

# **Sub-optimal care in stillbirths – a retrospective audit**

*Evaluation of the prenatal care and possibilities for quality  
improvements with special focus on non-western women*

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## Abstract

**Background:** Improved perinatal care has decreased stillbirth rates radically. Audits may identify main current quality of care issues in stillbirth to identify areas for further improvements. The aims of this study were to identify sub-optimal factors likely to have contributed to stillbirths and to test if sub-optimal factors were more frequent among non-western than western women.

**Material and method:** Perinatal deaths in Oslo and Akershus have systematically been audited by perinatal committees and attributed to optimal or sub-optimal care when compared to guidelines; categorised as maternal self-care, care from health care providers and communication. This is a summary of audit results of all the 356 stillbirths after 24 weeks of gestation in Oslo and Akershus during 1998-2003 (4.2 per 1000 deliveries). The study population consisted of 31% non-western women.

**Results:** Sub-optimal factors were identified in 37% of the deaths. When compared to western women, non-western women had increased risk of sub-optimal care (OR=2.4, 95% CI 1.5-3.9), they had increased risk of stillbirth (OR=2.2, 95% CI 1.3-8.7), and more often they received sub-optimal obstetric care (OR=3.8, 95% CI 1.6-3.9), as e.g. misinterpretation/lack of intervention at signs of fetal distress, or incorrect assessment of labour progression.

A common failure in antenatal care was unidentified or inadequate management of intrauterine growth restriction. Erroneous management of absent fetal movements was documented both within health care and with pregnant women. Non-western women were less prone to follow recommendations given by health professionals, e.g. not attending the program for antenatal care or not taking consequences of recommendations given by health care providers. Inadequate verbal communication was documented in 47% of the deaths among non-western mothers; interpreter was used in 29% of these.

**Conclusions:** Sub-optimal care factors were more common among non-western immigrants. Possibilities for improvements were reduction of language- and cultural barriers, better identification and management of growth restriction and absent fetal movements, and adequate intervention in complicated vaginal births; with increased vigilance towards non-western women.

## Abstract in Norwegian

### Dødfødte i Oslo og Akershus i 1998-2003

#### Evaluering av perinatalomsorgen og muligheter for kvalitetsforbedring – med spesielt fokus på ikke-vestlige innvandrere

**Formål:** Forbedret perinatalomsorg har redusert dødfødselsratene radikalt. Audit kan bidra til å identifisere områder for hvor ytterligere kvalitetsforbedring kan være mulig. Målet med denne oppgaven var å identifisere suboptimale faktorer ved svangerskap og fødsel ved dødfødsler, og om suboptimale forhold forekom hyppigere blant ikke-vestlige enn vestlige kvinner.

**Materiale og metode:** Alle dødfødsler har kontinuerlig blitt vurdert av perinatalkomiteene gjennom audit. Omsorgen har blitt klassifisert som optimal eller suboptimal relatert til retningslinjer, og kategorisert som mors egenomsorg, omsorg fra helsepersonell og kommunikasjon. Dette er en oppsummering av auditresultatene av alle dødfødte i Oslo og Akershus fra svangerskapsuke 24 i perioden 1998-2003 (356 dødfødsler, 4.2 per 1000 fødte). Studiepopulasjonen bestod av 30.9 % ikke-vestlige kvinner.

**Resultater:** Suboptimale faktorer var identifisert i 37 % av dødsfallene. Sammenlignet med vestlige kvinner, hadde ikke-vestlige kvinner økt risiko for suboptimal omsorg (OR=2.4, 95 % CI 1.5-3.9), økt risiko for dødfødsel (OR=2.2, 95 % CI 1.3-3.8) og hadde oftere fått suboptimal fødselsomsorg ( $p<0.001$ ), ved feiltolkning/manglende intervensjon av tegn på føtalt distress eller fødselsprogresjon.

I svangerskapsomsorgen var uidentifisert eller inadekvat håndtering av identifisert intrauterin veksthemming hyppig forekommende sviktsituasjoner. Mangelfull håndtering av opphørte fosterbevegelser var dokumentert både blant helsepersonell og blant de gravide. Ikke-vestlige kvinner fulgte anbefalinger fra helsepersonell i mindre grad, ved ikke å følge svangerskapsprogrammet eller ikke å følge gitte råd ved risikotilstander. Hos 47 % av ikke-vestlige kvinner var språkproblemer dokumentert; tolk ble dokumentert brukt i 29 % av disse.

**Konklusjon:** Suboptimal omsorg var mer vanlig blant ikke-vestlige kvinner. Områder hvor kvalitetsforbedring syntes mulig, var reduksjon av språklige og kulturelle barrierer, forbedret observasjon av fostervekst og fosteraktivitet, samt adekvat intervensjon ved kompliserte vaginale fødsler, med økt oppmerksomhet mot ikke-vestlige kvinner.

## Acknowledgements

The process leading to this thesis has been like a trip in an unknown terrain. I assumed that the end point was a good place to be, even though I did not know *how* this place was like or *where* it was. I had got maps and a compass, but I have been wandering in circles and in big curves and detours, sometimes I did not know where I were or in which direction I should go. Sometimes I was not sure to attain the final target, but at times I have glimpsed the end point between big trees and obstacles.

There are some people that have been absolute necessary for attaining this goal. First, I want to thank the members of the Perinatal Committees for giving me the opportunity to use data from the assessments. Then I want to thank my friend and study colleague Anna-Pia Häggkvist, which have given me support through this whole journey, from the first steps by searching for an area for the journey, during the passages down in the valleys, and to the shared pleasure having reach the goal. I also have to thank Nina Vøllestad at the Institute for Health Sciences at the University of Oslo, who has supported me with good maps and always being clear and explicit in her supervision. At last, I want to express my gratitude to each of my advisors, Siri Vangen and Frederik Frøen at the National Institute for Public Health, who have given me important and thoroughly advices and comments in a very competent, kindly and encouraging way!

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Climbing uphill request investments, it costs time, energy and sweat. I can promise; it was all worth it. Now I have come to the end point of this journey and it is good to be there!

## Abbreviations and definitions

Anonymising	The removal of information from medical records that would identify children, family members, professionals and institutions
Antenatal record	Preformed scheme for the antenatal care (“Helsekort for gravide”) (Appendix 1)
Antepartum	Before onset of labour
Autopsy	A surgical procedure postmortem, which involves the examination of body tissues (including internal organs), often to determine cause of death
Audit	Systematic, critical analysis of the quality of care, including procedures used for diagnosis and treatment, use of resources and the resultant outcome and quality of life
BMI	Body Mass Index ( $\text{kg}/\text{m}^2$ )
CTG - Cardiotocography	The electronic monitoring of the fetal heart rate and of uterine contractions. The recordings are graphically represented on a continuous paper printout
CI	Confidence Interval
Consanguinity	Two individuals are consanguineous if the two parents are related as cousins
ICD-10	International Classification of Diseases, version 10
Intrapartum	During labour
Intrauterine fetal death	Death of a fetus in utero after 24 weeks of gestation or at birth weighing at least 500 grams
MBRN	The Medical Birth Registry of Norway
Neonatal death	Death of a live born infant during the neonatal period, which begins with birth and covers the first 28 days after delivery
OR	Odds Ratio
Parity	The number of previous pregnancies of greater than 22 weeks of gestation
PNM	Perinatal Mortality; the number of stillbirths and first week deaths per 1000 total births
SD	Standard Deviation
SSB	Statistics Norway
Stillbirth	Death prior to the complete expulsion or extraction from its mother of a product of conception of 24 or more completed weeks of gestation or of weight of 400 grams or more. The death is indicated by the fact that after such separation the fetus does not breath or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movements of voluntary muscles
The Municipal Regular GP Scheme	The organisation of the primary health care where the GP’s are responsible for the general medical services for the persons on his/her list (“Fastlegeordningen”)



## **1. Preface**

Basis for this thesis was assessments by the Perinatal Committees in Oslo and Akershus. In 1984, the Norwegian Department of Social Affairs suggested the establishment of Perinatal Committees in all counties, presented in an official report called “The Norwegian governmental report on antenatal care” (NOU 1984:17)(1). The purpose by the Perinatal Committees was to examine and evaluate the local organization of perinatal care, conduct perinatal audits on a routine basis and arrange courses for relevant health professionals.

The background for these establishments was assessments done by an expert group of 270 perinatal deaths, where the group’s conclusion was that 65 of these deaths possibly could have been avoided. Furthermore, in Norway the perinatal mortality rates did not decline to the same degree as the other Nordic countries (2). These facts revealed a potential for improvements, and the health authorities wanted to systemize the standard program for antenatal care.

For about ten years I have been working as a midwife with women with serious pregnancy complications and mothers with a sick or stillborn child. This has made me curious if there were connections between antenatal care and the outcome. However, in other cases the antenatal care obviously had not been according to established standards. My work in Oslo Perinatal Committee from 1998 until today, has given me a curiousness to further investigate the preventive aspects of perinatal deaths; how information from perinatal audit could be used as a tool for improved clinical practice. In addition, the leaders of the Perinatal Committees in Oslo and Akershus required a summary of the evaluations performed by these two committees. A systemizing and summary of data from six years and from two counties would possibly make a better basis for suggestions for improvements of perinatal care for these two counties, than the standard one; with separate annual reports.

The target group for this thesis was primary colleges the obstetric milieus, but also organizational and political decision-makers. As this was assumed to be a

group with mixed level of knowledge, some substantial and statistical terms were defined probably more detailed than necessary for some groups.

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## 2. Overview and theoretical considerations

Usually people take contact with health services because of known health problems or acute illness. Pregnancy is a normal, physiological condition, and most of the pregnancies are uncomplicated and results in a vital, normally grown and a healthy child. However, every pregnancy has a potential for taking an irregular course. This signalizes a unique situation; pregnancy is considered as a normal condition, but official health authorities have initiated a program for antenatal care that pregnant women are recommended to follow.

Antenatal care is preventive care. The difficulties are to define risk factors and be able to give special attention to those who need it and leave the healthy and normal pregnancies without unnecessary medical interventions. Kean has described this individuality and the complexity of antenatal care like this:

*“Each and every pregnant woman perceives herself as an individual and as such management of the pregnancy needs to be individualized. In general, women with identifiable risk factors need a programme of care tailored to their individual needs. Where a pregnancy is perceived as problem-free a minimum level of care must be outlined, with the capacity to build on this as and when problems become identified. The principles of antenatal care for women with uncomplicated pregnancies are to provide education, reassurance and support, to address and treat the minor problems of pregnancy and lastly, to provide effective screening during the pregnancy to identify problems as they arise” (3).*

This citation describes the purpose of antenatal care with an ideal attitude; balancing between individual care and supervision; and simultaneously having a focus upon screening for risk conditions.

The content of Norwegian antenatal care was not regulated by official guidelines until 1984, when the Department of Social Affairs presented antenatal care guidelines in the official report mentioned earlier; “The Norwegian governmental report on antenatal care”(1). This was the first Norwegian official document that gave concrete instructions about care to pregnant women, the delivery services and care of the newborn child. The main purpose for standard antenatal care in Norway was:

- To ensure that pregnancy and delivery follows a natural course in a best possible way, so that the mothers physical and mental health and social well-being can be as good as possible
- To ensure the fetus' health, and a live born child without any illness/disease or injuries that could have been prevented
- To identify and treat disease and other threats to the mothers health, and ensure that the risk during pregnancy is the least possible for her and the fetus

(My translation)

These purposes are relatively wide and diffuse, and include medical, psychological and social circumstances in the antenatal period. Some of these circumstances are precisely defined, and the purposes may be seen as a superior ideal for the pregnant women and their families. Norwegian antenatal care is based on medical ideals with aims directed at early identification of and early intervention if health problems occur, but according to Backe et al, no evidence exist to decide which elements of antenatal care are important, useful or cost effective (2). The Perinatal Committee in Oslo has given critical comments to the care in the perinatal period in the annual reports (unpublished), and has identified possibilities for improvements.

## 2.1 Antenatal care in Norway

### 2.1.1 A historical review

Perinatal care is the term used about the health work related to pregnancy, birth and the newborn period, involving two medical specialities; obstetrics and paediatrics (4). In the *obstetric* tradition, the main attention was on the mothers, and the motivation for introducing antenatal programs in 1840, was to prevent preeclampsia. Control of the urine was regarded as the most important element in the antenatal care. Later, examinations for other conditions were introduced, like contracted pelvis and the fetus' site and position, mental diseases, hygiene, and

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socioeconomic problems (4). During recent years, the focus has focus changed from medical control into health information.

In the *paediatric* tradition, the attention was directed toward neonatal mortality. After the Second World War the National Government decided to integrate care for pregnant women in the established Child Health Centres (“Helsestasjoner”) and gave the local authorities the responsibility for this work. The first public Child Health Centres were established in 1936. There were no written guidelines for the management. In order to get a more effective control such guidelines were called for already at that time. Norway was the last among the Nordic countries to establish national care programs for all pregnant women (2) and was not introduced on a large scale until the 1950ies when repayment to doctors for antenatal visits was introduced. From the late 1950ies on, almost all pregnant women attended antenatal care programs, like in all modern, industrialized countries. General practitioners (GP) were performing most of the consultations. Midwives were not engaged in this work in a systematic way; they were mainly occupied with deliveries and post partum care. In 1995, it was laid down in law that the communities should offer antenatal care provided by midwives in the Child Health Centres (5). Due to the large amount of counties and the scattered population in many counties of Norway, problems to employ all the community midwives positions emerged, so even though the law was introduced, it was not fulfilled in clinical practice. In small counties the need for midwifery work was limited to one or two days a week which was not attractive for midwives. In 2001, 86% of the midwives were employed in part-time work, and 85% of these were employed in less than 50% appointments (6). Through this, midwives have not been given opportunities to perform the expanded role in accordance to their education, which include broader areas than earlier; more in the direction of women’s health in general.

The Municipal Regular GP Scheme (“Fastlegeordningen”) was implemented on June 1, 2001. According to this law, the GP’s are responsible for the general medical services for the persons on his/her list. The Norwegian Association for

Midwives and the Norwegian Medical Association both proclaim that who pregnant women want to attend for antenatal controls, remains their own choice. The Municipal Regular GP Scheme has changed the organization of the antenatal care, since the GP's are not employed to the Child Health Centres – like before this law – where the community midwives are. One possible consequence of this reorganization of the antenatal care is less continuity for the pregnant women, since they are recommended to attend care both from midwives and doctors in a non-systemized way. Backe has described the conflict situations between GP's and midwives in some districts in Norway and concluded that the recommended reduction in the frequency of antenatal visits was not followed up (7). He says here that the *content* of the antenatal care should be more important than which occupational group is responsible for the care. This current thesis is not an argument for the one or the other. However, this discussion is a part of changing processes in Norwegian antenatal care.

### **2.1.2 The official guidelines**

The NOU 1984:17 has been the official report that gave instructions about care to pregnant women, the delivery services and care for the newborn child (1). The intentions were to achieve a more differentiated care and give more attention to the women with risk pregnancy and less to the healthy multiparae women. This program has been of great importance in the Norwegian perinatal service and has been considered as a “gold standard” for Norwegian antenatal care until 2005. Revised guidelines were published in May 2005. A main impression of these new guidelines is a focus on demedicalization; with reduced frequency of standard antenatal controls and less screening tests (8). These guidelines were based on guidelines from National Institute for Clinical Excellence (NICE) from United Kingdom, since this organisation was regarded as “an organisation with great resources in that area” (8). The effects of the changes in guidelines are unknown.

