterdam bedanken voor het melden van de perinatale sterftes.

Mijn promotoren en co-promotoren: Otto Bleker, Gouke Bonsel, Karien

Stronks en Jan van Lith wil ik hartelijk bedanken voor hun vertrouwen en prettige samenwerking in de afgelopen jaren.

Beste Otto, jouw charisma en positieve instelling hebben de moed er bij mij altijd ingehouden. Bedankt voor alle ruimte die je me hebt gegeven om dit proefschrift op mijn eigen wijze en tijd af te ronden. Zelfs als ik anderhalf jaar niets was opgeschoten, bleef jij, naar mij toe in ieder geval, positief!
Beste Gouke, jouw scherpe blik voor grote lijnen en oog voor detail is voor mijn hele proefschrift erg belangrijk geweest. Je snelle en praktische commentaar, zeker toen alles gisteren af moest, was fantastisch. Jij wist ook altijd mijn enigszins wollige Engels binnen zeer korte tijd te verwerken tot dat, wat ik ook echt wilde zeggen.

Beste Karien, als enige twee vrouwen in de groep van mannen, en ook nog allebei afkomstig uit Zeeland voelde ik me met jou altijd extra verbonden. Je hulp bij het schrijven van de auditartikelen en je kennis over etniciteit en gezondheid zijn van groot belang geweest voor dit proefschrift. Je hebt me ook erg geholpen om in tijden van stress het hoofd koel te houden.
Beste Jan, de laatste tijd van iets meer afstand, maar ook in periodes intensief, hebben we de afgelopen jaren goed samengewerkt. Je hebt het initiatief genomen voor de MRI-studie en de kar getrokken van de audit, toen ik naar het Alkmaarse was verdwenen. Bedankt daarvoor.

De leden van de promotiecommissie: prof. dr. P.J.E. Bindels, dr. M. Eskes, prof. dr. J.G. Nijhuis, prof. dr. M. Offringa, prof. dr. E.A.P. Steegers en prof. dr. J. Stoker wil ik bedanken voor het kritisch doorlezen en beoordelen van mijn manuscript.

Maria Pel; beste Maria, samen met Karien, heb jij me aangenomen als promovenda voor dit onderzoek; bedankt voor het vertrouwen dat je in me stelde. Ooit zei je een keer tegen me: 'als je hier niet op promoveert, breek ik allebei je benen.' Kiek, das dan hulukkig nie nôdug!

Maarten van Campen; Beste Maarten, als voorzitter van de auditcommissie hebben we veel tijd samen doorgebracht en veel gepraat over de audit, maar ook over veel zaken daarbuiten. Ik heb veel van je geleerd, en altijd veel plezier gehad in deze gesprekken. Ik waardeerde het dat jij, met je grote ervaring met juridische procedures, altijd net een iets andere kijk op de zaken had.

Richard de Leeuw, bedankt voor de hulp vanuit de neonatologie bij het opzetten van de perinatal audit.

Bert Smit, beste Bert, jij hebt als vertegenwoordiger van de neonatologie altijd een grote betrokkenheid getoond bij het PARIS-onderzoek. Voor je begeleiding van mij, ook bij de andere delen van het onderzoek wil ik je hartelijk bedanken. Je kritische vragen hebben me 'op het rechte onderzoekspad' gehouden.

Victor van der Hulst, Hans Blaauwgeers en Jan Peringa wil ik bedanken voor de prettige samenwerking ten tijde van de uitvoer van de MRI-studie.

Mevr. Prof. dr. J.P. Holm, gynaecoloog, P.A.O.M. de Reu, verloskundige prof. dr. L.A.A. Kollée, kinderarts, prof. dr. M.P. Springer, huisarts en prof. dr. P.J. E. Bindels, huisarts, bedankt voor het zitting nemen in de externe audit commissie.

Dank aan Fabian Kooy voor de hulp bij het opzetten van de database.

Tanja Vrijkotte en Marcel van der Wal wil ik heel erg bedanken voor het verrichten van de analyses van het ABCD artikel, en alle andere hulp. Ik ben ervan overtuigd dat de ABCD data nog heel veel mooie, belangrijke informatie betreffende leefgewoonten in de zwangerschap zullen opleveren.

Op het laatste moment slaat vaak de stress toe, en moet er altijd nog van alles worden geregeld. De hulp van Thea Nanninga en Madelon Groeneveld, secretaresses van Otto en Gouke, maar ook vele anderen was op dat soort momenten onmisbaar.

Mary Mackintosh, from the CESDI-organisation: it is several years ago that I visited the CESDI organisation in London, but this has been very important for the design and execution of the perinatal audit in Amsterdam. Thank you for all the information and the pleasant stay.

I would like to thank Rosalind Rabin for the correction of the English language of my thesis.

Mijn opleiders Han Maathuis, Otto Bleker en Yvonne van Kasteren en andere gynaecologen in het AMC en in het Medisch Centrum Alkmaar; bedankt voor de extra tijd en praktische steun tijdens het schrijven en afronden van het proefschrift.

