Maternal Mortality in Sweden

Classification, Country of Birth, and Quality of Care

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Abstract

After decades of decrease, maternal mortality rates have shown a slight increase in Europe. Immigrants, especially Africans, have shown to be at higher risk than native women. This could not be explained solely by well-known obstetric and socio-economic risk factors. The aim of this thesis was to study incidence, classification and quality of care of maternal deaths in Sweden, with focus on the foreign-born population. The study population was identified through linkage of the Cause of Death Register, Medical Birth Register, and National Patient Register, and medical records obtained from hospitals. Data from registers, death certificates, and medical records were reviewed. Suboptimal care was studied by structured implicit review of medical records. Differences between foreign- and Swedish-born women were analysed by relative risks, Chi²- and Fisher’s exact test.

Underreporting of maternal mortality was shown to be substantial: as compared to the official statistics, 64% more maternal deaths were identified. Women born in low-income countries were identified as being at highest risk of dying during reproductive age in Sweden. The relative risk of dying from diseases related to pregnancy was 6.6 (95% confidence interval 2.6–16.5) for women born in low-income countries, as compared to Swedish-born women. Major and minor suboptimal factors related to care-seeking, accessibility, and quality of care were found to be associated with a majority of maternal deaths and significantly more often to foreign-born women. Suboptimal factors identified included non-compliance, communication barriers, and inadequate care. The rate of suicides during pregnancy or within one year after delivery did not change during the last three decades, and was higher for foreign-born women. A majority of women who committed suicide had been under psychiatric care, but such documentation at antenatal care was inconsistent, and planning for follow-up postpartum was generally lacking.

The conclusion of this thesis is that foreign-born women are a high-risk group for maternal death and morbidity that calls for clinical awareness with respect to their somatic and psychiatric history, care-seeking behaviour, and communication barriers. Cross-disciplinary care is necessary, both in obstetric emergencies and in cases of maternal psychiatric illness, to avert maternal death and suicide.

Keywords: underreporting, foreign-born, immigrants, low-income countries, suboptimal care, audit, suicide, reproductive age, maternal death, maternal care

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Ur Berömda män som varit i Sunne, av Göran Tunström

To my family
List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


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Cover: *Self-Portrait on Her 6th Wedding Anniversary*, by Paula Modersohn-Becker (1876-1907). The artist died of a lung embolus at the age of 31, eighteen days after giving birth to her first child. Hence she represents a maternal death. Reprint made with permission from Museen Böttcherstraße, Paula Modersohn-Becker Museum, Bremen.
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# Abbreviations

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<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired immune deficiency syndrome</td>
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<tr>
<td>BMI</td>
<td>Body mass index</td>
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<tr>
<td>CDR</td>
<td>Cause of death register</td>
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<tr>
<td>CI</td>
<td>Confidence interval</td>
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<td>CMACE</td>
<td>Centre for Maternal and Child Enquiries, since 2010: MBRRACE-UK (Mothers and Babies—Reducing Risk through Audits and Confidential Enquiries across the UK)</td>
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<tr>
<td>GNI</td>
<td>Gross national income</td>
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<td>EPDS</td>
<td>Edinburgh postnatal depression scale</td>
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<td>HIC</td>
<td>High-income country</td>
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<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<tr>
<td>ICD</td>
<td>International Statistical Classification of Diseases and Related Health Problems</td>
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<td>LIC</td>
<td>Low-income country</td>
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<td>MBR</td>
<td>Medical birth register</td>
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<tr>
<td>MIC</td>
<td>Middle-income country</td>
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<tr>
<td>MMR</td>
<td>Maternal mortality ratio</td>
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<tr>
<td>NFOG</td>
<td>Nordic Federation of Societies of Obstetrics and Gynaecology</td>
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<tr>
<td>NPR</td>
<td>National patient register</td>
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<tr>
<td>OR</td>
<td>Odds ratio</td>
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<tr>
<td>RR</td>
<td>Relative risk</td>
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<tr>
<td>SFOG</td>
<td>Svensk Förening för Obstetrik och Gynekologi, Swedish Society of Obstetrics and Gynaecology</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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Fortunately, a maternal death is a rare event in Sweden. A majority of Swedish doctors and midwives will not experience more than perhaps one single case during their entire professional life, if any. Those who have been involved in the care of a maternal death are usually deeply affected and will remember the sequence of events in great detail; they sometimes ruminate on their own role and feel part of the responsibility for years. They will also carry with them thoughts and concerns about the deceased woman’s family. Although I was not involved in these events, I will always carry with me the painful fates of the women whose histories I had the opportunity to gain insight into, and I feel a responsibility to ensure that we learn something from their deaths.

During my work with this research project I have met with a genuine interest in my research topic; from colleagues and other professionals working with maternal care, and also from lay people, family and friends. A number of colleagues have shared their personal experiences from events of maternal death that may have happened many years ago, and they have all contributed to my knowledge and understanding.

In low-income settings around the world, maternal deaths are still a part of everyday life. Despite a continued reduction in maternal death rates, the unimaginable number of between 700 and 800 maternal deaths occur globally every day, and the majority of these are due to causes that could have been avoided.

Women are not dying because of diseases we cannot treat. They are dying because societies have yet to make the decision that their lives are worth saving (1).

Professor Mahmoud Fathalla’s historical quote is, unfortunately, still valid. However, in Sweden our society took the decision early on that women’s lives are worth saving, resulting in an extraordinary decline in maternal mortality before labour wards, blood transfusions and antibiotics were available. Anna, my great-great-grandmother could not be saved, but luckily her daughter Ellen survived until the age of 92, and died when I was five years old. They are both a part of my history, but that is another story.
Introduction

Maternal mortality globally and in Sweden

Globally, maternal survival has improved substantially, with an annual maternal mortality decline of 1.9% reported between 1990 and 2011 (2). Although the progress on reducing maternal mortality in most countries is accelerating, between 700 and 800 maternal deaths occur globally every day. The fifth Millennium Development Goal (MDG 5), as determined by the World Health Organization (WHO), to reduce maternal mortality ratio by three-quarters between 1990 and 2015, seems to be one of those most difficult to achieve (2). The deaths continue to be concentrated in sub-Saharan African and South Asian countries, where the lifetime risk is 100 times higher for a mother to die of pregnancy-related causes than that of a woman from a high-income country (HIC) (2). The consequences of a maternal death are usually disastrous for the whole family (3), and maternal death is often additionally associated with death of the child. Obstetric complications, particularly in labour, are closely linked to stillbirth and neonatal death (4, 5). Furthermore, after the death of a mother, the children continue to be at higher risk of dying after the neonatal period, due to the absence of appropriate childcare and nutrition (3). Globally, a substantial number of women die as a result of the consequences of unwanted pregnancies, such as unsafe abortions. Satisfying the unmet need for family planning methods could be estimated to avert one-fourth of all maternal deaths yearly, by preventing unwanted pregnancies and spacing childbirth (6). For women who do not have access to family planning or when abortion is illegal, suicide may be the last resort. Unwanted pregnancy may be the principle cause of suicide in women from less well-off social conditions (7, 8). Furthermore, women die as a result of suicide associated with mental disorders, during pregnancy and after delivery, although no global estimates for the rate of suicides related to pregnancy are available.