It is not possible to assess quality of care without having measurement standards. In addition to the recommendations in NOU, two important books are used as a reference in the antenatal care. These are: “A guide for obstetric care” from the

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Norwegian Medical Association (9) and “Antenatal Care in general medical practice” (10). The last one is not an official guideline, but has been in general use because of its great relevance for clinical practise. These guidelines were used as antenatal care standards in the current thesis; not presented in details, but referred to when relevant.

## 2.2 Stillbirths

### 2.2.1 Definitions

The World Health Organization (WHO)’s definition for fetal death is: “Death prior to the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy; the death is indicated by the fact that after such separation the fetus does not breath or show any other evidence of life such as beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles.” (11). According to WHO, it should be defined as a birth only after 22 weeks of gestation or if the weight of child’s weight as newborn equals or exceeds 500 grams; before these limits, it is to be defined as an abortion.

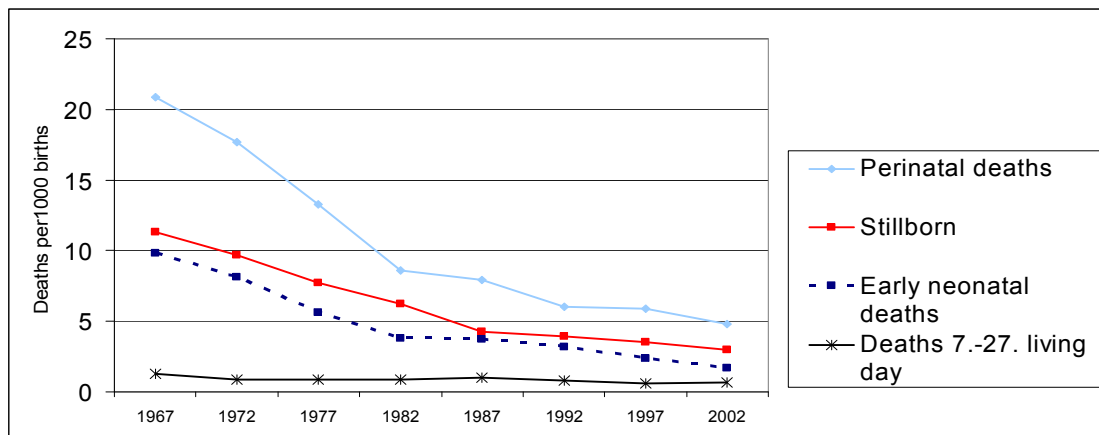
The term “perinatal mortality” was introduced in the 1940s, when it became clear that despite a huge fall in the total infant mortality rate, infants’ risk of dying shortly after birth was still considerable. WHO has recommended publishing the rates of stillbirths after 28 completed weeks of gestation or a birth weight that equals or exceeds 1.000 grams (11), but despite the attempts of the WHO to introduce common definitions of perinatal mortality, studies over the years have shown a substantial international variation in the definitions of perinatal mortality (12). The most used definition is: “The number of stillbirths and first-week deaths per 1000 total births” (13). The Euro Natal working group conclude that “differences between Western European countries in perinatal mortality rates are biased by differences in criteria for registering and publishing perinatal mortality, and that more should be done to harmonise perinatal mortality rates before they are included in international overviews” (12). This was the situation also for the

data from the Perinatal Committees from Oslo and Akershus for the included period. Data were not complete for stillbirths between 22 and 24 gestational weeks of gestation. Therefore, only stillbirths after 24 completed weeks of gestation have been included in this thesis. Data from week 28 of gestation was included when comparison with official statistics were performed.

### 2.2.2 Frequencies

One way to assess the quality of antenatal care has been to compare rates of perinatal mortality. These rates have declined drastically in the industrialized countries and throughout the world through the last five decades, except for the United Kingdom, where the rates have been increasing the last five years (14;15). There has been a steady decline of the perinatal mortality in Norway since the Medical Birth Registry Norway started the registrations in 1967 until the latest available statistics from 2002 (16) (Figure 1). The rates have declined steadily for this period, except for the late neonatal deaths, which has been stable at about 0.7-1.0 deaths per 1000 births during this period.

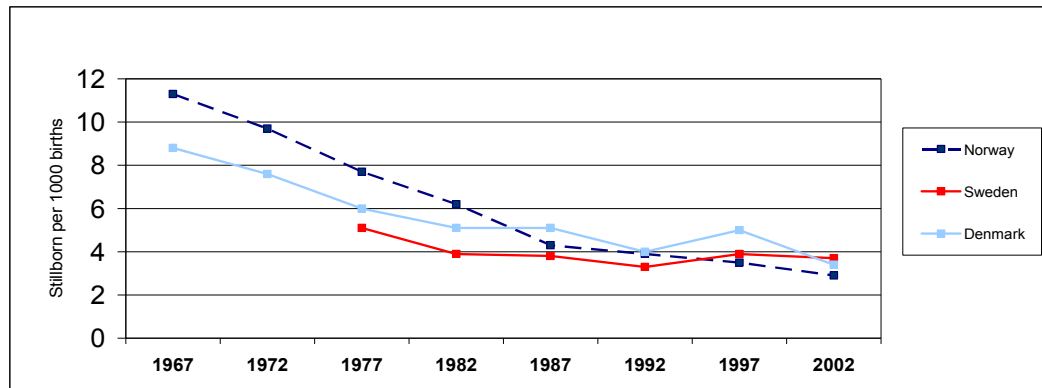
FIGURE 1: Perinatal mortality in Norway, 1967-2002



Rates for stillbirths after 28 weeks of gestation between Scandinavian countries showed that the Norwegian level is similar to the levels in comparable countries (12;17) (Figure 2).



**FIGURE 2: Rates of stillbirths in the Scandinavian countries, 1997-2002**



The rates of stillbirths in the Scandinavian countries have showed a similar, declining pattern, but the last two decades there are small differences in the levels between these neighbour countries. The explanations for the differences and the decrease in the mortality rates are not fully understood or known, but some aspects are presented in the next chapter.

### 2.2.3 Differences in stillbirth rates

The rates of perinatal mortality do not directly reflect the quality of antenatal and obstetric care, but can indirectly reflect a general level of the morbidity and mortality in a population. The decline in the rates of perinatal mortality can be attributed to different factors. Some improvements that have contributed to the better perinatal outcome are:

- General health improvement of the population due to social and environmental changes: Improved socio-economic conditions, better health conditions of the mothers through changes in life style, better life quality in generally, included improved nutrition and improvements in education
- Laws regulating the antenatal care, and establishing national and local guidelines which have lead to better organization and structure of the antenatal care, introduction of the preformed scheme for the antenatal care (“Helsekort for gravide”)(Appendix 1), risk selection and establishing of

perinatal regionalization and high-risk perinatal units for high-risk pregnancies

- Technical developments: Ultrasound screening (malformations detected, better term prediction, localization of placenta, diagnosing multiple pregnancies), ultrasound as a diagnostic tool in risk pregnancies and in pathological development and establishment of quality assurance of routine ultrasound, better screening for infections to prevent preterm births

Why is it important to focus on these topics in a rich and healthy country as Norway where the mortality rates are so low? Several studies have shown that mortality rates vary widely between different sub-groups of women and that some groups of immigrants have higher rates of perinatal mortality compared to native born women (18-21). Experiences from perinatal audit in the Perinatal Committees in Oslo and Akershus and from other studies of quality assessment (15;22;23) have exemplified that there *are* possibilities for improvements.

Therefore, we must be concerned about possible inequities and the challenges that still remain in promoting optimal outcomes. Not every woman enjoys the same likelihood of positive pregnancy outcome (20). Differences in health across groups of different origin in terms of both morbidity and mortality have been documented in Norway and other parts of the world (18;19;21). Pakistani and Somali women had an increased risk of stillbirths. Among Chinese and Vietnamese immigrants in the USA the converse situation was observed, with lower perinatal mortality among the immigrants than in the background population (24;25). One way to approach this question can therefore be to contrast the quality of care between foreign-born and native-born women in Oslo and Akershus. Studies that investigate health and disease in different groups of different origin can give new knowledge to the population, to health care providers and to the politicians. The rationale for investigating and grouping these deaths is an assumption that they share similar determinants and strategies for prevention. Differences in health and disease among different groups can be a help to give adjusted care and medical treatment. Therefore, by contrasting

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groups of immigrant's and native-born women there may be possibilities to identify situations and areas for quality improvements. This can indicate in which direction one should look for preventive measures in avoidable cases.

### 2.3 Perinatal audit – quality assessment

Donabedian was a pioneer in medical quality assessment. In the 1960ies he gave an account of the principles for evaluating the quality of medical care by emphasizing the importance of using well-defined outcomes as criteria of quality. Later he tabulated a classification system for use in quality assessment, divided into three levels: structure, process and outcome (26). In perinatal care the *outcome*; e.g. perinatal mortality, traditionally has been regarded as the most appropriate epidemiological tool for evaluating the outcome of pregnancy and childbirth and for monitoring the quality of perinatal care. Uncritical application of this indicator in international comparisons can be misleading. The difficulties by comparing these rates are related to use of different definitions of perinatal mortality. In addition to this, the perinatal mortality rate depends on a number of factors and important determinants that need to be assessed separately before reaching conclusions about quality-of-care issues (27). By using rates only, local circumstances, resources and socio economic conditions will not be included, though it is common knowledge that these are conditions with great importance for mortality rates. Another disadvantage by using perinatal mortality as the sole quality indicator in the western countries, is that the rates have decreased continuously and are so low that a significant further decrease is probably not realistic (4). At last, the rates themselves don't have clinical implications. It is difficult to undertake improvements on basis of rates of perinatal mortality alone. However, the last decades there has been increasing attention to the structure and the process behind the outcome, and this seems to be a far more fruitful approach to identify possible improvements.

Reviewing the circumstances of adverse health outcomes has long traditions. Several countries have national programs for this purpose (28). Through perinatal

audit, a broader quality assessment can be done, by which all three elements in Donabedian's triad is included. The European Association of Perinatal Medicine presented a definition on perinatal audit in 1993: "Perinatal audit is 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 children" (17). Perinatal audit is an observational study method from which valid information can be derived. Information is taken from antenatal care records and hospital records. An expert panel, mandated to perform the analysis, performs quality assessment of perinatal care in each case, in order to identify sub-optimal factors. The aim is to get experiences about deficient and unfortunate events and systemize them in order to suggest quality improvement efforts. In Norway, routine perinatal audit has been performed since 1984, when almost all counties established a Perinatal Committee as advised by the Norwegian Ministry of Health (1).

Through this study the purpose was to identify essential factors for improving antenatal care, and to attempt transforming data from perinatal audit about possible avoidable stillbirths into information for decision-making. This study investigated clinical practice, professional standards and health outcome, *not* quality assessment from the user's point of view. Assessment of the care given to patients could be expressed as outcome indicators, which measure mortality, morbidity, health status, health related quality of life, and patient satisfaction. Since focus in this thesis was quality improvement, the main focus was *process* indicators. Process indicators describe actual medical care such as diagnoses, treatment, referral, and prescriptions (29). The indicators used in this study are defined in chapter 4.

### **2.3.1 Audit procedure**

The efforts by the Perinatal Committees are to evaluate and assess local organisation of the perinatal care, do routine audit of the deaths and arrange courses for professional health care providers engaged in perinatal care. The Perinatal Committees are peer groups; i.e. that the groups are composed by the

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same categories of health professionals as the personnel involved in the care. The members of the Perinatal Committees in Oslo and Akershus consist of obstetricians, paediatricians, midwives, general practitioners and pathologists from all delivery and neonatal units in the county and from different levels in the health care services.

The current study was based on data from perinatal audit. The deaths are continuously identified in the databases of the birth clinics and neonatal units. When all laboratory results are available in the medical case reports, the midwives employed in the Perinatal Committees anonymised the case reports before distributing the complete case reports to members of the audit group ahead of the meeting. During the meetings the committee have broad discussions of the care in the areas presented in chapter 4, and the results of assessments are filled in a structured enquiry form, elaborated by the health authorities (Appendix 2) (30). As the aim is to detect sub-optimal care factors according to predefined standards, audits are performed without a control group. The results of the assessments are not reported back at an individual level, but only as annual reports where data and assessments are reported at an aggregated level. The aim for the work is to identify deficient care at a *system* level, not at the *individual* level (30).

Sub-optimal perinatal care – introduced by Scandinavian authors – is defined as: ”the failure to use all technical and human resources available to try to avoid fetal death” (31;32). This term refers to optimal care with all human and technological resources available without regard to local circumstances. Even if Norway has a long tradition for perinatal audit, the methods have not been standardized (33), regarding both classification of causes and the terminology used to grade the quality of the care. The most commonly used groups for assessment are: unavoidable – possibly avoidable – avoidable, failure – probable failure, or optimal – sub-optimal care (23).

Some intrauterine deaths are unavoidable catastrophic events, for example when an abruption of the placenta occurs without any identifiable risk factors on beforehand. Or if intrauterine growth restriction is identified; is it always possible

to prevent an intrauterine death? Probably not, but one of the aims for antenatal care should be to identify and prevent those deaths that *are* avoidable. *Avoidable* and *possibly avoidable* deaths have potential legal implications and have been misinterpreted outside the professional milieu (34). This have lead to hasty conclusions that cases with sub-optimal care is equal with a preventable death (31). The terms *failure – probable failure* are used in The Perinatal Committees in Oslo and Akershus' judgment of whether the care followed the standard or not. These terms are also recommended by the Ministry of Health (1). The terms *sub-optimal* was used in this thesis. This term is more neutral than possibly avoidable. There is a difference between giving optimal care and following established guidelines; the guidelines may not be optimal, but if the given care, observation and treatment have been in conformity with the recommended guidelines, the care can be regarded as optimal, even if the guidelines in themselves not are optimal from an evidence based point of view. However, without regard to definitions or terms, the main aim by audit is to find potentials for intervention to reduce the rates of perinatal mortality. These issues were not further discussed in the current thesis, and in the following, the assessment categories probable and obvious failures from the Perinatal Committees were combined and the variables are dichotomised and called *optimal* or *sub-optimal* care.

## 2.4 The immigrant population

Race, ethnicity and immigrants are used as variables in medical research. These terms are controversial and difficult epidemiological variables, but they can also be useful and effective to illuminate health inequities within populations (35). The term *race* can be misinterpreted in a stigmatizing way and was not used in this thesis. The term *ethnicity* is often used to classify groups of different origin (35), but has not been used as a grouping variable in this thesis since the term is a complex term and difficult to measure. *Migration* is used for movements across national boundaries. Statistics Norway has chosen not to use the term ethnicity, and use the term *immigrant* as a person with both parents born abroad. According

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to Statistics Norway the immigrant population consists of first generation immigrants and people who are born in Norway of two foreign-born parents (36). The last mentioned group, with two foreign-born parents, is also called second-generation immigrants. It could be disputed if it is correct to call these people immigrants, since they are born in Norway and therefore could be presumed not to have communication problems. Second-generation immigrants could also be presumed to have good possibilities for being integrated into the Norwegian society. They may have important characteristics in their way of living that differs radically from immigrants who have come to Norway later in life. On the other hand; second-generation immigrants may have a different genetic, social and cultural background from native-born Norwegians, even if cultural elements may have been changed when compared to the first generation immigrants. This is a part of a complex discussion, but in this thesis; the same definitions as used of Statistics Norway were used, in order to do comparison with the total population. Therefore, second-generation immigrants were not addressed separately.