Mijn collega-assistenten in AMC en MCA wil ik bedanken voor de opvang van extra werkzaamheden, die zeker zijn ontstaan door mijn geestelijke of fysieke afwezigheid tijdens de afronding van dit proefschrift. De afgelopen jaren waren zeer hectische en ik had soms het idee dat er met mij altijd wel iets aan de hand was; jullie steun heeft mij veel goed gedaan.

Lieve 'jonge onderzoekers'. Ik zal me nog lang herinneren dat ik op een dag huilend met mijn hoofd op het toetsenbord van mijn computer lag toen mijn 'reference manager' gecrashd was. Als je week in week uit met onderzoek bezig bent is het soms moeilijk dit soort gebeurtenissen te relativeren. Zonder jullie lag ik er misschien nog. De onderzoekers van het eerste uur: Marja, Saskia, Neriman, Judith, Madelon, Natalie en Wessel en in het laatste half jaar Etelka, Janne Meije, Henrike, Wouter, Sebastiaan, Liesbeth, Pieternel, Petra, Wouter, Christianne, Jan Willem en Karin, bedankt voor alle gezelligheid, steun en het delen van lief en leed op veel vlakken. Het is leuk om zoveel van jullie tijdens de opleiding weer tegen te komen.
Lieve Moira, we zijn klaar! Lang geleden zijn we rond dezelfde tijd begonnen met ons onderzoek, en we maken het nu ook bijna samen af. Met hierbij ook nog eens dezelfde promotoren, hadden we veel te delen. Het was fijn om de afgelopen tijd jou als 'partner in stress' te hebben.

Lieve André, bedankt dat je de inhoud van dit proefschrift op een heel bijzondere manier hebt weten te ondersteunen met een prachtige vorm. Het is, ook om hoe het er uitziet, een boekje geworden om trots op te zijn.

Vrienden en familie wil ik bedanken voor de afleiding van het (soms te) harde werken. Het was prettig om ook nog met andere dingen bezig te zijn. Die afleiding en jullie belangstelling gaf me de energie om verder te gaan.

Lieve Sneehities Anne en Danielle: eigenlijk is het 'onderzoek doen' bij ons allemaal begonnen: dankzij het "conceptual model" van prof. Mahadevan ben ik ooit aan dit onderzoek begonnen. Het onderwerp van ons onderzoek: "Autonomie van vrouwen op het gebied van hun family planning" bleek achteraf iets te breed, maar we hebben een fantastische tijd gehad, en we zijn sinds die tijd onafscheidelijke 'sneehities' geworden. Bij jullie huwelijk vond ik het erg leuk jullie getuige te zijn, nu ben ik blij dat jullie straks naast mij staan. Ik hoop nog lang veel met jullie te delen en het is een feest nu ook onze kinderen samen plezier te zien hebben.

Lieve Peter, ik ben blij dat ook jij op 20 april naast me staat. Je bent niet alleen mijn broer, maar ook mijn beste vriend. Van interrailen naar Turkije, met veel slappe lach, tot veel serieuzere en ook verdrietige zaken, we hebben het allemaal samen wel meegemaakt. Dat we allebei in Amsterdam wonen, dat ook Jeroen en jij het zo goed kunnen vinden en dat Gijs dol op je is, maakt onze band alleen maar sterker.

Lieve Tineke, jij woont verder weg, maar je grote belangstelling voor ons allemaal is heel belangrijk voor me. Ik heb veel bewondering voor

de manier waarop jij je leven invult en ik vind het geweldig om te zien dat je je absoluut niet klein laat krijgen door die dingen, die je niet kunt. Bedankt voor je hulp bij het opzoeken en invoeren van de adressen; dat heeft me veel tijd gescheeld!

Lieve papa en mama, zolang ik me kan herinneren heb ik gevoeld, dat jullie onvoorwaardelijk in me geloofden. Ook hebben jullie me altijd het gevoel gegeven dat ik op jullie terug kan vallen, en dat was soms ook nodig. Jullie praktische opvang van Gijs en Jonas, jullie correctie en typewerk heeft er voor gezorgd dat ik naast opleiding en gezin zonder al te nare stress dit proefschrift af kon ronden. Bedankt daarvoor en voor zoveel meer.

Lieve Jeroen. Ook jij zult blij zijn dat mijn proefschrift nu klaar is, al vond ik zélfs de promotiestress peanuts vergeleken met wat wij de afgelopen jaren samen hebben meegemaakt. Maar: het afgelopen jaar is voor ons wel uitzonderlijk druk geweest. Zonder jou was het allemaal nooit gelukt. Ik kan tot tranen toe geroerd zijn als ik zie hoe leuk we het maar blijven hebben, nu zelfs al met z'n vieren. Ik hou van jou voor altijd.

Lieve Gijs en Jonas, jullie zijn mijn grote helden. Wat een feest is het om jullie mee te maken, daar kunnen geen tien proefschriften tegenop. Ik ben blij dat er met de afronding meer rust komt om rondjes te maken, boekjes te lezen, muziek te maken en nog veel meer! Omdat jullie, voor mij toch een beetje met z'n drieën, zo belangrijk zijn, draag ik dit boek aan jullie op.

Coverdesign and lay-out: fieldtrip. Printed by Febodruk bv