Although 99% of maternal deaths occur in low-income countries (LIC) (9), young women still die in HICs due to complications of pregnancy and childbirth. Despite the fact that the absolute number is small, the death of a young mother or a pregnant woman is amongst the most tragic to encounter. Maternal deaths decreased in Europe up to the 1980s (10-15), but data from several European countries and the U.S. have lately indicated slightly
increasing maternal mortality rates (9, 16-20). In part, these changes are due to improved data assessment. However, demographic changes, such as increased maternal age and migration, might contribute to this rise (14-16, 18, 19, 21-23). Immigrants, especially women from sub-Saharan Africa, have shown, in several European countries, to be at higher risk of maternal death than native-born women (14, 18, 21-29). It has not always been straightforward to establish the causal relations between these data by adjusting for obstetric or well-known social risk factors. In Europe, we see increasing proportions of older and obese parturients, that is, women who are known to be at higher risk of obstetric complications (16, 17, 30). Furthermore, medical advances in the areas of assisted reproductive technology, cancer treatment, and congenital heart diseases, enable new groups of women to give birth, although their pregnancies and deliveries may be more complicated. Simultaneously, changes in obstetric practices do not always improve the maternal outcome. One such example is increasing caesarean section rates, which may increase the risk for the mother (19, 31).

In Sweden, maternal care was expanded during the 18th and 19th centuries. Foundations for this development were the priority of Swedish society as was the ambition of equal care for all, irrespective of domicile. The science of obstetrics was instituted as an academic discipline, and the implementation of national coverage of trained community midwives attending home deliveries was complete in the late 19th century. The introduction of aseptic techniques and task-shifting along with transfer of knowledge to the midwives, and team-work between province physicians and midwives all having complementary roles, were operative factors for the reduction of maternal mortality in Sweden over the same period (11, 32, 33). During the first decades of the 20th century the maternal mortality rate increased due to illegal unsafe abortions, but between 1930 and 1980 the steep decline in maternal mortality was one of the most impressive health achievements in the industrialised world. This success was made possible by improvements in maternal care, such as improved eclampsia treatment and safer caesarean sections, and by the introduction of antibiotics and safe blood transfusions. Furthermore, there was a demographic shift, with a smaller proportion of parturients of advanced age, poverty reduction, and general public health improvements (33, 34).

Definitions of maternal mortality

The WHO defines maternal death in its International Statistical Classification of Diseases and Related Health Problems Versions 9 and 10 (ICD-9 and ICD-10) (35) as the death of a woman while pregnant or within 42 days (that is, days 0-41) of termination of pregnancy – irrespective of the
duration and site of the pregnancy – from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes. This definition allows the identification of maternal deaths, based on their causes, as either direct or indirect. Direct obstetric deaths are those resulting from: obstetric complications (pregnancy, delivery, and postpartum); interventions, omissions, or incorrect treatment; or a chain of events resulting from any of the above. Indirect obstetric deaths are those resulting from pre-existing disease, or diseases that developed during pregnancy but were not due to direct obstetric causes, although they may have been aggravated by the physiological effects of pregnancy. Deaths due to haemorrhage, puerperal sepsis, or complications of anaesthesia, are examples of direct obstetric deaths; whereas deaths from epilepsy or aggravation of an existing cardiac disease are classified as indirect.

ICD-10 has been in use in Sweden since 1997, preceded from 1987 to 1996 by ICD-9. The concept of late maternal death was included in ICD-10 in order to capture deaths from pregnancy-related events that occur between six weeks and one year postpartum (36). A complication occurring during pregnancy can lead to death more than 42 days later, and increasingly available modern life-sustaining procedures and technologies enable more women to survive beyond this period. For the purpose of the international reporting of maternal mortality, only those maternal deaths occurring before the end of the 42-day period are included. However, the recording of late deaths is useful for national analytical purposes. The WHO definition of maternal mortality ratio (MMR) is the number of direct and indirect maternal deaths per 100,000 live births. It is important to note that MMR is a ratio, and not a measure of incidence, with the denominator of live births, a figure which is easy to count and therefore facilitates comparisons of statistics. In the UK the number of maternities, defined as a live birth at any point during gestation or stillbirths occurring at or after 24 weeks of complete gestation (25), is used as denominator.

Pregnancy-related mortality involves those deaths occurring during pregnancy or within 42 days after the end of pregnancy, irrespective of cause of death. This definition was introduced in ICD-10 to facilitate the identification of maternal deaths under circumstances in which cause of death attribution is inadequate. Fortuitous deaths are defined as death caused by unrelated causes which happened to occur during pregnancy or the puerperium. As with the reporting method of the UK Centre for Maternal and Child Enquiries (CMACE), we prefer to use the term ‘coincidental’ instead of ‘fortuitous’, since the term ‘coincidental’ is a more accurate description of the circumstance and the term fortuitous could imply that these events are ‘lucky’ (25).
Suicides are not included in the current ICD definition of maternal death, in contrast to both the UK Confidential Enquiry reports (25) and a proposal for coming ICD classification by the WHO Working Group on Maternal Mortality and Morbidity Classifications (37). Cancers, accidents, and homicides are classified as coincidental deaths, although the UK reports classify hormone-dependent cancers as indirect maternal deaths, and homicides as direct, indirect, or coincidental, depending on the individual circumstances (25). In addition to the ICD definitions, the U.S. Centers for Disease Control and Prevention and the American Congress of Obstetricians and Gynecologists coined the concept of ‘pregnancy-associated deaths’ in the late 1980s, including any death of a woman while pregnant or within one year of the end of pregnancy and irrespective of the cause of death (38, 39). This definition should not be confused with the ICD-definition of ‘pregnancy-related death’, and is avoided in this thesis.

Surveillance of maternal mortality

The necessity of recording the number and causes of death is not disputed. Mortality rates are widely used to monitor the health of a population and are essential in identifying groups at risk as well as problems within the health care system (40, 41). Accurate surveillance of maternal deaths may therefore lead to changes in patient care (25). Underreporting of maternal mortality appears to be substantial, even in HICs (27, 38, 42-44), including Sweden (13, 45, 46). Inadequate statistics not only impede the possibility of determining trends, but also affect inter-country comparisons of maternal mortality rates (43, 47).

In recent years, the rate of maternal near-miss, or severe maternal mortality, has been more commonly used and is considered to be the best quality indicator for maternity care (25, 41, 48). Maternal near-miss is defined as ‘a woman who almost died but survived a complication that occurred during pregnancy, delivery or within 42 days of termination of pregnancy’ (49). The advantage of studying near-miss in settings with low maternal mortality rates is that a much larger number of women suffer from near-miss morbidity than maternal death, which gives increasing power for studies to investigate the risk factors for the occurrence of disease and progression to death (49, 50). A recent Swedish study found a frequency of 2.9 maternal near-miss cases per 1000 deliveries (50). Moreover, investigating incidence of near-miss provides opportunities to interview the affected woman and her family about the event to broaden the understanding of factors that contribute to maternal morbidity (51, 52). However, surveillance of maternal near-miss should be seen as a complement to, and not a replacement of, surveillance of maternal deaths. This is because the same diseases and complications that cause
maternal life-threatening conditions do not necessarily cause maternal death (53-55).