With these important issues in mind, and with the knowledge that there may be a great variability within immigrants subgroups, the terms immigrant and immigration was used in this thesis as a criterion for classifying people with different origin – even though different immigrant groups may be completely different as regards “racial” characteristics (like skin colour and appearance moreover), religion, culture and language.

In order to plan the health services, we have to understand the development and the changes caused by immigration in the population. Since 1967, Norway has experienced net immigration and the Norwegian population, especially in Oslo, has changed. More than a half of the net growth of the population in Norway in the 1990ies directly or indirectly can be related to immigration (37). Generally, immigrants live in more central areas than the rest of the population, and many, particularly non-western immigrants live in regions in and around Oslo. Today, Oslo and Akershus have a multi-ethnic population and non-western immigrants

constitute a considerable portion of the total net immigration. Forty eight per cent of the non-western immigrants in Norway live in Oslo and Akershus (36).

The immigration pattern differs between Oslo and Akershus. At the end of 2003 Oslo and Akershus had 1.010.504 inhabitants; 521.886 in Oslo and 488.618 in Akershus. Twenty-two per cent of Oslo's citizens were immigrants and 69.6% of these were immigrants from non-western countries, respectively in Akershus the numbers were 19.357 (4.0%) immigrants and 45.4% of these were from non-western countries (38). There were, however, logical reasons for assessing these counties as one unit. Oslo and great parts of Akershus are urban districts and of the most densely populated areas in Norway. It is a near connection between these counties as regards communication, welfare services and cultural services, and the labour market is mainly shared between these counties. Pregnant women can to a certain degree choose which delivery unit they want to attend; choices that not are limited by boundaries between the counties.



### **3. Aims**

The aims of the current thesis was to identify sub-optimal factors in the antenatal and obstetric care which were likely to have contributed to stillbirths and to test whether these sub-optimal factors were more common among non-western mothers compared to western women. The stillbirths in Oslo and Akershus have continuously been assessed by perinatal audit by the Perinatal Committees and this thesis is a summary of these audits.

The aims were to gain experiences about deficient care and identify sub-optimal factors as areas for quality improvements in the antenatal care and to identify the essential factors to reduce the stillbirth rates.

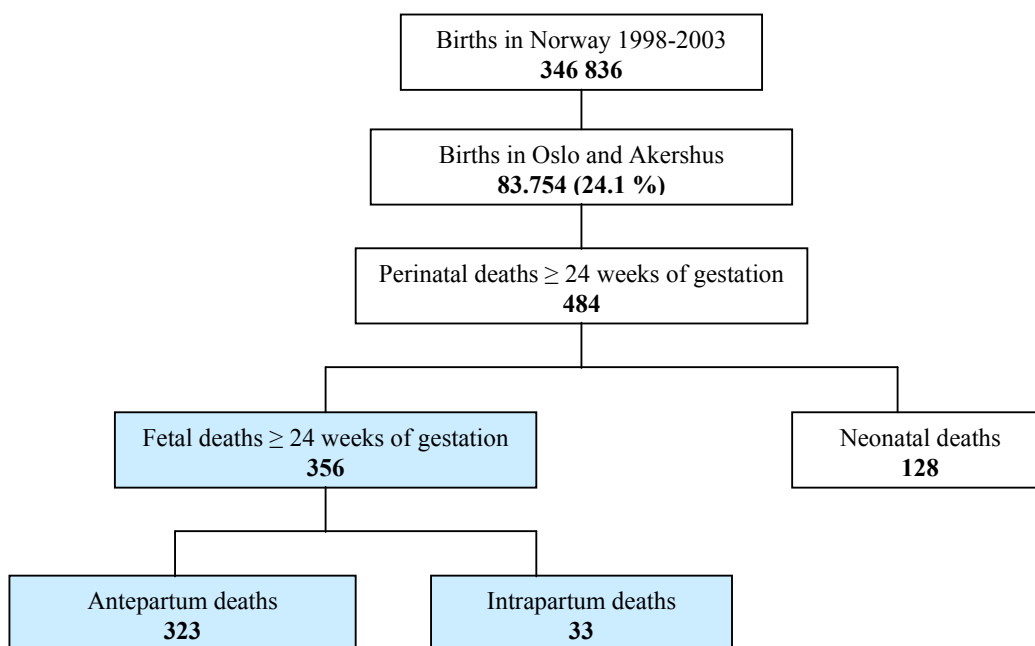
In order to reach these purposes, the areas for investigation were:

- Characteristics of the mothers and the stillborn
- The main causes of death
- Systematically failures in care during the antenatal or intrapartum period
- The associations between sub-optimal care and country of origin

## 4. Study population and methods

This study investigated case reports from a full cohort of stillbirths after 23 weeks of gestation in Oslo and Akershus in the period 1998-2003. This included 356 stillbirths (4.2 per 1000 deliveries). An overview of the population is presented in figure 3.

*FIGURE 3: An overview over the study population – the blue boxes illustrate the study population*



### 4.1 Data sources

#### 4.1.1 Medical records

Information about pregnancy and delivery was obtained from the medical records from the Perinatal Committees. Before assessment, the medical records were anonymised, so that whether patients or health care professionals could be identified. If data were missing in the antenatal records, the lacking data were sought other places in the medical records, making the information as complete as possible.

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### **4.1.2 The Medical Birth Registry of Norway**

The Medical Birth Registry of Norway (MBRN) was established in 1967 to survey and detect changes in perinatal health. The registry should contain information on all live births and stillbirths from gestational week 12 in Norway (16). Audit is performed without a control group, but in order to get a more elaborate description of the stillborn in this thesis, the stillborn were compared to the live born children with data from the MBRN. In this thesis information about the mothers' age, marital status, parity, the newborn's gender and gestational age at birth, were retrieved from the MBRN. This was possible since the data in the thesis represented a full cohort; data from the MBRN could represent a group for comparisons between the stillborn and live born children.

### **4.1.3 Statistics Norway**

Summary information on the country of birth was obtained from Statistics Norway (SSB). The Country of Birth File was established by SSB in 1988 and provides the basis for statistical analyses of the immigrant population. The information on country of birth is recorded at the time of immigration to Norway and reported to the Central Population Registry. SSB gives information if the women are first- or second-generation immigrants. SSB considers the information on country of birth to be of high quality with close to 100% ascertainment (39).

## **4.2 Variables**

### **4.2.1 Outcome variables – classification of the quality of care**

This is a descriptive, retrospective study; describing sub-optimal factors and deviant care. Outcome variables were assessments of the care done by the Perinatal Committees. Main outcome measures included deficient events in antenatal care, defined as sub-optimal care related to the pathology that caused the death, when compared with the national guidelines for antenatal care.

The variables for risk factors for sub-optimal care were behaviour pattern which are modifiable in a positive direction. These include the human factors – the

mothers and the caregivers – but may also be inherent in the health care system itself or the available time or equipment in the care situations.

The deficient cases were categorized in the groups used in the Perinatal Committee's assessment of the care; now presented.

### *The mothers' self-care*

Self-care is a term that can be interpreted in a number of ways. Many lifestyle choices are related to health problems that may influence pregnancy outcomes. Health promoting life style can be regarded as adequate self-care, but it will not be correct to proclaim the opposite assertion. Smoking and consanguinity are elements not included in the general assessment of self-care by the following reasons:

#### **Smoking**

During the last years official health authorities and media have focused on the harmful effects of smoking. There are reasons to believe that the harmful effects of smoking in pregnancy may be regarded as well known in the population, especially smoking in pregnancy. Because of the different interpretations of the reasons why some mothers were smoking, and to avoid methodological problems as regards such interpretations, smoking was classified in a separate category. Therefore, smoking habits will be presented in a separate category as a covariate.

#### **Consanguinity**

Another issue with analogue discussions is consanguinity; marriage between near relatives. Consanguinity is the most probable explanation for increased rates of hereditary disorders among non-western immigrants. Stoltenberg studied the influence of consanguinity and maternal education on stillbirth and infant death for children born in Norway between 1967 and 1993 (19). Consanguinity increased the relative risk of stillbirth (OR=2.4, 95% CI 2.0-3.0). Marriages between close relatives are common among non-western immigrants. This has been regarded as cultural and/or religious phenomena, but according to Stoltenberg there are no absolute associations between religious affinity and rules

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concerning consanguineous marriages (19). Norwegian media have regularly focused on these topics during the last years and health authorities and researchers have provided written and verbal information about the risk of hereditary disorders if the parents are relatives of first degree. However, in some milieus, for example in Pakistan and Turkey, marriage between close biological relatives still is the norm (40-42).

These are complicated questions; what are the limits for sub-optimal self-care and who have the authority to determine those limits? This is a complex ethical and philosophical discussion at a level far beyond the scope of this thesis. Whether smoking or marriage between near relatives was lack of self-care or not, will not be further discussed, but these aspects were described and adjusted for in relevant analyses.

#### **Areas for assessment within self-care**

Compliance means following recommendations given by health care providers.

The areas for assessment as regards self-care in this thesis were:

- If the pregnant women attended the program for standard antenatal care, which implies regularly contact with a midwife or a GP. Recommended number of controls is 12 times for nulliparae and eight times for multiparae, with the first control recommended in pregnancy week 6-10 (1). The self-care was assessed as sub-optimal if the pregnant woman came to the first antenatal control later than week 15 of pregnancy
- Following recommendations from health care professionals – the self-care was assessed as sub-optimal if the pregnant woman obviously did not take consequences of advices or followed explicitly noted recommendations from health care providers, or did not present at appointments
- Use of alcohol or drugs in pregnancy – if any use of alcohol and/or drugs was documented in the case reports, it was classified as sub-optimal self-care

- Attendance to health care services without delay. Generally, health care providers should inform the expectant women to contact health care professionals if the following conditions occur: rupture of membranes when ever in pregnancy, bleeding, pain, contractions, reduction or absence of fetal movements or if they are worried about anything that concerns the pregnancy or the child. Based upon my own experiences, these indications for contacting health care professionals seem well known among pregnant women. There are no evidence-based guidelines for optimal behaviour regarding absent or reduced fetal movements, neither for the pregnant nor for the caregivers. There are different limits for when pregnant women are recommended to contact health care providers, but there is consensus that no pregnant should wait more than 24 hours before contacting health care professionals if fetal movements are absent (43). In this thesis, the waiting time with absent fetal movements was grouped into five groups: < 12 hours, 12-23 hours, 24-47 hours, and > 2 days. It was classified as sub-optimal self-care if the woman waited more than two days with absent fetal movements before contacting health care professionals, although clinical recommendations may differ from this

### *Assessment of the professional antenatal care*

Professional antenatal care is a term used in the sense of the total care given to the women during pregnancy and birth. This includes observation, intervention, treatment and information given by all kinds of health care professionals; mainly physicians and midwives involved in the care to the women, both in the primary and secondary health services. This is a broad field, and in this thesis only a few aspects are selected, based on experiences from the Perinatal Committees. The areas for assessment of the professional care included mainly compliance with the guidelines. In general, guidelines are relatively vague, but there are some areas that are clear and consistent. The areas for assessment in this thesis are presented in the following:

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### **Gestational diabetes**

There is an ongoing discussion about the screening routines for gestational diabetes, but according to the current Norwegian clinical guidelines, screening for gestational diabetes by an oral glucose tolerance testing should be performed in week 28-30 of gestation, if glucosuria ( $\geq$  +++ ) is detected in morning urine by urine sticks, if the pregnant is over 38 years old, hereditary (1.degree) diabetes mellitus, BMI  $> 27$  kg/m<sup>2</sup>, previous gestational diabetes, or immigrants from Indian subcontinent or from North Africa. All cases where the pregnancy had reached the actual gestational age were assessed and compared to these guidelines, in order to identify non-compliance.

### **Fetal growth**

Normal fetal growth depends on the genetic disposition, the intrauterine environment, nutrition supply and growth regulation hormone systems (44). Detection of growth-restricted fetuses represents a serious problem and is a great challenge in the antenatal care. Screening of fetal growth is performed by tape measuring of the symphysis-fundus distance and plotting the measure at the preformed scheme with a curve for normal growth with  $\pm 2$  Standard Deviation (SD). According to the guidelines, measure of the symphysis-fundus distance should be performed at each antenatal appointment to detect fetal growth deviation (1). Intrauterine growth restriction means that the fetus has a growth less than expected when compared to the reference curve for growth parameters (9). The guidelines have pointed out some risk factors and clinical signs for growth restriction, and give instructions for situations where referral is recommended (9). The elements used in the assessments in the audit process, and therefore in this thesis, are mainly symphysis-fundus measure as a screening for fetal growth, and use of ultrasound if growth restriction was suspected or verified. Sub-optimal care was defined if the symphysis-fundus measure were diverging more than  $\pm 2$  SD from the 50-centile and the mother was not referred to specialist health care, or if growth restriction was verified, but the mother was not followed up in an adequate way.

**Detecting risk pregnancies**

These assessments included to what degree the health care providers were able to detect risk pregnancies or risk development in an earlier healthy pregnancy. Area for assessment was whether the women were referred to a higher level of health care services according to the guidelines, for example whether women with a medical diagnosis that according to the guidelines ought to be referred, were referred or not. Assessment of the specialist health care services' ability to detect risk pregnancies, or the management and intervention in risk pregnancies when the pregnant women have been referred to this level of health care services

**Interpretation of Cardiotocography**

Indications for use of cardiotocography (CTG) have clear criteria in the guidelines. In interpretation of the non-stress-test pattern different scoring systems exist, but they are quite similar in clinical use. The CTG should be classified as normal, possibly pathological (to be further observed), and pathological (intervention is needed)(9). The assessment of the care was classified as sub-optimal if obvious pathological signs were ignored or intervention not done within adequate limits of time. This thesis does not include any considerations of the value of routine use of this technology, but only an assessment of the clinical practice compared to guidelines.

***Obstetric care***

Obstetric care was the care given by midwives and doctors at the delivery clinics to the mothers who are hospitalised giving birth, not to mothers hospitalised by other reasons during pregnancy. Areas for assessment as regards obstetric care were:

- Observation and interpretation of clinical and biochemical signs: progression of birth process, adequate use of and interpretation of CTG
- Method used and/or point of time for induction: adequate assessment of post term pregnancy, choice of method for induction of labour



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- Mode of delivery, for example at breech presentation: Were the mother recommended vaginal birth or caesarean section according to the guidelines?
  - Detection and treatment of serious complications, like clinical signs of abruption of the placenta

### *Communication*

Good communication involves being given the information you need in a way you can understand, being listened to and being able to build relationship between the involved persons. In the current thesis, communication was assessed at two levels; between the pregnant woman and the health care professionals, and communication between health care providers, including record keeping. This division was done because of the specificity and qualitative differences between the ways to handle possible problems within these two areas.