In Sweden, national vital statistics have been available since 1749, before they were available in any other European country (33, 56). Swedish cause of death statistics are based on information given on the death certificate completed by the attending physician. The first part includes information about the death, and the second part is the cause-of-death certificate. The thoroughness of the cause-of-death investigation varies greatly, from a medical history gained from speaking to the relatives of the deceased, to a full forensic investigation involving a review of the full medical history and medical records, a comprehensive autopsy and toxicological examinations. Consequently, the reliability of the diagnosis varies with the thoroughness of the investigations that are carried out while the patient was still alive and those performed on the body of the deceased (56). The autopsy rate has declined in Sweden since the 1970s, and is lower for women than for men (57). High autopsy rates usually contribute to better data quality (56).

According to Swedish law, in cases of sudden, unexpected death, if the death is or may be suspected to have been caused by external cause – including errors and omissions in the health care, or if no pre-existing diseases can explain the death – then the criteria for a forensic post-mortem examination are fulfilled (58, 59). In such cases the police must be contacted and take the decision about whether a forensic investigation will be performed.

The National Board of Health and Welfare (Socialstyrelsen) is responsible for assigning ICD-codes to the diagnoses on the cause-of-death certificates as defined according to coding rules of the WHO (35). One underlying cause of death is identified and defined as the disease or injury that initiated the pathological chain resulting in death; or the circumstances surrounding the accident or act of violence that caused a lethal injury. Other relevant diagnoses are assigned as contributory causes of death. Underlying and contributory causes of death are recorded in the Cause of Death register (CDR), a record maintained by the National Board of Health and Welfare. This register includes all residents, whether or not the person in question was a citizen or was present in Sweden at the time of death. However, undocumented migrants and those who died while seeking asylum or visiting Sweden are not included.

Sweden’s official statistics on maternal mortality, reported to the WHO by the National Board of Health and Welfare, are based on the underlying cause of death. Thus, only deaths with an underlying cause of death identified in ICD-9 chapter XI (codes 630-676) or ICD-10 chapter XV (codes O00-O99) are reported as maternal deaths. The thought behind this policy is to capture deaths directly associated with a pregnancy, whereas death caused by an
aggravated pre-existing condition will be assigned the same code as the primary disease. For example, when a woman dies from an intrapartum myocardial infarction, the underlying cause of death will most likely be coded as cardiac disease (ICD chapter IX), and the pregnancy as a contributing cause of death. She will not be reported as a maternal death, although the definition of a maternal death clearly embraces this indirect death.

Internationally, different methods have been used to overcome the problem of underreporting maternal mortality. In a recent WHO report, an adjustment factor of 1.5 is applied to account for the misclassification of maternal deaths in countries with a civil registration characterised as complete, with good attribution of cause of death (9). This adjustment factor is the median of underreporting of maternal deaths in civil registration based on available studies. Early pregnancy deaths, deaths in later postpartum period, deaths at extremes of maternal age (youngest and oldest), and indirect deaths caused by miscoded cerebro- and cardiovascular diseases are the most common cases not reported as maternal death (43, 60, 61). The benefits of routine linkage of births and deaths registers have been shown to be useful in several studies (42, 44, 46, 60, 62), and this practice has been implemented in Denmark. Confidential enquiries are systematic multi-disciplinary anonymous investigations of maternal death which identify the numbers, causes and avoidable or remediable factors associated with them (41). In several countries, confidential enquiries have been able to identify more maternal deaths than the civil registration (21, 27, 43, 62).

Counting maternal deaths alone does not save lives, and, in contexts with small numbers of maternal deaths, it is not always possible to demonstrate statistically significant changes and draw conclusions from maternal death rates. The UK Confidential Enquiries began in England and Wales more than 50 years ago (25), and have since thoroughly reviewed each maternal death case, audited suboptimal factors, created hypotheses, shown trend lines, and made recommendations to improve maternal health. In their latest report, which has been disseminated internationally, the dramatic decrease in thromboembolic deaths is ascribed to recommendations made from earlier reports (22, 25). Confidential enquiries is an approach for reducing maternal mortality assessed by WHO to be the methodology that has the potential to make the greatest impact on the largest number of women’s lives (41). However, national enquiries have been criticised for the limited evidence as to the impact their recommendations have had on improving the safety of health care, and the high costs for running them (63). Nevertheless, the UK Confidential Enquiries serve as the gold standard for other national groups performing confidential enquiries into maternal death (21, 28, 62, 64, 65). The Swedish Society of Obstetrics and Gynaecology (SFOG) Maternal
Mortality Group was formed in 2007, and has thus far assessed between five and seven deaths yearly, reported from obstetrics and gynaecology departments, but a routine linkage system of registers is not yet in place. The Nordic Federation of Societies of Obstetrics and Gynaecology (NFOG) maternal mortality collaboration (Sweden, Denmark, Finland, Iceland, and Norway) was established in 2011, increasing the possibilities of following trends in a population with almost 300 000 live births per year (66).

Reproductive health among immigrants

As most European societies are today, Sweden is a country with many minority groups. Sweden’s 1.5 million foreign-born residents constitute 15% of its population (67). Following the labour immigration of the 1950s and 1960s, new waves of refugees from conflict zones in both European and non-European countries began to arrive (68, 69). The official Swedish definition of an immigrant is a person who was born in one country and has migrated to Sweden, irrespective of age or cause of migration (70). The ethnic background of immigrants could also be defined by country of birth of the parents (71), nationality (28, 72), or self-selected ethnic group or race. The latter is commonly used in studies from the U.S. (19, 73) and UK (25). In Sweden, persons of foreign background are defined as those who were born in Sweden, but who have either one or both parents who were born abroad (70).

Substantial inequalities in mortality between ethnic groups have been reported from several countries (74, 75). The mortality risk of immigrant populations may be higher or lower than the native population, and can vary greatly by cause of death, cause of migration, origin, sex, and age (69, 76-80). As do all people, migrants carry with them ‘footprints’ of the genetic, socioeconomic and cultural environments of their countries of origin (69, 81), although some studies suggest that socioeconomic position and social network in Sweden may be even more important for health and health care utilisation (82, 83). The self-rated psychiatric and somatic health is lower among immigrants than Swedish-born women (84). Those coming from LICs may bring with them diseases common in their countries of origin, such as rheumatic heart disease (85, 86), anaemia (87), vitamin D deficiency (88, 89), and infectious diseases (90-92), disparate from what is usually seen in Swedish women today.