According to the guidelines, language differences needs special attention and have to be duly noted (1;4). In regard to communication between the pregnant and the health care providers, a marker for problems was if there had been identified problems with communication between patient and health care provider and if interpretation was *acquired* or *attempted acquired* by ordering an interpreter. These assessments were based on written documentation in the medical case reports.

The communication was regarded as sub-optimal if communication problems were registered, but no interpreter was documented used or attempted used, once or more times in relation to antenatal or obstetric care. If communication difficulties or need for interpreter was not mentioned in the non-western immigrants' case reports, it was assumed that no communication problems existed.

Areas for assessment regarding communication between health care providers were verbal or telephonic communication in the care situations and between different health care providers, for example when referring to other health care

institutions or departments within a hospital. The communication was regarded as sub-optimal care if the referring procedure was inadequate to the extent that follow up of the pregnant woman was delayed because of miscommunication.

### *Summary of assessments*

In a summary of the assessments presented in chapter 5.5., some variables were combined and dichotomised. Three of these categories of sub-optimal care are mostly related to the care given by the health care providers; antenatal care, obstetric care, and communication between caregivers. These three categories were combined and dichotomised in the following way: If the care once or more had been classified as sub-optimal care, the care was classified as sub-optimal; else the care was classified as optimal.

### **4.2.2 Explanatory variable**

The only explanatory variable for this study was population group, defined according to maternal country of birth without regard to citizenship. Did the mother's country of origin have any effect on identified areas for sub-optimal care and deviant factors in the care in the pregnancies resulting in stillbirth? As will be discussed later, identification of sub-optimal elements does not proclaim causality between identified sub-optimal factors and the death. Rather, this may indicate areas for improvement.

The preformed antenatal record to use in the antenatal care has the term citizenship to be filled out. Citizenship does not give a complete characteristic of ethnicity or origin, since the most immigrants seeks Norwegian citizenship as soon as possible after immigration. Immigration status in this thesis was based upon citizenship *and* country of origin, in addition to information about religious community. If the records had missing data, information was supplied with information in the medical journals.

Because of the great diversity of countries of origin, sub-groups were made, according to Statistics Norway and based on maternal country of birth. The groups were as follows:

- 
- Western: Nordic countries, Western Europe (except Turkey), North America and Oceania
  - Non-western: Eastern Europe, Asia, Africa, South and Central America and Turkey

### **4.2.3 Background variables**

These are elements associated with individual characteristics, like maternal age, parity, educational level, marital status, maternal BMI, maternal smoking and immigration status, which are presented in the following.

#### **Maternal age**

Both high and low maternal ages are risk factors for adverse birth outcomes (44). Maternal age was stratified into three groups ( $\leq 19$  years, 20-34 years and  $\geq 35$  years), according to the MBR, in order to compare the stillborn with the live born as a reference group.

#### **Parity**

Parity is defined as the number of previous pregnancies greater than 22 weeks of gestation, and is considered both as a measure of a woman's fertility status as well as her reproductive success. Parity is commonly classified in different levels, but no universal definitions exist. Parity was dichotomised, into nulliparae and multiparae.

#### **Educational level**

Social class and other measures of social deprivation are important determinants of ill health, leading to wide regional variations in mortality and morbidity. Several studies have concluded that there is a strong negative association between maternal education and rates of perinatal mortality and morbidity (21;45). Educational level may have a connection to the outcome (1). In the case records used in Norwegian Antenatal Care, the only information about parental background was maternal education. In this thesis, maternal education was classified as:  $< 9$  years, 9-12 years, and  $> 12$  years. Educational level has shown a

strong correlation with socio-economic conditions (19), and the information in the case reports could be used as a proxy of socio-economic status.

### **Marital status**

Marital status is a risk indicator, and single mothers have increased risk for several adverse outcomes of the pregnancy (1). The information at the preformed records about marital status was grouped into married/cohabitant and single.

### **Maternal BMI**

Pregnancies among underweight or overweight women are often regarded as high-risk pregnancies (44;46;47). According to common used definitions (48), pre-pregnancy body mass index (BMI) was classified as underweight (BMI <18.5 kg/m<sup>2</sup>), normal weight (BMI 18.5-24.9 kg/m<sup>2</sup>), overweight (BMI 25-29.9 kg/m<sup>2</sup>), and obese (BMI 30.0 kg/m<sup>2</sup> or more).

### **Maternal smoking**

Smoking is related to low birth weight, increased risk for preterm birth and spontaneous abortions and is the most well known risk factor for perinatal death – that is possible for the mothers to change – mainly because of abruptio placentae (1;9;49). The harmful effects of smoking in pregnancy have been focused for several years. In spite of information campaigns and supporting programmes for smoking cessation, in Norway still about 20% of the pregnant smoke at onset of pregnancy, and 14.6% at end of pregnancy (50). Preliminary results from the 8000 first cases from the Norwegian Mother and Child Cohort Study have shown that 33% of the mothers were smokers before pregnancy. Of the smokers, 33% were occasional smokers (51). The conclusion here was that occasional smoking may have greater implications for health than previously assumed. Therefore, in this thesis, occasional smokers were classified in the same group as daily smokers.

## Gestational age

Duration of a pregnancy may be a determinant of birth outcome. Pregnancies over 28 weeks were grouped according to groups used in the MBR; gestational week 28-36, 37-42, and week 43 or more.

## Causes of death

Classification of causes is difficult in perinatal medicine because of the complexity; including three “sets” of organs to be assessed in the diagnosing process; the mother, the fetus and the placenta. In addition, perinatal deaths are heterogeneous, and chains of events and causes of deaths differs widely (52). The Perinatal Committees use a classification system given by official instructions (30)(Appendix 2), which classifies the deaths in broad groups and without including underlying causes or the pathogenesis processes that lead to the death. This thesis is a summary of the assessments of the Perinatal Committees according to the recommended system (Table 1). Since some of the groups are rarely used, some causes are combined.

TABLE 1: Description of causes of deaths

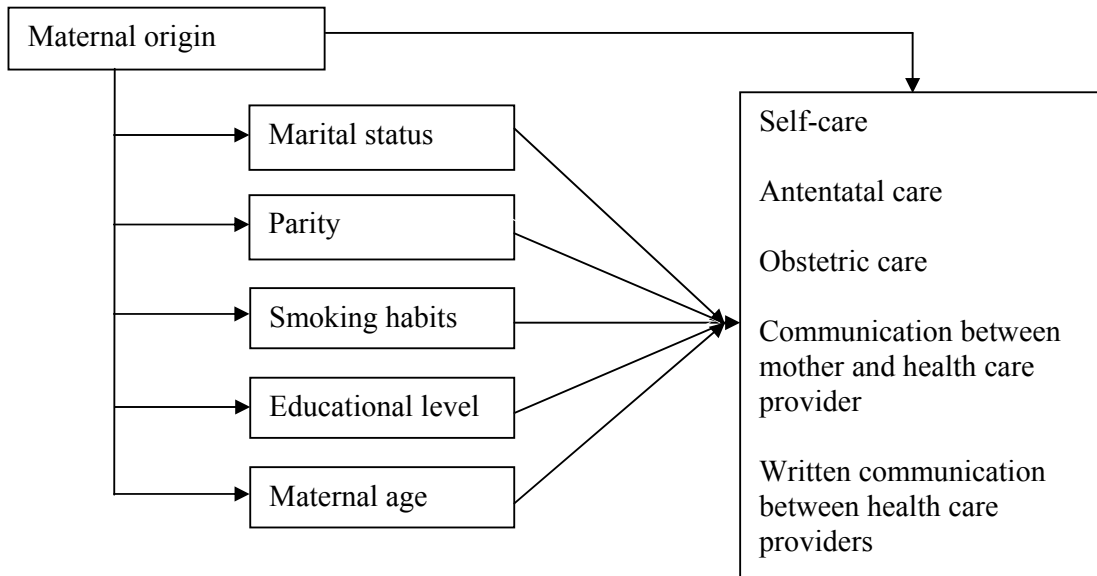
Category	Description
Malformations	Any structural or genetic defect incompatible with life
Infection	Clinical and/or biochemical signs of infection, like chorioamnionitis, prolonged rupture of the membranes, maternal fever
Umbilical cord complications	All umbilical cord complications that may have lead to compression, e.g. cord prolapse/compromise or velamentous insertion
Placental abruption	Total or partial abruption of the placenta
Placenta dysfunction	Abnormal development of the placenta, like intervillous thrombosis, fetomaternal haemorrhage, placental infarction or clinical manifestations of chronic placenta pathology in the fetus where the fetal death was regarded to be a result of chronic placental malfunction
Intrapartum asphyxia	Birth injuries caused by obstetrical complications and/or mode of delivery
Twin-to-twin transfusion syndrome	Placental maldevelopment in monochorionic twins that have resulted in disturbance of the blood flow between the twins
Unexplained	No cause of death was possible to determine
Other	Rare causes of death, only single cases not suitable in the other groups

## Model for possible associations

Antenatal care and birth outcome are influenced by a number of medical, socio-economic and environmental factors, illustrating the complexity of audit procedure and the assessments that have to be done in each case. The most essential variables have been included in current thesis. This was illustrated in a

model, including the elements to be investigated in this study (Figure 4). Positive or negative connections between these variables were investigated. The eventual effects upon the explanatory variables may be direct or indirect, via the individual characteristics.

FIGURE 4: Possible associations between selected variables



### 4.3 Statistical analyses

Statistical analyses were performed by SPSS 12.0.1 (SPSS Inc.Ill) (53) and by Confidence Interval Analyses (54).

Age and BMI are continuous variables, but were categorised according to groups mentioned in chapter 4.2.3. The other variables were all categorical variables. To be able to compare immigration status of the stillborn with live born controls, the deaths before 28 weeks of gestation in these analyses were excluded, since the categorisations in registrations from the Medical Birth Registry of Norway not were comparable with the data from the Perinatal Committees. By data from Statistics Norway, the number of non-western mothers giving birth to a stillborn child was compared to the total number of live children in the same period. In these comparisons only births  $\geq 28$  weeks of gestation were included.

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In the statistical analyses, proportions, means and cross tables with  $\chi^2$ -tests were used in order to describe univariate relationship between the dependent and the independent variables. Cross tables were also used to detect possible associations between covariates. A difference was considered statistically significant if  $p < 0.05$ . By understanding of 95% confidence interval (CI), the analyses of differences between proportions, a difference is considered statistically significant if both the lower and upper limit were under or over 0. Generally, the emphasis was on 95% CI rather than p-values when the differences between the groups were considered. Multiple logistic regression analysis was used to analyze the relationship between the dichotomous dependent variable – maternal origin – and the risk for sub-optimal care, categorized as described in chapter 4.2.1. Cross tables and logistic regression with one covariate were used to find crude (unadjusted) odds ratios with 95% CI, and to decide whether observed differences were statistically significant. Odds Ratio estimated risk with 95% CI. By the understanding of odds ratio, it is evident that the totality of the 95% CI should be either above or below 1, if the differences between the two groups should be considered significant. In these situations, the p-value is mainly superfluous when ratios and CI are presented.

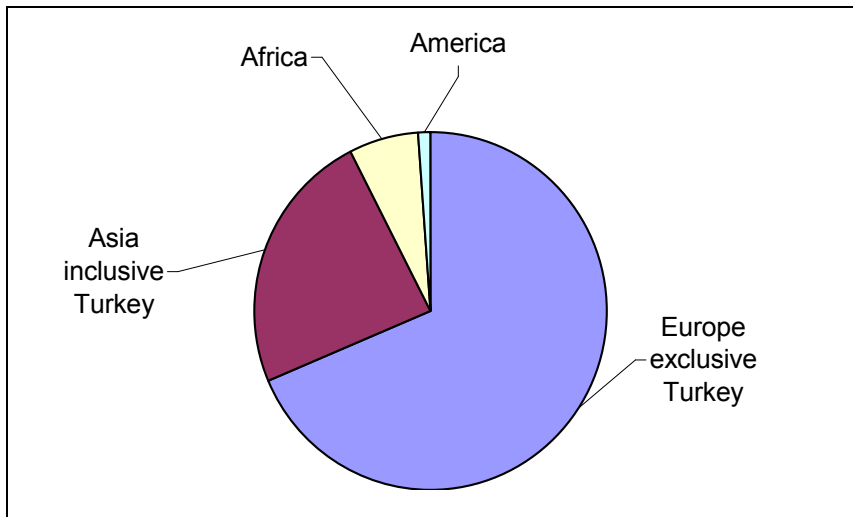
## 4.4 Maternal characteristics

In 1998-2003, there were 356 stillborn among the 83.754 births in Oslo and Akershus. This chapter is a description of the stillborn and their mothers; first comparisons between the stillborn mothers of different origin, and second comparisons of the live born with the stillborn.

### 4.4.1 Western versus non-western mothers

Totally, the mothers in the population with a stillborn child came from 36 different countries, and were categorised into greater groups (Figure 5). The vast majority came from Pakistan, Somalia, Sri Lanka, and Turkey.

*FIGURE 5: Continent of origin among the mothers with a stillborn child after 24 weeks of gestation in Oslo and Akershus 1998-2003, (n=356)*



Of the mothers with a stillborn child, 246 (69.1%) were of western origin and 110 were non-western women (30.9%).

Of the *total* amount of births in Oslo and Akershus in the study period, 15.3% was of non-western immigrants (38). Among 70.603 western mothers giving birth in these counties during these six years, there were 197 stillborn (0.3%); among the 13.201 non-western women, 93 stillborn were observed (0.7%). Non-western mothers had increased risk for giving birth to a stillborn child when compared to western mothers, (OR = 2.2, 95% CI 1.3-3.8). The rates of stillbirths showed significant differences between the origin groups also when dividing into antepartum and intrapartum deaths per year for this period (Figures 6 and 7); with 95% CI for the differences between proportions 0.3-0.6 for the antepartum deaths, and 0.003-0.1 for the intrapartum deaths.



FIGURE 6: Rates of *antepartum* deaths  $\geq 28$  weeks of gestation among western and non-western mothers in Oslo and Akershus 1998-2003

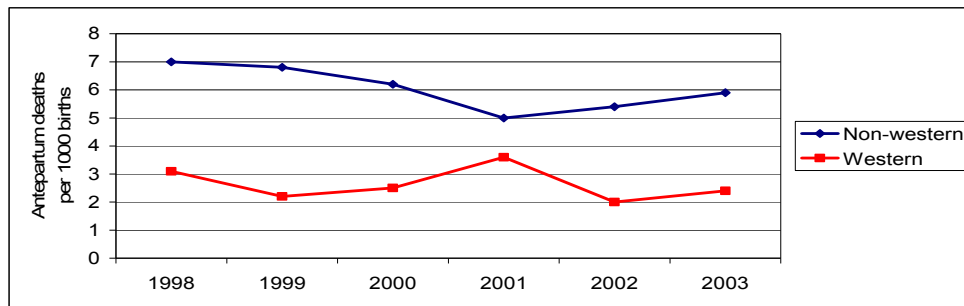
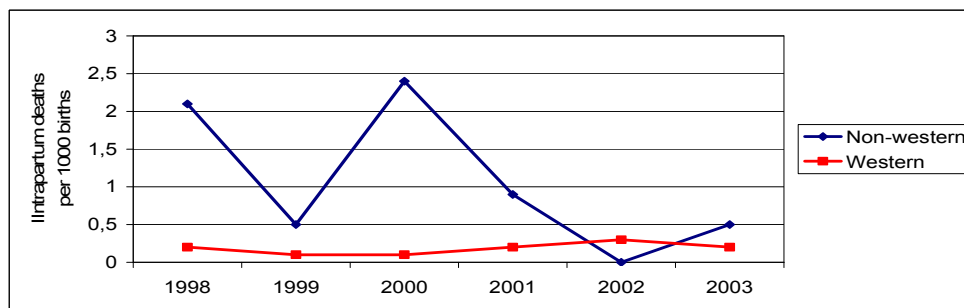


FIGURE 7: Rates of *intrapartum* deaths  $\geq 28$  weeks of gestation among western and non-western mothers in Oslo and Akershus 1998-2003



Among the 13.201 non-western mothers giving birth in Oslo and Akershus during these six years; there were 388 second-generation immigrants. Among these, there were five mothers who had a stillborn child; a stillbirth rate of 1.3%. Among the first generation immigrants, 104 of 12.813 were stillborn (0.8%). The difference between these proportions was not statistically significant.