Women who have migrated from LICs to Europe are reported to be at higher risk for maternal adverse outcomes as compared to native women. A recent meta-analysis of the level of risk for immigrants to suffer a maternal death in Western Europe was doubled as compared to native-born women (29). Over
the last decade the Confidential Enquiries in the UK have consistently shown that maternal deaths are more common among ‘Black’ African mothers, including women from LIC settings in sub-Saharan Africa, are significantly more prevalent and have more frequently resulted from direct deaths when compared to ‘White’ British-born women (22, 25). Increased maternal mortality rates were found in the Netherlands for women born in sub-Saharan Africa or Asia, with an odds ratio (OR) of 3.3 (95% CI 2.3–4.8) reported between 1996 and 2005 (18). In France the MMR for women with a sub-Saharan African nationality had an OR of 23.6 (95% CI 15.4–34.6) as compared to French women during the years 2003 to 2007 (28), while in Spain, they assessed a relative risk (RR) of 1.67 (95% CI 1.22–2.33) for all foreign-born women as compared to Spanish-born women in 1999 to 2006 (23). In Switzerland, the corresponding OR was 2.76 (95% CI 1.58–4.8) (27). Furthermore, several Scandinavian studies report higher perinatal deaths amongst immigrant women than in native women (76, 93-98). Severe maternal morbidity has also shown to be more common among immigrant women in HICs (50, 54, 55).

The care-seeking behaviours of Swedish immigrant pregnant women are reported to be different from those of native-born women, with a generally later first appointment booking and fewer planned visits to antenatal care, but more unplanned visits at the labour ward (97, 99, 100). The risk of instrumental delivery is increased for several immigrant groups (101, 102), while the use of epidural analgesia during labour is reportedly less common (103).

The objective of the Swedish health care system is to provide good health and good care on equal terms to the whole population (104). A recent report summarises that, although inequities in health are to a larger extent determined by inequities in society as a whole than by the results of the health care system, the latter carries a great burden (105). Substandard care has been shown to be disproportionately more common among non-Western immigrant women in cases of maternal and perinatal death (72, 93, 106, 107). Additionally, medical challenges are posed by immigrant patients with a spectrum of diseases that Scandinavian doctors and midwives may not be trained to recognise and manage (85, 88, 90, 101, 108), and the importance of awareness and preparedness to meet the linguistic and cultural challenges in the care encounter with a foreign-born woman may be neglected (106, 109-112). Essén et al. reported in 2002 that language barriers contributed to a higher perinatal mortality among women from the Horn of Africa living in Sweden (106). Since then, the issue of using professional interpreter services has been raised as one of the top ten recommendations to improve maternity services, based on an audit of maternal deaths in the UK (25). Swedish Law establishes that non-Swedish-speaking patients have the right to a
professional interpreter (104, 113). However, in Europe generally, getting care providers to consistently use interpretation services remains a challenge (112).

Furthermore, maternal pregnancy strategies, founded on experiences from poor health care and traditions in their countries of origin, may contribute to potentially avoidable adverse maternal outcomes after migration to Sweden (111, 114-117). One example is the fear of caesarean section among Somali women, a fear that is rational in their country of origin (111). Limited insight into these strategies by health care providers may contribute to the increased risk of adverse outcomes amongst immigrants, aside from the well-known obstetric risks.

From the ‘three delays’ to the ‘migration three delays’ framework

In 1994, Thaddeus and Maine (118) developed the ‘Three delays’ framework to identify obstacles to the provision and utilisation of high quality, timely obstetric care, assuming that a lack of timely and adequate care was the foundation of maternal death. The original model was developed for low-income, high-mortality African settings where giving birth at home is the norm; however, the three phases are posited by the authors as being viable across income contexts.

The three phases focused on the potential for delay occurring on the timeframe between a woman’s first suspicion of an obstetric complication and the outcome. A chronological order was emphasised. The first delay (Phase 1) is the decision to seek care, where delays mainly result from either perceived or actual barriers that create disincentives to act, such as having to negotiate with a partner involved in the decision-making process, or from a woman’s low status. These may influence an ability to judge the severity of a complication in relation to whether an appropriate care facility is accessible. Perceived barriers from negative expectations rely on a woman’s prior experience or those of others close to her. The second delay (Phase 2) consists of the infrastructure involved in reaching the health facility, where delays can result from the actual barriers of cost, bad roads, and lack of ambulances. Finally, the third delay (Phase 3) is the receipt of adequate treatment where the delays result from actual barriers at the health facility. This includes lack of skilled staff, technological equipment and medical supplies. Both actual Phase 2 and Phase 3 barriers, such as far distance to the health facility and the knowledge that the quality of care at the health-facility
is low, can act as Phase 1 barriers, reinforcing the disincentives to seek care (118).

To conceptualise sociocultural factors that can constitute barriers for the receipt of timely and high-quality obstetric care in a high-income setting among immigrant women who have migrated from a LIC to HIC (where facility-based care and childbirth is the norm), Binder et al. modified the original ‘Three delays’ to create the ‘Migration three delays’ framework (115), see Figure 1. The development of the migration framework was supported by interviews with immigrant African women and maternal care providers in an urban, Western European care context. Women avoid delays in an African context by overcoming both actual and perceived barriers. Maternal death results in situations when such attempts to avoid delays are not successful, and thus women are more likely to die while in pursuit of care rather than while at an actual care facility. In LICs, women’s care choices are severely limited by a host of unavailable or inaccessible options. In Western high-income settings, however, maternal care options are more readily accessible, but a care-seeking immigrant woman may still be delayed because of her negative expectations (Phase 1), especially about care quality (Phase 3) resulting from her LIC experiences. She may not trust the new health care system (Phase 3), especially if she has heard rumours from her social network about quality of care in the new host setting (Phase 1). The combination of broken trust between the woman and the care provider (Phase 1) can combine with misconceptions about the care procedures and lead to low-adherence, delayed care-seeking, late-booking, or outright refusal of preventive interventions thereby restricting the woman’s ability to receive high-quality care (Phase 3). Additionally, in contrast to the LIC African context where availability of transport is a major obstacle to reaching the maternal care facility (Phase 2), women in HICs do not experience this barrier. Instead, language discordance during the care encounter restricts the ability to reach the knowledge of the health care providers and thereby creates a problem of accessibility (Phase 2). This Phase 2 accessibility barrier is also reciprocal because it adversely affects the providers’ ability to understand the woman and offer quality care in Phase 3.
Quality of care and assessment of quality of care

Health care quality can be defined as:

… the extent to which health services provided to individuals and patient populations improve desired health outcomes. The care should be based on the strongest clinical evidence and provided in a technically and culturally competent manner with good communication and shared decision making (119).

Patient safety is defined as:

… the absence of the potential for, or the occurrence of, health care associated injury to patients created by avoiding medical errors as well as taking action to prevent errors from causing injury (120).

Patient safety is a cornerstone of high-quality health care. Three approaches have been emphasised in the patient safety literature: to prevent errors; to learn from the errors that occur; and to build on a culture of safety that involves health care professionals, organisations, and the patients (121).
In 2011, Sweden enacted a new patient safety law that gives the care providers a clear responsibility to work systematically and preventively for improved patient safety and reduction of harm related to care (122). The caregivers are obliged to investigate events which actually did cause harm, or could have led to the harm of patients (122). ‘Root cause analyses’ of adverse events have become routine in Swedish health care services (123), and, in cases of severe events of care injuries, the caregivers are obliged to report those to the National Board of Health and Welfare, under a direction of a paragraph in the Patient Safety Act called ‘lex Maria’ (122). However, the science of how to measure preventable harm is still developing (124).

Quality of care assessment optimally includes the categories structure, process, and outcome (125). **Structure** denotes the attributes of the setting in which the care occurs and includes material resources, human resources, and organisational structure. **Process**, which denotes what is actually done in the giving and receiving of care. It includes the patients’ activities during seeking care and advice adherence as well as the care provider’s activities while making a diagnosis and recommending or implementing treatment. **Outcome**, represents the effect of care on the health status of patients and populations.

An audit could be defined as “the systematic critical analysis of medical care” (126) by which structure, process, and outcome can be assessed. A maternal mortality audit is a critical incident audit that begins with the occurrence of an adverse outcome (40). It can be performed at a number of different levels, the most basic of which simply records the number of deaths in an area. The next level of audit can result from assessing registered causes of death. The third level is to assess avoidable factors or suboptimal care (40). The basic assumption is that by examining an adverse event, solutions to the identified inadequacies will improve not only the quality of care provided for similar future cases, but also the quality of care provided for all other women (40). However, the scientific evidence of the audit’s effectiveness when it comes to improvement in clinical practice is thus far sparse (127, 128). The longest running and the most successful maternal audit is the UK Confidential Enquiries into Maternal Death (25). Because of the low a priori risk of maternal death, a thorough assessment of each case can provide important information on suboptimal factors in both structure and process (25). Based on this information, recommendations evolve and are disseminated to all maternal care providers, regardless of their involvement in a case, and implemented with the aim of improving their preparedness and patient safety.

Studying medical records is a widely used method to assess the quality of care. Three basic approaches to the recording of reviews are described:
implicit (holistic) review, explicit (criterion-based) review, and structured implicit review (129). In explicit review the care actually given is compared with a set of predefined criteria, which makes the method easy to reproduce and the inter-rater agreement high. When studying maternal death, the explicit review could be used for specific diagnoses, for which there are accepted standards for the care, like hypertensive disease in pregnancy (130, 131). However, in HICs, maternal mortality is rare, and a majority of deaths are caused by a disease or combination of diseases and events for which standards could not be specified. In the implicit review the reviewer judges the quality of care with his/her own internalised standards of good care, which allows freedom to judge care not covered by predefined criteria. The implicit review has been criticised for being idiosyncratic and reviewer dependent (132). However, this method could be improved by using the structured implicit review, where the reviewer is directed to look at specific issues and is instructed by information on the chart about where the reviewer should base any judgment. When all reviewers are guided to look at certain elements, without overly strict direction, the inter-rater reliability is enhanced, without losing the strengths of the implicit review (129).

Suicides during pregnancy and postpartum

The awareness of psychiatric disorders occurring during pregnancy and postpartum has increased considerably in recent years. The estimated prevalence of major depressive disorder is approximately 7% during pregnancy and 6% during the first three months postpartum (133). Women with bipolar disease constitute a particular challenge, as the risk for a manic/depressive or psychotic episode is substantially elevated postpartum (134, 135). The overall risk of developing a psychotic episode is increased during the first year after childbirth (136), and from 1/1000 to 2/1000 women are admitted to hospital due to puerperal psychosis (137).

Suicides are almost always associated with mental illness (138), and the suicide incidence has been reported to decrease in all groups in Sweden, except for women aged between 15 and 24 years (139). Despite a lower incidence of suicides among pregnant women and during the twelve months following delivery (140, 141), suicide remains one of the most common causes of death among women during the year following their pregnancy (13, 142). At no other time in their reproductive lifespan do women have more frequent contact with health care professionals. Because the objective of the provision of maternal health care is to identify and reduce risks and ill-health (143, 144), every suicide may represent a lost opportunity to diagnose and treat psychiatric illness.
Women who are not native-born in a specific setting are more likely to report symptoms of depression, post-traumatic stress, anxiety, and psychosomatic symptoms during pregnancy and postpartum (145-147), although there are studies showing that the opposite is true (148). Despite the known increased risk of mental symptoms among immigrants, a number of Swedish studies aimed at determining the prevalence of psychiatric ill-health excluded non-Swedish speaking women (133, 145, 149, 150). The screening of mothers at 6 to 8 weeks postpartum with the Edinburgh Postnatal Depression Scale (EPDS) is today recommended at Swedish child health centres (151), although a study from 2007 showed that it was rarely used for non-Swedish speaking mothers (152). At least some groups of foreign-born women (irrespective of pregnancy) seem to be at increased risk of committing suicide as compared to both Swedish-born women and other women in their countries of birth (153, 154). However, a recent Danish study did not find any difference in suicide incidence between immigrant or refugee women, as compared to native Danes (155).

Rationale for the project

Although maternal mortality in Sweden is low, surveillance remains important. Nevertheless, it is well-known that underreporting of maternal deaths is impeding its surveillance. Moreover, maternal death by suicide should optimally be included in the case surveillance. However, our present knowledge gap has yet to be filled about which women are dying as a result of suicide during pregnancy and after delivery.

Today, more than every fifth newborn in Sweden has a mother born abroad (156). This coincidentally represents women who are also well-known as being vulnerable to psychiatric ill-health and adverse perinatal outcomes. The elevated mortality risk among foreign-born parturients in other European countries is worth our attention, as is identifying potential causal relationships. Investigation into the quality of maternal health care for foreign-born women should therefore remain a top health system priority in Sweden.
Aims

The overall aim of this thesis is to study maternal deaths in Sweden with a focus on the foreign-born population.

The specific aims are:

- To analyse the causes of death in women of reproductive age and to seek a correlation between the underlying cause of death and country of birth 1988–2007 (Study I);
- To use the existing information in national registers and death certificates to acquire a more accurate number of maternal deaths in Sweden for calculating maternal mortality ratio and pregnancy-related mortality, 1988–2007 (Study II);
- To identify suboptimal factors of maternity care of women suffering a maternal death 1988–2010, and to explore these in relation to clinical care and sociocultural influences (Study III);
- To characterise the population of women who died as a result of suicide during and within one year after pregnancy in Sweden 1980–2007, from the maternal care perspective by analyses of: time trends and psychiatric disorders; and care, sociodemographic and obstetric factors (Study IV).
Material and methods

Table 1. Overview of the studies in this thesis. Study objectives, methods, periods, sources of data, and population