Comparing maternal characteristics between western and non-western mothers showed that the non-western mothers were about one year younger and had lower education than the western mothers (Table 2). There were no significant differences between the groups in marital status, but there was a tendency towards a higher frequency of single mothers among the non-western mothers when compared to the western mothers. The single women most often came from Somalia and Vietnam. There were no differences as regards gestational age between western and non-western mothers

**TABLE 2: Descriptive characteristics of the western and non-western women with a stillborn child in Oslo and Akershus 1998-2003\***

	Western		Non-western		P**
	n	%	n	%	
<b>Age</b>	<b>246</b>		<b>109</b>		
Mean (min-max)	30.4 (16-42)		29.5 (17-42)		
< 20 years	3	12.2	2	18.2	
20-34 years	187	76.0	85	78.0	0.036
≥ 35 years	56	22.8	22	20.2	
<b>Education</b>	<b>198</b>		<b>81</b>		
≤ 9 years	18	9.1	29	35.8	
10-12 years	74	37.4	31	38.3	< 0.001
> 12 years	106	53.5	21	25.9	
<b>Marital status</b>	<b>240</b>		<b>109</b>		
Married/cohabitant	192	93.3	95	87.2	0.065
<b>BMI</b>	<b>176</b>		<b>54</b>		
< 20	24	13.6	10	18.5	
20-24.9	81	46.0	25	46.3	0.68
25-29.9	46	26.1	12	22.2	
≥ 30	25	14.2	7	13.0	
<b>Parity</b>	<b>246</b>		<b>109</b>		
0	139	56.5	46	42.2	
1	66	26.8	29	26.6	
2	36	14.6	20	18.3	< 0.001
≥ 3	6	2.0	14	12.8	
<b>Smoking</b>	<b>236</b>		<b>103</b>		
Occasionally/ daily smokers	66	28.0	12	11.7	< 0.001
<b>Consanguinity</b>					
Cousins	0		19	17.4	< 0.001

\* Number of cases differs because of missing data. This was remarked at the rows for each variable

\*\*  $\chi^2$ -test for difference between proportions between western and non-western women

There were no differences in BMI between the groups of different origin, but a major part of the total group was overweight. 90 mothers (39.1%) had a BMI  $\geq$  25 kg/m<sup>2</sup>. There were, however, 126 (35.4%) cases where BMI not was possible to estimate because of missing data in the case records. BMI is not available in the MBRN, therefore only a description of BMI of the mothers with a stillborn child is presented, without comparison to the mothers with live born children.

Western mothers were significant more often nulliparae and more often they were smokers. Seven of the non-western smoking mothers came from the earlier Eastern Europe; the others came from different countries both in Asia, Africa and South America.

There were also significant differences as regards smoking habits between Oslo and Akershus. 18.5% of the mothers with a stillborn child in Oslo were smokers,

versus 29.6% in Akershus ( $p=0.02$ ). Among non-western mothers, 11.7% were smokers, compared to 28.0% of the western mothers ( $p=0.001$ ). National data about smoking habits in groups of different origin does not exist, and it was not possible to compare these data with the total population in these counties. In total, 22.6% of the mothers to stillborn children were smokers.

#### 4.4.2 Causes of death

Among the stillbirths, there were 29 twins. In 23 of these cases one of the twins was stillborn. In the remaining three, both died. Except for the increased risk of intrapartum asphyxia among the non-western mothers, there were no differences between western and non-western women in regard to causes of death recorded (Table 3). However, the rate of unexplained stillbirths may be overrated among non-western cases because of a significantly lower autopsy rates; 45.9% versus 83.6%. Placenta dysfunction was the major cause of the death in both groups.

TABLE 3: Causes of deaths among the stillbirths, ( $n=356$ )

	Western 247 (69.4%)		Non-western 109 (30.6%)		Total		P*
	n	%	n	%	n	%	
Malformations	19	7.8	7	6.4	26	7.3	0.67
Infection	20	8.2	8	7.3	28	7.9	0.84
Umbilical cord complications	18	7.3	8	7.3	26	7.3	1.0
Placentae abruption	31	12.7	9	8.3	39	11.0	0.28
Placentae dysfunction	83	33.9	39	35.8	122	34.4	0.81
Intrapartum asphyxia	1	0.4	4	3.7	5	1.4	0.03
Twin-to-twin transfusion syndrome	9	3.7	3	2.8	12	3.4	0.76
Unexplained	56	22.9	27	24.8	83	23.4	0.79
Other	3	1.2	0		3	2.0	0.56
Missing	2	0.8	0		2	0.6	0.98

\*  $\chi^2$ -test for the differences between proportions of western and non-western mothers

#### 4.4.3 Live born versus stillborn

These analyses compared characteristics of total amounts of mothers with a *live* child, with the mothers who had a *stillborn* child in Oslo and Akershus in the same period. There were two case reports where the sex of the child was not registered.

Totally, there were 170 girls (47.8%) and 184 boys (51.7%); approximately the same distribution between sexes as the total population of births.

*TABLE 4: Maternal characteristics, n (%) and 95% CI for the difference between proportions – live born and stillborn in Oslo and Akershus 1998-2003<sup>1</sup>*

	Live born n=83 754		Stillborn n=356		95% CI
	n	%	n	%	
<b>Age</b>					
≤ 19 years	1 089	1.3	5	1.4	+1.3 – 1.1
20-39 years	80 739	96.4	343	96.3	+1.9 – 2.0
≥ 40 years	1 926	2.3	8	2.2	+1.5 – 1.6
<b>Marital status</b>					
Married/cohabitant	77 266	92.3	320	89.9	+0.7 – 5.5
<b>Parity</b>					
0	44 222	52.8	186	52.2	+4.6 – 5.8
1	21 860	26.1	95	26.7	+5.2 – 4.0
2	12 479	14.9	56	15.7	+4.6 – 3.0
≥ 3	5 276	6.3	19	5.3	+1.4 – 3.3
<b>Gestational age</b>					
28-36	5 666	7.0	139	47.9	+46.7 – +35.2*
37-42	74 852	92.3	149	51.4	35.1 – 46.6*
43+	613	0.8	2	0.7	+0.9 – 1.0

<sup>1</sup> For 2003 the amount is estimated by a mean of the period 1998-2002

\* p<0.05

There were no differences between the mothers who gave birth to a live and a stillborn child in age, marital status or parity, but among the stillbirths there were more preterm births. The stillborn rates for pregnancies in pregnancy week 43+ were not more frequent than among live born children (Table 4). Gestational age of the child was the only significant differences between the live born and the stillborn.

## 5. Audit results

Sub-optimal self-care of the mothers, sub-optimal obstetric care and miscommunication were significantly more common among non-western immigrants (Table 5).

TABLE 5: Results from perinatal audit\*

Categories of assessments of the care	Western		Non-western		P**
	n	%	n	%	
Sub-optimal self-care of the mothers (n=345)	17	7	19	18	0.004
Sub-optimal antenatal care (n=340)	52	23	24	23	ns
Sub-optimal obstetric care (n=355)	10	4	15	14	<0.001
Miscommunication between patient and caregiver (n=340)	2	1	51	47	<0.001
Miscommunication between caregivers (n=339)	13	6	9	9	ns

\* The same case may be included in more than one group. Due to missing information in some case reports, the number of included cases differed between the different categories

\*\*  $\chi^2$ -test for the differences between proportions of western and non-western mothers

In order to identify some reasons for these differences, each category was analysed separately and adjusted for relevant covariates in the next chapters.

### 5.1 Mothers' self-care

Elements included in the mothers' self-care were presented in chapter 4. Non-western women had an increased risk for sub-optimal self-care when compared to western mothers (Table 5).

Bivariate analyses of the covariate's effects on the mother's self-care showed that factors associated with sub-optimal self-care were: being below 20 years, having education 9 years or less, being nulliparae and being single (Table 6). Multiple logistic regression analysis were performed and background factors were entered as covariates, first *maternal age, parity and marital status* in one model. This showed that non-western mothers had an increased risk for sub-optimal self-care, even though the risk was reduced. When adjusting for *education*, this increased

risk was not present, but if adjusting for *smoking*, the risk for sub-optimal self-care increased. In the final model, when corrected for all these factors, the increased risk for sub-optimal self-care among non-western immigrants remained as a tendency.

**TABLE 6: Crude and adjusted Odds ratio (OR) for “sub-optimal self-care” – western versus non-western mothers, (n=356)**

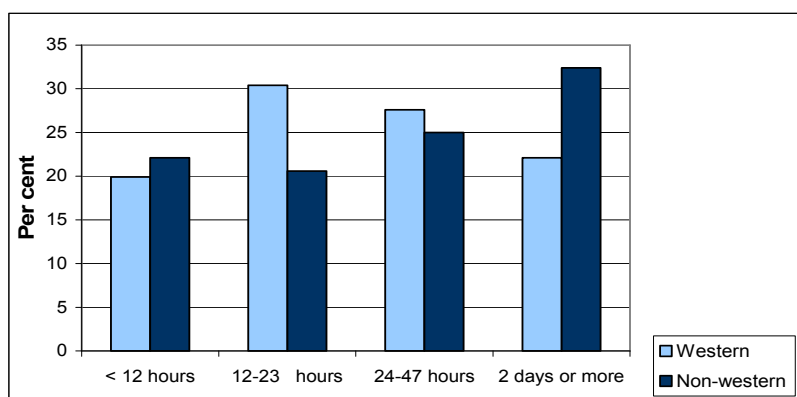
Factors	Crude OR (95% CI)	Adjusted for maternal age, parity and marital status (95% CI)	Adjusted for education (95% CI)	Adjusted for smoking (95% CI)	Adjusted for all variables (95% CI)
<b>Maternal ethnic origin</b>	Western	1.0	1.0	1.0	1.0
	Non-western	2.9* (1.4-5.8)	2.4* (1.2-5.1)	1.6 (0.7-4.0)	4.1* (1.9-9.0)
<b>Maternal age</b>	< 20 years	14.0* (2.3-86.8)	15.0* (2.3-94.5)		14.6* (2.1-106.8)
	≥ 20 years	1.0	1.0		1.0
<b>Education</b>	≤ 9 years	4.0* (1.4-11.5)		3.2* (1.02-9.9)	2.6 (1.0-8.7)
	10-12 years	1.8 (0.7-4.9)		1.7 (0.6-4.6)	1.6 (0.5-5.1)
	> 12 years	1.0		1.0	1.00
<b>Parity</b>	Nulliparae	2.4* (1.2-5.0)	2.1* (1.02-4.5)		2.3 (0.9-6.2)
	Multiparae	1.0	1.0		1.0
<b>Maternal smoking</b>	No smoking	1.0		1.0	1.0
	Smoking	2.0 (0.9-4.3)		2.9* (1.3-6.6)	3.3* (1.1-9.4)
<b>Cohabiting</b>	Married/cohabitant	1.0	1.0		1.0
	Single	3.0* (1.2-7.5)	2.4 (0.9-6.6)		2.7 (0.2-4.6)

\* p < 0.05

### Absent fetal movements

There were 248 deaths where absent fetal movements were described. In these cases, the time from last felt movement till contact with health care professionals was registered (Figure 7).

**FIGURE 7: Absent fetal movements and waiting time, (n=248)**



In the other 108 cases, there were not noticed that the mother felt any reduction or absence of fetal movements – even if the child was dead when the mother arrived

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to the hospital. There may be variations in behavior between the groups of different origin, although it did not reach significant levels in this study.

### **Hospitalisation**

Among the mothers in this study, causes for contacting health care professionals were: Absence or reduction of fetal movements 124 (35.0%), contractions or rupture of membranes or other signs of ongoing birth 94 (26.4%), bleeding or pain different from contractions 33 (9.3%), the death was discovered by a standard prenatal care visit 77 (21.6%), and by other reasons 26 (7.3%). There were no significant differences between groups of different origin.

### **Attending antenatal care program**

Eight women had not booked in to an antenatal control before week 19-20 in pregnancy, did not arrive to planned appointments or had not attended any control in pregnancy at all. The three western mothers in this group were all drug abusing women. Three non-western mothers refused fundal height measurements or refused to undress to allow an appropriate fundal height measurement. Four non-western mothers refused to stay at the hospital when the doctor recommended hospitalisation. Low education and non-western origin were associated with not bringing urine sample at antenatal visits ( $p=0.04$ )

## **5.2 Antenatal care**

There were no significant differences between groups of different origin as regards antenatal care, but sub-optimal antenatal care was identified in almost  $\frac{1}{4}$  of the deaths (Table 6). Areas for sub-optimal antenatal care were:

- Misdiagnosed or ignored growth restriction (16 cases)
- Inadequate reaction to information of reduced fetal movements (12 cases)
- Measurement of fundal height: in six cases documentation about the fetal growth was totally missing during the whole pregnancy

- Lack of compliance with screening for women with risk factors for gestational diabetes (in 70% of western and 83% of non-western mothers). The differences in test rates between the groups was not significant
- Delayed referral for verified medical diagnoses that require follow up by a specialist, like hypothyroidism, epilepsy, pathological levels of haemoglobin, known risk factors in obstetric anamnesis and clinical signs of rupture of membranes (15 cases)

### 5.3 Obstetric care

Sub-optimal obstetric care was strongly associated with non-western women with an OR=3.8 (95% CI 1.6-8.7) when compared to the western women. Areas where deficient obstetric care were overrepresented among non-western women:

- Failure to observe and prevent fetal distress by misinterpretation of cardiotocography
- Erroneous interpretation of labour progress and late intervention during vaginal delivery
- Erroneous interpretation of signs of abruption of the placenta

### 5.4 Communication

Being of non-western origin was a significant risk factor for communication problems, and the risks for these problems were significantly increased if the women had 9 years of education or less. Single living women had an increased risk for communication problems. Adjusting for maternal age, education, parity and marital status in a multiple regression analyses, further strengthen the association of non-western origin with sub-optimal communication (Table 7).