<table>
<thead>
<tr>
<th>Study</th>
<th>Objectives</th>
<th>Study design</th>
<th>Study period</th>
<th>Source of data</th>
<th>Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>To analyse causes of death in women of reproductive age.</td>
<td>National register study</td>
<td>1988–2007</td>
<td>CDR</td>
<td>27 952 deaths of women of reproductive age</td>
</tr>
<tr>
<td>II</td>
<td>To use the information in national registers and death certificates to acquire a more accurate number of maternal deaths</td>
<td>National register study and review of death certificates</td>
<td>1988–2007</td>
<td>CDR, MBR, NPR and death certificates</td>
<td>478 women who died within one year after pregnancy</td>
</tr>
<tr>
<td>III</td>
<td>To identify suboptimal factors of maternal care preceding maternal death</td>
<td>Case-referent study with audit by structured implicit review</td>
<td>1988–2010</td>
<td>CDR, medical records</td>
<td>25 maternal deaths of women born in LIC and MIC and 50 Swedish-born maternal deaths</td>
</tr>
<tr>
<td>IV</td>
<td>To characterise women who died as a result of suicide during pregnancy and one year postpartum</td>
<td>National register study and review of medical records</td>
<td>1980–2007</td>
<td>CDR, MBR, medical records</td>
<td>103 deaths by suicide during pregnancy and one year postpartum</td>
</tr>
</tbody>
</table>

Study setting

All studies included in this thesis were performed in Sweden. Maternal care reaches practically all pregnant women (100, 157). The care, which is free of charge, is funded by taxes and almost all births occur in a hospital. Home deliveries account for less than 0.1% (157). Midwives and obstetricians have complementary roles and work in teams. Normal pregnancies and deliveries are managed by midwives. From 1980 to 2010, the mean age of primiparae has increased from 25 to more than 28 years, and for multiparae from 28.5 to
The Body Mass Index (BMI) of pregnant women has increased, and in 2010 about 25% of the parturients were overweight (BMI >25) and 12% were obese (BMI >30) (158). The proportion of foreign-born women in the total population of women of reproductive age increased dramatically from 1988 to 2007, as shown in Figure 2. In 2007 17% of women of reproductive age were born abroad (67), and more than every fifth newborn had a mother born outside Sweden (156), although during the years 1988 to 2007, 15% of the newborns had a foreign-born mother.

![Figure 2. Composition of Swedish female population of reproductive age, 1988–2007, by country of birth (please, note that the y-axis begins at 1 500 000). Reprint made with the permission of the European Journal of Public Health](image)

Study population

The base of all four studies in this thesis was the population of 27,957 female deaths of reproductive age (defined by the World Health Organization as 15 to 49 years old) in Sweden between 1988 and 2007, identified through the CDR. After excluding five women because of unknown countries of birth, 27,952 women born between 1939 and 1992 were included in Study I. Among these women there were 478 who had at least one diagnosis related to pregnancy within one year prior to death, and were included in Study II. From the population in Study II, a sample of 58
maternal deaths were included in Study III together with 17 maternal deaths from the years 2008 to 2010 obtained from the SFOG Maternal Mortality Group. The study population in Study IV was constituted by 73 suicides identified in Study II, and 30 postpartum suicides from 1980 to 1987 identified through an earlier study on maternal mortality (13), however the suicides were not earlier analysed (see Figure 3).

<table>
<thead>
<tr>
<th>Study Population</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>27,952</td>
<td>27,952 women of reproductive age who died in Sweden 1988–2007 identified through the CDR (Study I)</td>
</tr>
<tr>
<td>151</td>
<td>151 pregnancy-related deaths (deaths within 42 days after termination of pregnancy) (Study II)</td>
</tr>
<tr>
<td>123</td>
<td>123 maternal deaths (Study II)</td>
</tr>
<tr>
<td>73</td>
<td>73 suicides within one year after being registered with a diagnosis related to pregnancy in CDR, MBR, or NPR (Study II and III)</td>
</tr>
<tr>
<td>478</td>
<td>478 women who died within one year after being registered with a diagnosis related to pregnancy in CDR, MBR, or NPR (Study II and III)</td>
</tr>
<tr>
<td>30</td>
<td>30 suicides 1980–1987 (Study III)</td>
</tr>
<tr>
<td>17</td>
<td>17 maternal deaths 2008–2010 (Study IV)</td>
</tr>
<tr>
<td>58</td>
<td>58 maternal deaths (Study IV)</td>
</tr>
</tbody>
</table>

**Methods**

A person’s country of birth is recorded in the Swedish Population Register and linked to the CDR, the Medical Birth Register (MBR) and the National Patient Register (NPR) by means of each resident’s personal identification number. The deceased women in the studies of this thesis were categorised by country of birth according to the World Bank Country classification, based on the Gross National Income (GNI) in contrast to many studies grouping immigrants according to geographical regions. GNI is defined as the total value produced within a country (i.e. its gross domestic product) plus income received from other countries (interest and dividends), less similar payments made to other countries. Since GNI has been shown to be a major socioeconomic determinant of population health (159, 160), we hypothesised that women from poor countries would continue to be the most vulnerable group with regard to mortality after migration. The World Bank classification is revised every year, and we used the classification from 2007 (161) (Appendix 1), defining LICs to be those having a GNI per capita of
<936 USD, middle-income countries (MIC), often divided into lower and upper middle income, 936–11 455 USD, and HICs >11 455 USD. The most common HICs of birth among immigrant women in Sweden from 1988 to 2007 were Finland, Norway, Denmark, Germany and South Korea. The former Yugoslavia, Poland, Iran, Iraq and Turkey were the most common MICs, and Ethiopia, Somalia, Vietnam, Afghanistan and Pakistan were the most common LICs of birth in the population of women of reproductive age.

In Study I the underlying causes of death were grouped according to the chapters in ICD-10 (162) and the age-standardised mortality rate was calculated per 100 000 person years, using the Swedish-born women as a standard. RR with 95% CI for death and underlying causes of death were calculated in comparison with the Swedish-born group, using Poisson regression.

In order to identify all women who had been pregnant within one year before their deaths, the CDR, MBR, and NPR were linked in Study II. First, both underlying and multiple (contributory) causes of death of all deceased women of reproductive age in the CDR were reviewed. Second, the population was linked to the MBR to identify women who had given birth within one year before the death. Finally, by linking the population to the NPR women who had sought specialist care due to a diagnosis related to pregnancy were identified. Death certificates of all women who had given birth or who had had at least one pregnancy-related diagnosis in CDR or NPR where obtained. All information available in the registers and death certificates were reviewed to ascertain maternal deaths, classified as direct/indirect, early/late, or coincidental deaths. The number of maternal deaths identified through register linkage and review of death certificates was compared to the official number of maternal deaths, which counts the number of women who had a pregnancy-related diagnosis as an underlying cause of death in the CDR.

The analysis in Study I and the register linkage in Study II were performed with SAS version 9.2 and SAS Enterprise Guide 4.2 software packages (SAS Institute, Cary, NC, USA).

For Study III, all maternal deaths of women born in LICs and MICs (n = 26, but one was excluded because the medical record was not retrievable) were identified and each foreign-born case was matched with two Swedish-born maternal deaths. Medical records were obtained from all clinical departments where the woman had received care during her last pregnancy, delivery and postpartum period. A protocol was developed that applied both the ‘migration three delays’ framework (115) and a modified version of the Confidential Enquiry from the United Kingdom (163) (Appendix 2). The
medical records were summarised by two obstetricians independently. An audit group, comprising senior obstetricians, assessed whether the maternal death was direct or indirect. The audit group also identified and assessed suboptimal factors, categorised as being related to care-seeking (Phase 1), accessibility of services (Phase 2), or quality of medical care (Phase 3), by a structured implicit review (129). The severity of suboptimal factors were assessed as minor if it was a relevant contributory factor and an alternative care management strategy might have made a difference to the outcome, but the mother’s survival was unlikely in any case. A factor was labelled as major if it contributed significantly to the death of the mother, and if the death could have most likely been avoided by different management of the case (25).

Fisher’s exact test was used to compare suboptimal factors (major + minor) between Swedish-born and foreign-born women considering a $p$-value of <0.05 as being statistically significant. The analysis and interpretation of sociocultural factors involved the contribution of a medical anthropologist.

Antenatal and maternity records of 103 cases of suicide during pregnancy and within one year after delivery were obtained and reviewed in Study IV. Information on socioeconomic situation, somatic and psychiatric history, complications, medication, and care during pregnancy, delivery and postpartum period was collected. The data from medical records were complemented by data from NPR on all earlier psychiatric specialist admissions and out-patient appointments for each woman and from MBR on all pregnancies and deliveries. Socioeconomic background was compared to a reference population consisting of mothers of all live births in Sweden during the years 1980 to 2007 obtained from MBR, and differences were calculated using the chi-squared test considering $p$-values of <0.05 as being statistically significant. The chi-squared test was also used for testing for differences in psychiatric morbidity between women who died within six months as compared to 6 to 12 months after delivery. The analyses in Studies III and IV were performed with IBM SPSS statistics for Windows version 20.0 (IBM Corp., Armonk, NY, USA).

Ethics considerations

Ethics approval for this study was not needed according to Swedish laws on ethical review, because all women included were deceased. The Regional Ethics Committee in Uppsala, Sweden, confirmed that the study did not fall into the category of research requiring ethical clearance [2008/381, 2009-01-14]. All heads of clinical departments where a woman had been cared for were asked for consent to share a copy of the medical records.
The medical records were handled confidentially. We strived to de-identify the cases with the intent that no deceased woman, her relatives, involved hospitals, or individual care providers would be recognisable.
Results

Between 1988 and 2007, total mortality for women of reproductive age decreased. However, mortality for this period was significantly higher among women born in LICs and HICs, and lower among women born in MICs, as compared to Swedish-born. The most common underlying cause of death in all groups was neoplasm, followed by external causes of death, mainly suicide and traffic accidents. Death as a result of infectious diseases or complications of pregnancy and childbirth was uncommon, but among women who died of those diseases, large differences were found between the Swedish- and foreign-born women.

The age-standardised mortality rate for maternal death, according to the official method for identifying such death (i.e. reviewing the underlying cause of death), was 0.2 per 100 000 person years during the study period. Nevertheless, women born in LICs were found to be more likely to die due to diseases and complications related to pregnancy and childbirth at a RR of 6.6 (95% CI 2.6–16.5) as compared to Swedish-born. For women born in MICs and HICs no difference in risk compared to Swedish-born women was found. The risk of women born in LICs to die of infectious diseases was 15-fold, which could partly be explained by an uneven distribution of deaths from HIV/AIDS, but the risk remained 7-fold even after excluding HIV cases. Women born in LICs were also at a slightly higher risk of dying from malignant neoplasms. As compared to Swedish-born women, women born in HICs were at a higher RR of death due to diagnoses categorised in ICD as ‘mental and behavioural diseases’ (mainly alcohol and drug misuse), ‘external causes’ (suicides and accidents), and diseases of the circulatory system. In contrast, women born in MICs were at a lower risk of dying due to alcohol and drug misuse, and diseases of the circulatory system.

The total of 75 women who were registered with an underlying cause of death due to complications of pregnancy, childbirth and the puerperium (ICD-9 chapter XI and ICD-10 chapter XV) constituted the official number of maternal deaths in Sweden from 1988 to 2007, giving an MMR of 3.6 per 100 000 live birth. Through stepwise linkage of registers and review of death certificates we identified 123 maternal deaths, which is 64% higher than the official figure. In addition, two late maternal deaths and 75 suicides
occuring during pregnancy or within one year after delivery or early pregnancy loss were identified.

The MMR during the years 1988 to 2007 was 6.0, and for women born in Sweden 5.9, HIC 5.5, MIC 4.7, and for LIC 21.1 per 100 000 live births. Ratios over time for all, Swedish-born women, and women born in LICs and MICs are illustrated in Figure 4. The pregnancy-related mortality was 7.3 per 100 000 live births.

Figure 4. Maternal mortality ratio in Sweden 1988–2007 by country of birth. Sliding five year mean values

The care preceding the death of 73 direct and indirect maternal deaths that occurred between 1988 and 2007 was reviewed, and major and minor suboptimal factors were found to be associated with the majority (n = 51). In 36 assessed deaths at least one major suboptimal factor was identified, and hence the deaths were assessed as potentially preventable. In the remaining 15 cases, there were no major but at least one minor suboptimal relevant factor identified. Overall, significantly more suboptimal factors occurred in the care of the foreign-born women. Phase 1 factors (related to care-seeking) and Phase 3 factors (quality of medical care) occurred in both Swedish- and foreign-born women, but were significantly more common among the foreign-born women, whereas Phase 2 factors (related to accessibility of services) occurred in foreign-born women only.
Non-compliance (such as failure to turn up at follow-up appointments) was the most common Phase 1 barrier to optimal care-seeking, assessed as a major factor in three women and as a minor factor in seven, followed by late- or non-booking, and unhealthy lifestyle (substance misuse). Late- or non-booking was a minor factor among foreign-born women, whereas the three women who had suboptimal factors, all major, related to their substance misuse were Swedish-born. None of the women had planned for a home delivery, although one Swedish-born woman with a history of substance misuse gave birth at home.

Limited language congruence created a Phase 2 barrier to accessing health care services among 13 foreign-born women, and their care providers. In ten cases language incongruence was assessed as a minor factor, whereas in three it was a major factor, that is, it contributed significantly to the death of the mother, and could have most likely been avoided by different care management.

Among the Phase 3 barriers, inadequate care was the most common contributor (31 major and 18 minor) in both groups, but more commonly occurring among the foreign-born women. Inadequate care included missed or delayed diagnosis, and inadequate treatment. Delays in consultation or referral was the second most commonly occurring barrier in Phase 3, assessed as being a major factor in 16 women and minor in 8, followed by delayed treatment, in the category ‘appropriate care, but too late’. There was no difference in occurrence of the other suboptimal Phase 3 factors, such as: consultation or referral; appropriate care, but too late; miscommunication between care providers; and limited use/priority of resources, between the groups. Among the foreign-born women, the influence of delay-causing barriers from Phase 1 and 2 on Phase 3 could not be ignored. To demonstrate, out of 14 cases of major inadequate care, 10 also had Phase 2 barriers from, for example, limited language congruence, and 8 of these also had Phase 1 barriers, including non-compliance or late-booking.