TABLE 7: Risk factors for sub-optimal communication, (n=341)

Factors		Univariate		Multivariate	
		Crude OR	95% CI	Adjusted OR	95% CI
Maternal ethnic origin	Western	1.0	Reference	1.0	Reference
	Non-western	28.6*	6.5-124.8	79.2*	7.3-856.8
Maternal age	< 20 years	0.9	0.9-1.0	1.0	0.9-1.2
	≥ 20 years	1.0	Reference	1.0	Reference
Educational level	≤ 9 years	29.1*	3.6-237.4	18.1*	1.5-216.0
	10-12 years	9.1*	1.1-74.9	9.7*	7.6-72.6
	> 12 years	1.0	Reference	1.0	Reference
Parity	Nulliparae	1.6	0.7-3.8	0.5	0.1-1.8
	Multiparae	1.0	Reference	1.0	Reference
Maternal smoking	No smoking	1.0	Reference	1.0	Reference
	Smoking	1.2	0.5-3.3	4.9	0.9-27.0
Cohabiting	Married/cohabitant	1.0	Reference	1.0	Reference
	Single	4.6*	1.6-12.7	2.1	0.5-9.1

\* p &lt; 0.05

Areas of deficient communication *between the women and the health care providers* were in situations with delayed detection and treatment of serious complications where signs and symptoms to a far degree were based upon the pregnant women's descriptions, like signs of abruption of the placenta, reduced fetal movements and clinical signs of rupture of membranes.

There were no significant differences between the western and non-western mothers as regards communication *between health care providers*. However, areas with possibilities for improvements for both groups were identified in 22 cases. There were three recurring themes. The first was related to situations in the context of written referrals between primary and secondary care; the second was uncertainties described by the obstetrician, where consultations with more experienced colleagues was lacking, and the last theme was related to routines for reporting between laboratories back to the health care professional which were responsible for the mother if there were pathological test results. These were situations where this delay seemed to have been an obstacle for intervention in risk pregnancies.

## 5.5 Summary of findings

This investigation has showed that, to a significant degree, sub-optimal factors in perinatal care that could be linked to stillbirths were more often observed among non-western mothers. The results can be summed up as follows:

- ✚ Non-western mothers were about one year younger than western mothers
- ✚ Western mothers were more educated than non-western mothers
- ✚ Western mothers were more often daily smokers than non-western mothers
- ✚ There were no significant differences in gestational age, BMI or marital status between western and non-western women
- ✚ Consanguinity was present at 17% of non-western mothers; consanguineous marital relations were not observed among of western mothers
- ✚ Non-western women had an increased risk for giving birth to a stillborn child than compared to western women, OR = 2.2 (95% CI 1.3-3.8)
- ✚ There were no differences between the groups as regards causes of death
- ✚ Among the stillborn, non-western women tended to have increased risk for intrapartum death compared to western women, OR = 2.4 (95% CI 0.9-5.9)
- ✚ In antenatal care both unidentified growth restriction and inadequate management of IUGR were common causes of sub-optimal care. Non-western women more often received sub-optimal obstetric care, OR = 3.8 (95% CI 1.6-8.7), as e.g. misinterpretation of cardiotocographic signs of fetal distress and incorrect assessment of labour progression
- ✚ Non-western women were less prone to follow recommendations given by health care providers, as e.g. not attending program for standard antenatal care, or not taking consequences of recommendations given by health care providers
- ✚ Communication problems were documented in case reports. Inadequate communication was documented in 47% of the deaths among non-western mothers. Use of interpreter was documented in only 29% of these cases. There were no differences between western and non-western mothers with regard to communication between health-care providers

Health professionals have performed sub-optimal care in 99 of 349 the stillbirths in this period (28.4%), no differences between women of western or non-western origin, OR=1.2 (95% CI 0.7-2.0). If including self-care and miscommunication, non-western immigrants had more than twice increased risk of sub-optimal care than compared to western women, OR=2.4 (95% CI 1.5-3.9). By this combination of all “care variables”, sub-optimal care was identified in 53 of 103

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stillbirths among the non-western immigrants (51.5%), versus 73 of 238 western women (30.7%). In total, sub-optimal care was identified in 126 of 341 stillbirths (37.0%).

The reasons for the increased risk of experiencing a stillbirth were not assessed here, since the issue for this thesis was risk for sub-optimal care.

## **6. Discussion**

This study has identified sub-optimal care factors in 126 of 341 (37%) stillbirths. This number does not reflect that all these stillbirths were avoidable, as causal mechanisms between stillbirths, quality of care and risk factors are complex. However, clinically significant improvements seemed possible.

The main challenge was to interpret the results in a fruitful way in order to suggest quality improvements as regards care of the pregnant women. Is it possible to identify those interventions in pregnancies that appear most promising in terms of reducing stillbirth rates? Since this thesis is a review over a broad field – assessment of the care during the pregnancy and the birth – the frames for this thesis implies that there is no room for suggestions at a concrete or detailed clinical level. Each area of improvement suggestions requires a separate study and investigations in order to get evidence-based knowledge. Therefore, only main areas for improvement were suggested here.

Stillbirths with elements of sub-optimal care documented in the non-western group in this thesis may be related to maternal pregnancy strategies, deficiencies in medical care and miscommunication. These are the same groups used by Essén (21). Each group will be presented in the following.

### **6.1 Interpretation and implications**

#### **6.1.1 Care from health care providers**

##### **Monitoring of intrauterine fetal growth**

Growth restriction is present in a large proportion for stillbirth in our region (55) and studies suggest that optimal observation of fetal growth, and identification and intervention of growth restriction, may reduce stillbirth rates (23;27;56;57).

The method for measuring the symphysis-fundus height is simple, inexpensive, and widely used as a primary screening tool for intrauterine growth restriction. The method has low sensitivity for detection for growth restriction, about 15-30%

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(58;59). Studies have emphasized a low intra personal correlation, and that the symphysis-fundus height cannot be measured by different observers with sufficient agreement to identify too small fetuses (60). In spite of these weaknesses, this method is the only recommended method in national guidelines for screening of fetal growth. In order to identify to what degree the growth restricted fetuses were identified by the health care providers, the material in the current thesis, was assessed with special focus upon fetal growth restriction. By this means the treatment both in the primary and specialist health care services, were analysed with regard to adequate reaction upon alarming signals of growth restriction. This study has documented failure both in identification of fetal growth, misdiagnosed or ignored growth restriction and following up identified growth restriction. There were no differences in the surveillance and intervention between non-western and western mothers, but lack of compliance to guidelines that may have affected the risk of stillbirth was identified.

### **Fetal movements**

The pregnant woman presenting concerns for reduced fetal movements is a common challenge in obstetric care – ranging from 4 to 15 % of all pregnancies in various populations (43). These pregnancies have increased risk of adverse outcomes as fetal growth restriction, preterm birth and stillbirth. Yet, a survey of all delivery units in Norway showed that only two delivery units had any written protocol or guidelines for management of such pregnancies (61). In fact, there are no evidence-based guidelines available internationally, as the issue has remained unexplored (62).

Despite debates on what information women should actually get, there seems to be widespread consensus on basic elements as e.g. no woman should wait 24 hours or more without any fetal activity before contacting health professionals (62). In the current population, 52% waited more than 24 hours without any fetal movements before they contacted health professionals, and 1/4 waited more than 48 hours. They did not understand the urgency and severity of this sign.

Professionals did not either, as they failed to respond adequately when mothers finally turns to her health care providers. Women do not get sufficient information on the importance of fetal activity to act in a way that would protect their child (62). It is documented significant variation in clinical routines in Norway, which do not correlate with information given to pregnant women, the literature or guidelines (61). This can lead to uncertainty for both pregnant women and health care professionals and may put patient safety at risk. There is obviously plenty of room for improvement in the information given to expectant mothers in our population, as there is in management in hospitals.

### **Registration and interpretation of fetal hearth rate pattern**

The audit revealed that one of the most frequent failures was related to the use and interpretation of fetal signs of stress or asphyxia. Künzel has described a similar finding. He documented that fetal death was closely related to fetal surveillance, i.e. the number of antenatal visits, ultrasound measurements and fetal heart rate monitoring. He also documented that antepartum fetal death can be reduced at least by 50% if the available methods for fetal surveillance are employed aiming to detect indications of fetal oxygen deprivation at an early stage (56). A regular and obligatory training programme for use and interpretation of cardiotocography should be performed for all midwives and obstetricians at units where this technology is used. This could improve the competence level among the midwives and physicians involved in the care. Some hospitals have already established such a system, giving certification for those who have participated in these programmes. This implies certifying all the individuals. Improvements have to involve the lowest level of care; those who are performing the care and are responsible for the interpretations and interventions in clinical situations.

### **Compliance with guidelines and referral practice**

A potential for possible improvements were found in the referral routines. Delayed referral of expectant mother with diagnoses like; hypothyroidism,

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epilepsy, pathological levels of haemoglobin, and known risk factors in obstetric anamnesis were observed. According to the national guidelines a specialist should have followed up women with such diagnoses. Obesity, primiparity and maternal smoking are elements that should give a lower threshold for referral to an obstetric specialist (1;9). The guidelines should be followed when a diagnosis is verified.

In situations with referring, lack of precision was identified; lack of written referring with explicit description of the cause(s) for referral, or a diffuse description of the reason(s) for referral. This may have lead to overlooking of the essential problems by the specialists. Use of telephone is necessary when referring in urgent situations, but this has to be combined with a written referring with explicit description of the cause(s) for referral.

As regards screening for gestational diabetes, this thesis has documented a great lack of compliance to the guidelines. This may be due to lack of knowledge of the indications for screening among the primary health professionals or an ignorance of the guidelines. The necessity of the screening routine is currently being questioned, but these controversies will not be further discussed her. However, the oral glucose tolerance procedure is inconvenient and intake of the glucose liquid constitutes problems for some pregnant women. An easier screening method with a similar screening effect should be considered.

Non-compliance to guidelines in care was identified most often in association with non-western women and different attitudes towards women origin can not be ruled out.

### **Social elements**

Single mothers needs special attention (1). Several studies have described social elements like single living and/or low educated mothers and psychological burden as significant risk factors for unexpected death during pregnancy, in addition to several medical conditions (18;56;63;64). Being an immigrant may for some reinforce the adverse effects of being single because of a poorer psychosocial

network. This current material has not shown differences in the care between single and cohabiting or married mothers, but lower education was associated with a greater risk of sub-optimal self-care.

Information and public awareness of the harmful effects for the fetus of a hazardous life-style must be of high priority. Individuals at risk that need help, should be offered help to change their lifestyle. In all health promoting information that affects life style choices, there is a difficult balance between information based on facts and to avoid frightening effects upon those it concerns. Culturally competent care which implies a successful improvement of individual health behaviours without “blaming” individuals for health care choices (like overeating, alcohol use, smoking, inactivity and marriage between first cousins), may be particularly helpful in reducing the stress of poverty and may be of special importance in the future.

### **6.1.2 Maternal pregnancy strategies**

Aspects involving maternal pregnancy strategies included here, are choices at an individual level, except communication and cultural aspects, which is discussed later.

Smoking was the factor with strongest adverse effect upon self-care. Some of the characteristics of our non-western immigrant population (younger, less educated, more often multiparae), as well as other markers of social disadvantage and psychological burden, are significant risk factors for unexpected death during pregnancy, in addition to several medical conditions (1;18;55;56).

#### **Life style choices**

Differences between non-western and western women as regards some behaviour during the pregnancy were identified. Life style choices; as smoking, use of alcohols, consanguinity, and education level were differently distributed between the two groups. Western mothers were more frequent daily smokers, but non-western mothers were more often low educated and living in consanguineous



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relations. There were no differences between the western and non-western mothers as regards overweight.

### **Adhering to recommendations**

Failure or delay in attending standard programme for antenatal care was more frequent among non-western women. This may be due to communication problems, but may also be due to different interpretation of clinical signs and symptoms because of cultural differences. The western women in this material not attending the antenatal care program were all drug abusers; the non-western women in similar situations did not have other common characteristics except of being a non-western immigrant. In a literature review of perinatal problems and challenges among Scandinavian pregnant immigrant women, Essén addressed the problem of non-compliance among immigrants (65). She recommended health care providers to discuss and inform the pregnant immigrant women about the importance of antenatal care; about fetal movements and fetal growth pattern. She emphasised the importance of being explicit and clear in defining serious symptoms. Non-western women may have a different risk orientation when compared to the traditional western attitudes to pregnancy. The common knowledge among the native born population about pregnancy and important signals requiring special attention may be absent among immigrant women.

### **Consanguinity**

As mentioned earlier, consanguinity is described as a risk factor for stillbirth. Evidence based knowledge about well-known risk factors have to be clear messages to all actual milieus, both at individual and collective levels.

### **6.1.3 Minimize barriers**

In the actual situations here, there are two parts, since both communication and cultural areas involve both the pregnant women and the caregivers. A barrier can be defined as a hindering for something wanted from one or both sides. Intervention directed towards language problems, lifestyle, and cultural and religious factors simultaneously may lead to reduced barriers between immigrants

and the Norwegian welfare system. Better integration of all immigrant groups in the existing multicultural society of the Norwegians is important, as culturally sensitive approach by health care professionals towards these groups.

### *Communication*

This study has documented communication problems in the care situations as regards the non-western mothers with a stillborn child. It is difficult to assess the impact of communication failure on the risk of deaths. Few studies have studied poor communication and its association with adverse outcome (14). In this thesis, assessments were based on clinical records, while parental information was not included. This provides only one part of the communication process. However, since some specific communication problems were highlighted, some aspects should be discussed.

### **Effects of miscommunication**

Poor communication may affect our self-esteem. This has been described by several authors (20;66;67). Without regard to the reasons for immigration, the immigrants have lost something important; their social network and behaviour, food and smells they have been brought up with. Our surroundings are our mirrors that tell us who we are. When the accustomed surroundings are lost, the mirrors are lost; this may affect the self-esteem, the self-identity and an experience of belonging (68). In situations with illness, pain or anxiety – often present when women attend care in pregnancy and childbirth – the language competence decreases. Lack of language competence is often followed by shame, grief and frustration, and may lead to an experience of being infantile (69). In ones own language, they may express themselves as adults and competent persons; in a childish language in unknown surroundings, the self-identity may be threatened and an adequate communication hindered. Several studies have claimed insufficient use of trained interpreters to be an obstetric risk factor (21;64;70). Experience from clinical situations is that some non-western immigrants have a different way of expressing pain and suffering, for example

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with louder voices than Norwegian mothers. There is a risk for overlooking essential messages, because of use of different verbal and non-verbal languages. The different modes of expressions may lead to confusion among health care providers, and it is a challenge to develop culturally competent personnel that is able to interpret and act according to these signals.

Norwegian authorities have emphasized this in official reports. The Norwegian Ministry of Health has pointed out that it is in both the health care professionals and the patients' interest that an interpreter is used (66) and emphasis the health care professionals to be responsible for using an interpreter. The law about patient rights calls attention to that "the information shall be adapted to the recipients individual qualifications, like age, maturity, experience, cultural and language background" (my translation)(64). There are no doubt about the official recommendations and laws as regarding use of interpreter in actual situations. Lack of interpreter may lead to important changes in the mothers' ability to tell about essential signs and symptoms to health care providers. When you have missed the most important channel for communication of your own situation, there are great possibilities for misunderstanding and neglect of important and threatening signals. This study has identified sub-optimal care as regards detection and treatment of serious complications, like signs of abruption of the placenta and clinical signs of rupture of membranes. Making such diagnoses is to a far degree based upon the pregnant women's descriptions and language competence may be very important. Miscommunication may lead to delay in identification of serious conditions that may have led to possible avoidable stillbirths, especially among non-western women.

### **Official interpreter**

Use of an official interpreter instead of using a family member, is emphasized in both Norwegian and international documents (69;71-73). Even if family members may be more competent in speaking and understanding Norwegian than the expecting mother, there are several disadvantages by using a family member as an interpreter. It has been reported that the interpretation often has been biased;

messages both ways may be selected in order to “protect” the mother; misunderstandings because of lack of competence in the Norwegian language by the interpreting family member (72;74). Difficulties may also occur, as a family member is almost always emotionally involved in the care situation. Being an interpreter is a profession; interpreters play an essential role in the care of non-western women during in the perinatal period.

Essén found that identified inadequate verbal communication could be a sub-optimal factor likely to have contributed to some intrapartal deaths among children born to mothers from Africa’s Horn. She assumed that some stillbirths could have been avoided if an interpreter had been present during emergency situations (21). Communication problems were also documented in the current study, but it was not possible to conclude that there was causality between these problems and the deaths, only that it may have been one of several probably factors leading to the death.

However, communication problems were identified and this seemed to be an obvious area for improvements. There is no doubt about the importance of adequate communication, and the official recommendations and the laws have defined the patient’s right to have an interpreter in clinical situations. The clinical world is however complex and some of the obstacles for using an interpreter are that the availability of interpreters is limited, and sometimes it is difficult to get interpreters in acute situations. In addition, economic aspects may have adverse effects on the frequency of use of interpreters, since the costs for use of an interpreter are charged to the one that ordered the interpreter. Interpreters may be used in many ways, in addition to the presence of an interpreter in the clinical situations; it is possible to interpret by use of a telephone, visual telephone, translation of written information, and use of audio-visual material. This is both an organisational and an economic problem, both of them are possible to solve, if the will is present.

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## ***Culture***

Norway is a democratic society with equality as a ruling ideology for all official services. Norwegian antenatal care is based upon these principles (1). Equality is a heroic and well-meant principle, but the question is whether it may result in adverse outcomes for immigrants partly or totally excluded from the mainstream society by socio-economic disadvantage and discrimination. Essén has emphasised the importance of taking the individual cultural and religious aspects in consideration in all patient care and writes: “Good pregnancy outcomes have a combination of biological, social and cultural origins. Anthropological research methods combined with traditional epidemiological and statistical methods, seem appropriate tools for health care givers in providing new information about perinatal care in Sweden in a broader perspective” (21). Norway and Sweden are quite similar as regarding culture, political, and socioeconomic conditions and these aspects can directly be adapted on the Norwegian society.

### **Culturally sensitive care**

In order to give individual adjusted care, health care have to be “un-equal” and take into account the changes the immigrant often go through after coming to a new country; with changes as regards diet, life style, and employment. Gennaro speaks about “culturally competent care” (20) and Åsard and Runblom (75) are discussing the term “positive special care or treatment”. This can be used for groups of people, if the criterions and aims are precisely defined. It is possible that some groups of women or families need special care or treatment in order to fulfil the purpose about equal health rights in the perinatal care.

The interaction between those seeking health care and health care providers may differ systematically between women of majority and minority groups. Race and ethnicity has been cited as important cultural barriers in patient-physician communication (76). Health care providers may be less experienced in surveillance of non-western mothers, and there may be less active and belated management of non-western mothers, when compared to western mothers. A similar association was described by Essén (21).

The interaction may be improved by being taken care of by persons of their own country of origin or subgroup. This may lead to more cultural sensitive care, which have shown to reduce miscommunication, inherent racism, or medical decision-making that is unintentionally influenced by patient background. This has also proved to lead to more patient involvement in care, higher levels of patient satisfaction, and better health outcomes (76). Gennaro has pointed out the importance of development of a culturally competent health care delivery system (20). This means not only development of systems of care that are acceptable to and address specific health needs of minority populations, but also increasing the number of minority health care providers.

Gennaro has documented that minority women perceive that they are less likely to receive health-promoting messages during prenatal care (20). Health-care providers may provide – intentionally or unintentionally – biased care; not taking into account for and promote individual and community strengths. Differences in the provided care in this thesis may explain, in part, some of the disparities in pregnancy outcomes identified between the western and non-western women. Lack of experience in surveillance of non-western mothers may result in belated management when compared to western mothers. Developing culturally competent personnel is a challenge. A Danish study has demonstrated that health personnel with frequent contact with minority groups and health personnel with longer education seemed to more satisfied with the contacts with patients from minority groups (77). Establishing competence centre with expert competence in health promoting care during pregnancy may be an important initiative in order to improve quality of care for immigrant families.

Immigrants educated in different health care professions may be a great resource in this respect. As suggested by Hylland-Eriksen and Arntsen Sørheim, young immigrants should be stimulated to educate as health care providers at all levels. In addition, Hylland-Eriksen and Arntsen Sørheim discuss some problems that may arise in situations when health care providers and patient are of similar country of origin as the patient (66); some health care providers want to be

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available for all kinds of patients and not being specialists upon immigrants. If they belong to different groups as regards language, religion or social class, this may be a hindering for the interaction between health care provider and the patient. Therefore, in some situations it may be a hindering to be of the same country of origin. However, with these latter aspects in mind, use of immigrant health care providers may reduce communication and cultural barriers if patient and health care providers are of the same origin. Immigrant health providers could also be used as resources for native health care providers.

These aspects will not be concretised in this thesis, since the adjusted care necessarily have to be adjusted to the specific culture, and this to a great extent will differ between women of different origin. However, this thesis has documented lower education among the non-western mothers with stillborn children; these women had increased risk of sub-optimal care and communication problems. Communication and education seemed to be essential factors for improvements in general. These factors are to a certain degree linked to social class. The association between social class and educational level has an adverse effect upon pregnancy outcome (18;21;27;78;79). Education has been expected to result in better health outcomes, due to the assumption that educated women are more knowledgeable about how to promote a healthy pregnancy (20).

### **Acculturation**

Migration as a process is not completed by the arrival of an individual in a foreign place; it is a life-long process that affects all aspects of a migrant's existence. Migration also affects the following generations, as well as the lives of non-migrants and communities in both sending and receiving countries. For many immigrants there is a strong interchange and interconnection between the new and the old country and their cultural and social identity can belong to their country of origin for many years and generations after they arrived in the new country, like the Norwegian immigrants to the United States after emigration from Norway in the 1800th century. Immigrants may constitute minorities, sometimes partly or totally excluded from the mainstream society by socio-

economic disadvantage and discrimination. Acculturation is a concept that refers to the complete process occurring an individual or a group from a given culture is required to adapt and adjust to the cultural views, language, customs and traditions of the mainstream group (80). The process of incorporating characteristic ways of living from an unfamiliar culture may have both positive and adverse effects. A low level of acculturation is not necessarily leading to poor perinatal outcome (21). Essén has described the worse possible combination of risk habits on two levels of acculturation, for example adopting the smoking and drinking habits in the new culture, but not learning the language in the new country and not participating in the antenatal care program. Acculturation is not necessarily positive, and there ought to be a clearly defined aim to prevent the immigrants adopting the smoking habits that is described among Norwegian mothers in this thesis. However, acculturation should be stimulated by building up stronger bonding to the positive aspects in the culture in the new country. This may be fruitful in order to get a more adequate use of health services in the perinatal period.

Nøttveit has in a qualitative study of Pakistani women's experiences in encounter with Norwegian health care personnel in prenatal clinics. The respondents anticipated professional examination and information about their own health and the health of the fetus (67). Their experiences were that the focus was upon the fetus, rather on holistic care, which was emphasised as important for them. They described special needs of health-education related to marriage, pregnancy, birth and care of the newborn. Factors with restraining effect on the interaction between the client and the health care providers were described as use of the husband as an interpreter instead of a female, official interpreter, and care with main focus upon the instrumental aspects, not focus upon the pregnant women as a whole person. More health education and more use of interpreters were these women's most important needs (67).



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#### **6.1.4 Autopsy**

Autopsy rates were significantly lower among non-western than western mothers. It is essential both for patients and the health care professionals to determine the cause of death. Identification of possible explanations for the stillbirth can often relieve the parents and the health care professionals of blame and may identify disorders or conditions that may lead to specific preventive strategies in future pregnancies. Autopsy may also be a tool for quality control in medical care, since this procedure can illuminate and verify conditions prior to and related to the death. Autopsy is regarded as the best method of investigating stillbirths and neonatal deaths and “may be valuable in three ways: the confirmation of ante-mortem diagnoses; the identification of unexpected disorders; and exclusion of other (perhaps inheritable) conditions which might be have caused the intrauterine death”(81).

It is a family’s right to have the opportunity to give consent to an autopsy to be done. A critical review on the value of perinatal autopsies has been performed to see whether parents could be counselled regarding their main motive; to find the exact cause of the death (81). Their conclusions were that clinicians confidently can advise parents of the usefulness of the perinatal autopsy and that autopsy is a useful investigation. Autopsy rates have had a continuous decline in many countries in Europe. In UK, the Royal College of Pathologists and Royal College of Gynaecologists and Obstetricians has recommended a perinatal autopsy rate of at least 75% (82). These rates have not been achieved for any country (81). In the material behind this thesis, this goal almost was reached, with an autopsy rate of 72.1%, as mentioned in chapter 5, but with a significant lower rate among non-western immigrants, which probably could be increased.

There is a common assumption that non-western people do not want autopsy because of religious reasons. My experience from 10 years as a midwife with bereaved parents is that this perhaps may be a myth and that the parents from non-western countries may not be given adequate information about the importance of the autopsy and the techniques being used. Assumptions that the

parents don't want autopsy to be done, may imply that these parents may get another kind of information than western parents. If the parents are given adequate and empathic information, preferably by the health professional that has an established relationship with the parents, or the pathologist who is the one that is performing the autopsy, the parents may be willing to let their child being autopsied to a greater degree. PSANZ (Perinatal Society of Australia and New Zealand) has made information pamphlets for both bereaved parents and for health professionals (72). These guidelines emphasise giving the parents written information, in addition to the verbal information. The advices from PSANZ are detailed and with psychological and social aspects incorporated. The pamphlets for bereaved parents should be translated into actual languages in order to standardise the information for the parents.

## 6.2 Ethical considerations

### 6.2.1 Perinatal audit

Perinatal audit is a part of a continuous assessment of quality of health care services. The bereaved parents are not involved in these assessments and are not receiving any individual results of the assessments of the committees (30). This is clearly expressed in the guidelines for the Perinatal Committees. The assessments are though based upon case reports, and even if these were anonymised, some parents may feel that their case and their child have been assessed without being informed. This is a discussion for the work done in general by the Perinatal Committees, not especially for this thesis; and will not be further discussed here. The current thesis is a summary of results from an official initiated assessment as a product control study of the work in the Perinatal Committees. The study was approved by The Regional Committees for Medical Research Ethics and advised by the Personal Data Act of The Norwegian Data Inspectorate.

### **6.2.2 Categorising people**

This study focused upon immigrants. Some may disagree in making categories of people. Every person is a unique person and can be quite different from persons in the same ethnic population. There are great interpersonal differences, as well as there are great intrapersonal differences. There is no doubt about this, and the categorising process is done only to get an overview over a topic in search for systematic patterns of deviant events. Being in focus may be felt stigmatizing if you not feel welcome or if you are not included in a society; it may be an extra strain to be in a focus, even if it as a group and not as an individual. Used in a wrong way, it may be stigmatizing. It has been important in this thesis to prevent this. But, even if the results can mean a strain on the implied persons, the results cannot be “killed in silence” if the findings can improve life conditions for the care before and during a birth. It has been the intention to present the results with respect for all the persons being included.

## **6.3 Methodological considerations**

This chapter consists of considerations at different levels. Since the main part of this thesis was based on audit, this section starts with a discussion of the audit procedure in general, followed by some considerations about the validity of the data and the classification system, and at last some comments of the reliability for the audit procedure and the assessments in this thesis.

### **6.3.1 Audit procedure – strength and limitations**

Audit has a great strength as a method for quality assessment because of the continuous and systematic assessment of the circumstances and the care of all the deaths, done by a peer review group. Audit enables identification of unique aspects by comparisons to established guidelines; a method for quality improvements not used by any other formal organs. This creates possibilities for improvements at different levels of care.

There are, however, diverging opinions about the utility of perinatal audit. Some report effect in decreasing risk of perinatal mortality by improving practice of health care providers (83-85), while others claims that benefits have never been adequately evaluated (29;86). There are some problems and limitations with perinatal audit, which are presented in the following.

### **Lack of clinical implications**

There have been a lot of discussions in the professional milieus about protocols for reporting back to the Health Authorities and to the original institutions and the caregivers. Different routines exist in Norway for giving feedback to the care givers. National instructions on how this should be done have existed for several years. The instructions to the Perinatal Committees are to give feedback as annual reports with aggregated data and assessments. These reports should consist of practical implications and concrete suggestions for improvements; otherwise it is not possible to evaluate the value of the audit process.

### **Use of time**

Another possible negative aspect of audit is the use of the time. Collection of data and regular meetings when discussing the cases necessarily has to take some time. This has to be associated to difficulties by measuring effects of audit. In countries with low stillbirths rates, the ability to detect changes in order to further reduce mortality is severely limited. Lack of change might reflect the effect of the low mortality level rather than lack of the effect of audit and feedback.

### **Known outcome**

The Perinatal Committees evaluate the process when the outcome is known, as the end point for all cases to be assessed is stillbirth. This knowledge could have biased the assessors to focus on sub-optimal maternal factors, rather than inadequate medical care factors, resulting in an overestimation of the importance of such factors for potentially avoidable perinatal death, also described by Essén (21). The assessments are done retrospectively, and a retrospective view of results already known for the assessors is different from assessments done prospectively,

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where the situation may be complex and one out of many complex situations simultaneously. During recent years the hospitals have developed good routines for evaluating inappropriate events and births with poor outcome. Such routines involve meetings with health care professionals (and parents if wished) to discuss and evaluate difficult situations and if failures are identified, quality improvements are carried out.

Experiences from the Perinatal Committee in Oslo are that discussions and assessments during the meetings are characterized by emphasis on the complexity of the care situations, and the members of the committee trying to put them in the health care professional's situation and to assess which efforts seemed to be the most appropriate in the specific situation.

### **Small milieus**

The case reports are anonymised before audit, and it is not possible to identify the mothers. There are no link between the case reports and the manual register for all deaths. However, for the members of the committee, it may be possible to identify the cases and the involved personnel. The milieus are rather small and some cases are special and tragic. Sometimes it may be possible for the members to remember who was involved in the care situations, and sometimes a member of the committee has been involved in a direct or indirect way. The instructions for the Perinatal Committees says: "The Perinatal Committee and its members must assess own legal competence each individual case" (30) (my translation). My experience from the Perinatal Committee in Oslo is that the issue of legal competence does not represent a problem; the assessments seem to be done in an objective and unbiased way. In all assessments of the stillborn in this material there has been intern consensus between the members.

Perinatal audit is based upon information from the case reports. This may not give a complete description of the complexity in these situations. It is not possible to describe all what is said and done during a consultation, and this may be a lack in the audit process. However, there is no reason to believe that this aspect has affected the quality assessment in a systematic way.

Although perinatal audit has some limitations, it seems to be fruitful to have an ongoing peer review for systematic assessment of all the deaths in a region. It affords opportunities to learn from mistakes, if the audit results and suggestions for improvement are presented at a précis and concrete level. This is important to have in mind when evaluation of the utility of the Perinatal Committees is performed. Additionally, the annual reports for aggregated summaries and the meetings arranged for professionals; with relevant themes according to the areas for quality improvements, seem important.

### **6.3.2 Validity**

There are possible sources of systematic errors that may influence the accuracy of the results presented here. Do the assessments represent valid information of the care to the pregnant women in this period? Health care consists of both quantitative and qualitative dimensions. It is difficult to quantify qualitative care and the non-verbal parts of the important communication between involved persons. Therefore, conclusions have to be interpreted with care. This chapter is a discussion of some elements to be considered when interpreting the results.

Stillbirths are fortunately rare events in Norway and therefore from a statistical point of view, the number of cases was low. Some of the groups consist of a small number of cases, and this could have affected these results, for example as regarded causes of death and ante- and intrapartum rates of stillbirths.

#### **Selection bias**

Selection bias is present when the study population is not representative for the population in focus. For this thesis, it could be proclaimed that the stillborn cases were complete with almost 100% ascertainness. The cases are regularly identified and double checked in the databases and birth protocols in a way that no cases are missing. The same could be said about the data from both the Medical Birth Registry of Norway and the Statistics Norway.

However, it could be disputed whether the non-western population were representative of the population of their country origin; they could possibly

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represent a selected group with regard to reproductive health and complications. The immigrants may represent the poorest part from the origin country, or they may represent a relatively healthy group, who had been able to emigrate. The poorest and most underprivileged part of the origin population may not be able to move to a different country. Some immigrants may be refugees, and may represent a group that have experienced physical or psychological trauma. Interpretation of the results may be done on the basis that selected groups of people from their home countries were compared to the total Norwegian population. Therefore, any generalizations should be done with some reservation.

### **Guidelines as a quality indicator**

Quality of care was defined as a divergence between optimal care and the performed care (87). In this thesis, guidelines have been used as quality indicators, like the procedure is in the assessments of the Perinatal Committees. Recommendations in the guidelines are relatively broad. There is no consensus on definitions for the most actual clinical situations; like prolonged labor, fetal distress, fetal movement pattern or language skills. Lack of established evidence based criterions and agreed definitions for the most actual clinical situations, may weaken the validity of the findings. There is, however, no reason to believe that this has affected the results differently between the groups. Existence of such criterions and agreed definitions would have strengthened the validity of the audit and made national and international comparisons possible. Perinatal audit could probably gain in validity of such were developed.

### **Medical records**

Medical records are supposed to give a complete description of a mother's background and present situation. The information is given on a voluntarily basis. There are a lot of different preformed records for antenatal and obstetric care. The only record that is official and standardised is the preformed antenatal record (Appendix 1). The other schemes and preformed records differ between the hospitals. This is not optimal, but was not regarded giving bias in data collection.

There were possibilities for biases in this registration, because of an explicit question about these issues were missing in these preformed schemes. However, at two hospitals that recruited a great number of stillbirths in this material, there are explicit questions in the preformed schemes about anamnestic information and mothers' status. These schemes have a specific question about the need of interpreter, with boxes for "yes" or "no" to be ticked off. Some of the identified sub-optimal care may be linked to failure in documentation; especially as regarded in assessments of language problems. There is a possibility that interpreter had been used, but that these situations are so common that it was not documented. This may be the situation in the antenatal care, but my experience have told me that this almost always have been documented in the case reports from the hospital stay; the women's need of interpreter, language skills, and communication problems *have been* documented in the antenatal and medical records and that it was possible to get an almost complete description of these processes.

In cases with communication problems and difficulties in the communication process, information may be incomplete. Especially among the immigrant women, lack of information about life-style, smoking, and anxiety or non-well-being of different kinds, may have resulted in an underestimation of the odds ration for sub-optimal self-care among the non-western women. Smoking has been described underreported (51), this may affected the validity of the data in this thesis.

### **Compliance to the use of the preformed records**

A problem documented by Backe, is compliance to the use of the preformed records (88). He identified deficient performance of antenatal care providers as regards filling out the preformed records. This was also documented in the current study. The preformed records consist of rubrics to be filled in different ways; some questions are to be filled in only if the answer is positive, while others should be filled for both positive and negative outcomes. These schemes are the only schemes that give systematic information about the mothers. Through the



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data collection for this study, lacks of compliance with the antenatal records were registered in 202 cases (58.3%), according to that 18 of the preformed antenatal journals were not possible to retrieve for the audit panel (in almost all cases the antenatal journal were documented being present at the time the mothers were hospitalised). This may have weakened the results in this study. Cases where information has been missing have been excluded from analyses, which have implied that the number of cases has been different between some analyses. This has been remarked where it was relevant. An impression from clinical practice is that antenatal schemes from women where communication problems exist contain less information than schemes from women where the communication is adequate. This may have reduced the documentation of symptoms and signs among some non-western women. The possible underreporting of signs from the non-western women may have lead to a lack of documentation here, but there is a reason to believe that the severe and significant signs are documented also among these women. This possible lack may have affected the results, but if the documentation has been optimal for both groups, there is a reason to believe that the results would have been worse, not better.

Are the data good enough to illuminate the mother's situation and to identify needs for observation, supervision and intervention when needed? A possible weak point by using medical records could be that only written information about the mothers is used, and the fact this information has to be written in short terms on a small place. The most health care providers are informed about the use of the schemes and to use continuation sheets if needed. These schemes are used when needed, but the main style is short comments in key words. There may be a lot of non-verbal information and conservation that is not possible to describe within these frames, but it is a reason to believe that the main things are noted. Possible underreporting of maternal smoking among western mothers and of communication difficulties among the immigrants indicates that the risk of sub-optimal care due to communication problems among the immigrants is a minimum estimation.

### **Classification of causes of death**

As mentioned in chapter 4, the Perinatal Committees use a very simple classification system, a system which is recommended by the Norwegian health authorities by the circular that regulate the committees work (30). In clinical situations, stillbirths are classified after WHO's International Classifications of Diseases, version 10 (ICD-10), but in publications of results from quality assessments, there has been a need for a simpler classifying system than the detailed ICD-10. Differences in the distribution of causes form year to year and between regions may be difficult to identify if the classification system is too detailed. In this thesis the causes of deaths were classified in wide groups, which make the classification of the causes of deaths simpler. Uncertainties about causes of the deaths in this material were non-existent.

In the classifications where the assessments were dichotomised in the summary, this was taken into consideration, with a relatively high level of the definition of sub-optimality (chapter 4.2.1). This was done in order to increase the registration reliability if there have been differences in the assessments of the care.

### **6.3.3 Reliability**

The data in this thesis consists of audit results from two different Perinatal Committees. There are common guidelines for the committees. During the registration period of six years, the leaders and some members of the committees changed. In spite of the common guidelines, different cultures and traditions between these two committees may have been established, and it is a theoretical possibility for differences in assessments between these committees, especially as regards classification of the care. There have been broad discussions in the cases where necessary, but panel consensus was reached for each case. Since the panels were peer review groups, there is a reason to believe that these assessments are reliable. The reliability of the assessments of the care is further strengthened by the fact that several of the committee members are colleagues; employed at the same hospitals with common guidelines and culture.

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The total sample of births in the period was large, but the sample of stillbirths was relatively small. However, all stillbirths were included, and there was no opportunity to increase the precision of the results by enlarging the sample size.

Perinatal audit is a continuous process done by experienced clinicians. In spite of these remarks, there was a reason to believe that the assessments and the results can represent a true description of the perinatal care in this region during these years.

## 6.4 Future research

The process of this current thesis has illuminated several areas where further research is both important and necessary. These areas are at different levels and of qualitative and quantitative character. Only themes for research are presented in the following; first elements that involve the audit process, and then elements that regard the health behaviour and communication aspects.

### **Evaluation of the audit procedure**

Bergsjø et al has made a review over experiences with 20 year of audit in Norway (52). This article recommends testing the benefit of perinatal audit by comparing areas using audit with areas not using a systematic audit. The results of the current thesis support this recommendation.

### **Classification of causes of death**

De Galan-Roosen et al writes: “The goal of a classification system for registration of perinatal death should be to give as much insight as possible in the underlying cause of death in order to know if and which preventive measures can be used for reducing perinatal mortality in the future”(89). Their conclusion was that if classification was based upon underlying causes, it could reveal areas for quality improvements in antenatal care. Indications about underlying factors are lacking in the classification system currently used by the Perinatal Committees. The current system and these causes of deaths classification have rubrics for describing “unavailable factors” and “suggestions for improvement”, but no

rubrics for possible underlying factors. There is a need for a better classification system of the causes of stillbirths that includes underlying causes.

### **Health behaviour – effect upon adverse perinatal outcome**

Gennaro has made an overview of current state of research on pregnancy outcome in minority populations (20). This article illuminated lack of research of the different types of health educations effect upon change of behaviour in pregnant women. Changing health behaviour has a potential for large payoffs in the improvement of the health, but research is needed to indicate in which direction and in which ways this may be optimal, for example to changing attitudes to consanguinity and to attitudes upon risky life style. There is a need to look at how best to deliver parent education programmes to meet those groups with specialised needs; like immigrant women and teenage mothers.

### **Assess the effect of poor communication on outcome**

How will improved language skills influence the pregnancy outcome? It is a reason to believe that there in the future will be an increased rate of second-generation immigrant mothers in Oslo and Akershus. For these women, language problems probably will be eliminated. An interesting question will be if the perinatal outcomes for the second-generation immigrants will differ from the first generation immigrants. These aspects have to be illuminated within broad spectres of factors; like social and economic status, nutritional and genetic aspects. There are a lot of confounders here, and it may be difficult to proclaim single components as causes for death, but a focus upon the increased mortality rates among non-western women would be essential, also when a greater part of the pregnant women are second-generation immigrants.

### **Effect of implementation of the new guidelines for antenatal care**

The Municipal Regular GP Scheme has changed the organization of the antenatal care, as mentioned in chapter 2.1. In the professional milieus, there are ongoing discussions in what way this has affected the quality of the antenatal care. Reduced continuity is a possible negative effect, which could especially affect the

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immigrant women. The new guidelines for Norwegian antenatal care was published in may 2005. These guidelines recommend a reduced number of standard controls during healthy pregnancies. The effects of these changes have to be analysed in order to illuminate any changes related to the results in this thesis; like changes in the rates of sub-optimal care in all aspects included in this thesis. Evaluation programmes should automatically follow changes in the organisation of the health care systems.

## 7. Conclusions

The scientific question for this thesis was whether non-western immigrant mothers were more likely to have sub-optimal care when compared to western mothers. Sub-optimal care was identified *totally* in 126 of 341 stillbirths (37.0%); 51.5% of the non-western versus 30.7% of the non-western mothers. Non-western women had more than twice risk of sub-optimal care when compared to western mothers, OR=2.4 (95% CI 1.5-3.9).

Sub-optimal care *from the health care providers* was identified in 99 of 349 the stillbirths (28.4%). With regard to the care received from health care providers, there was no significant difference between women of western or non-western origin, OR=1.2 (95% CI 0.7-2.0).

With regard to *self-care* and *miscommunication*, non-western immigrants had more than twice increased risk of sub-optimal care than compared to western women, OR=2.4 (95% CI 1.5-3.9).

There remain significant areas for improved care in the prevention of stillbirths. Important examples are detection and management of growth restriction and reduced fetal movements in antenatal care, and communication both within health care and with pregnant women. Non-western women are an important risk population, in part of a higher prevalence of known risk factors, like lower education and the language competence of the mothers. Efforts to reduce language barriers, better identification and management of growth restriction and rapid intervention in complicated vaginal births seems warranted to improve perinatal care among non-western women. There is a need for increased vigilance in women from non-western origin.

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## **Appendix**

**Appendix 1:** Preformed scheme for antenatal care (“Helsekort for gravide”)

**Appendix 2:** Structured enquiry form for perinatal audit (“Registreringskjema for perinatalkomiteenes vurderinger”)





## Appendix 2: Structured enquiry form for perinatal audit ("Registreringskjema for perinataalkomiteenes vurderinger")

### PERINATALKOMITEENS VURDERING - KONKLUSJON

Peri-/ Neonatalt dødsfall år:    More fødselsdato:    Bosted kom.:

Sivilstand : gift  , ugift  , samboer  Paritet: \_\_\_\_\_ Termin: Naegle  Ultralyd

Røyking ved første svangerskapskontroll: Ja  Nei  Ved avslutning av svangerskapet: Ja  Nei

Fødsel:	Dag	Mnd.	Time	Min.	Svangerskapsalder ved fødsel i uker: _____
Fostervanssavgang					Hvis dødfødt: Fosterlyd ved innkomst: Ja <input type="checkbox"/> Nei <input type="checkbox"/> Døde før fødsel begynte Ja <input type="checkbox"/> Nei <input type="checkbox"/> Døde under fødsel Ja <input type="checkbox"/> Nei <input type="checkbox"/> Dødssted: Fødselavdeling <input type="checkbox"/> Barselavdeling <input type="checkbox"/> Barneavdeling <input type="checkbox"/> Annet sted _____
Innleggelse i fødselavdeling					
Intrauterin død					
Fødselstidspunkt					
Transport til barneavdeling startet					
Innleggelse i barneavdeling					
Neonatal død					

Pluralitet: Enkel   
Flerling nr

Kjønn: Gutt   
Jente   
Usikkert

Kroppsmål: Vekt \_\_\_\_\_ gram  
Hodeomkrets \_\_\_\_\_ cm  
Lengde \_\_\_\_\_ cm  
Apgar-score: 1 min: \_\_\_\_\_ 5 min: \_\_\_\_\_ 10 min: \_\_\_\_\_

Obstetriske diagnoser (ICD-10):

Neonatale diagnoser (ICD-10)

Placenta vekt: \_\_\_\_\_ gram Pat. anat. undersøkt: Ja  Nei  Funn: \_\_\_\_\_

Obduksjon: Ja  Nei  Pat. anat. diagn. v/obduksjon: \_\_\_\_\_

Dødsårsak: IA: \_\_\_\_\_  
IB: \_\_\_\_\_  
IC: \_\_\_\_\_  
IIC: \_\_\_\_\_

Merknader:

#### Perinataalkomiteens vurdering:

	Ja	Nei	Tvill	Manglende opplysning
Avvik i omsorg				
Egenomsorg				
Svangerskapsomsorg				
Transport til fødselavdeling				
Fødselshjelp				
Neonatal behandling på fødselavdeling				
Neonatal behandling på barneavdeling				
Transport til barneavdeling				
Kommunikasjon innen helsevesen				

Begrunnelse: Unngåelige faktorer \_\_\_\_\_

Forslag til forbedring \_\_\_\_\_

Årsak: Misdannelse  Isoimmunisering  Preeklampsi  Antepartum blødning   
Mekanisk årsak  Maternell sykdom  Placenta dysfunksjon  Infeksjon   
Uforklarlig  Ikke klassifiserbar  Andre