Four foreign-born women had medical conditions that most probably originated in the LICs of their birth. Only one woman was HIV-positive, although she died of a rheumatic heart disease. Two women died of complications caused by tuberculosis, and one woman who had recently arrived in Sweden suffered from severe chronic anaemia.

One-hundred-and-three suicides during pregnancy and within one year postpartum were identified between 1980 and 2007, corresponding to a ratio of 3.7 suicides per 100 000 live births during the entire study period. The rate did not change over time. In comparison to the background population (consisting of mothers of all live births in Sweden during the study period)
the women who committed suicide were significantly more often >35 years, smoked, lived alone, and were born in LICs or MICs.

Nearly half (48/103) of the women had a psychiatric history, either recorded in the antenatal records, in the NPR or both. Although almost all of these women had experienced at least one hospitalisation due to mental illness, the psychiatric history it was not documented in the antenatal record of 18 women. Seventeen women had sought specialist care due to an injury caused by intentional self-harm between 2 and 17 years before the index pregnancy, but only three suicide attempts were documented in the antenatal records. Thirty-one women received psychiatric care during pregnancy. Despite evidence that psychiatric disorders were common in these women’s medical histories, and one-third received psychiatric care during pregnancy, only 20 women had a documented plan for psychiatric follow-up at discharge from the maternity ward. Nevertheless, half of the women received psychiatric specialist care in between discharge and death according to the NPR. One-fourth of the women expressed no indication of psychiatric disorder, either in their medical records or in the NPR.

The number of women who died as a result of suicide within the first six months was equal to that at 6 to 12 months postpartum, but women who took their lives within the first six months more often used violent methods of suicide. Furthermore, women who died as a result of suicide during the first six months less often had a psychiatric history prior to pregnancy as compared to the women who died from 6 to 12 months postpartum. The proportion of foreign-born among the women who died as a result of suicide increased from 5% during the first half of the study period to 32% during the latter half. A language barrier was documented in three cases, although a professional interpreter was only used in one.
Discussion

Maternal mortality in Sweden from 1988 to 2007 seem to be rather stable, despite increasing age of the parturients, increasing prevalence of obesity, and a substantial influx of foreign-born women. Nevertheless, the gap between the lines of the total maternal mortality and the maternal mortality of Swedish-born women illustrates the elevated maternal mortality among foreign-born women. Despite small absolute numbers, the MMR for women born in LICs was 6 to 7 times higher than that of Swedish-born women. Underreporting of maternal deaths was shown to be substantial: as compared to the official statistics, 64% more maternal deaths were identified. Major and minor suboptimal factors related to care-seeking, accessibility and quality of care were found to be associated with a majority of maternal deaths and significantly more often with foreign-born women. The rate of suicides during pregnancy or within one year after delivery did not change during the last three decades, and was higher for foreign-born women. A majority of women who died as a result of suicide had been under psychiatric care, but documentation at antenatal care was inconsistent, and planning for follow-up postpartum was generally lacking.

Classification of maternal deaths

Doubtless, maternal mortality in Sweden is among the lowest in the world, although both inconsistencies in definitions and underreporting of maternal deaths complicate the comparison between countries. We found 64% more maternal deaths than the ‘official’ number reported, which is equivalent to the adjustment factor that is applied by WHO to account for misclassification of maternal death in countries whose civil registration otherwise is characterised as complete (9). We identified flaws on three different levels. The first was that the pregnancy was not always recorded on the death certificate. Either the doctors completing these death certificates were unaware of the recent pregnancy, or they failed to recognise the importance of recording associations between a death and a pregnancy. Furthermore, we found cases where the pregnancy was recorded on the death certificate, but not coded in the CDR. Finally, although codes for indirect maternal death exist in ICD-10, the ICD-rules for assigning an underlying cause of death seem to aim at identifying direct maternal deaths only, not
indirect, and thus do not follow the ICD definition of a maternal death (35). However, we found that direct as well as indirect maternal deaths were registered as maternal death. At the same time, both direct and indirect maternal deaths were missed.

The proportion of late maternal deaths is probably higher in HICs, where the MMR is low, than in LICs and MICs, owing to high-quality care (164). Identifying late maternal deaths can be expected to be even more complicated than for the early deaths. On average, in ICD-10 datasets, less than 2% of maternal deaths are coded as late maternal. We identified two late maternal deaths only (0.6%), and it can be questioned whether review of register data and death certificates would sufficiently identify an accurate number of those deaths.

In Sweden, the absolute number of maternal deaths is so small that it could be questioned whether it is important to know whether four or six deaths occur yearly. However, it is important to illuminate the different levels where flaws occur in maternal death reporting, including in Sweden with its high-quality civil registration. Furthermore, the necessity to distinguish between direct and indirect maternal deaths needs to be highlighted (165, 166), because interventions for averting direct deaths do not necessarily reduce the indirect deaths, and vice versa. Therefore, when addressing the burden of maternal mortality in a particular context, by planning, monitoring and evaluating interventions for improving maternal health, analyses by disaggregating direct and indirect maternal deaths are essential. Accurate differentiation of direct and indirect maternal deaths requires the existence of specific mechanisms, not only for identifying and counting maternal deaths, but also for collecting detailed information on the cause of death. This presents a considerably greater challenge, than simply measuring and reporting all-cause maternal mortality, which, as previously discussed, is already difficult (166).

Review of all diagnoses in the CDR, together with linkage of the CDR and the MBR, showed to be effective in identifying additional maternal deaths. The linkage of the CDR to the NPR did not add equally as many maternal deaths, although this linkage is important to identify deaths after early pregnancy loss. Exclusion of legal abortions from the Swedish NPR inhibits studies on mortality after legal abortions, a method which is possible in other countries, for example, Finland (141). Register linkage needs to be supplemented by the examination of death certificates, or medical records, in order to differentiate direct and indirect maternal deaths. This process is time-consuming and requires obstetric expertise. With the publication of ICD-10, WHO recommended in 1991 the inclusion on death certificates of a checkbox of questions regarding current pregnancy and pregnancy within
one year preceding death (35), and this has been implemented other high-income settings (28, 167), however, not in Sweden. In France, a checkbox was introduced in 2000 and was expected to increase the number of previously unidentified maternal deaths, but it did not (28). In Maryland, the checkbox identified nearly all maternal deaths and about half of other deaths, such as suicides, accidents and homicides, occurring during the first year postpartum (167).

Precise classification of direct and indirect deaths depends on accurate assignment of cause of death. Knowing the pathology behind the cause of death is equally as important as knowing the death rate (40). As mentioned in the introduction, the thoroughness of the cause-of-death investigation varies greatly. In Study III we identified cases in which the quality of autopsy could be questioned which hampered the identification of cause of death. Some cases of sudden unexpected death also fulfilled the criteria for the need of forensic autopsy according to Swedish law, but these were then not performed (59). This finding suggests that some clinicians have limited knowledge about laws regulating post-mortem examinations. It also occurred that some of the relatives of the deceased women opposed autopsy. However, although the will of relatives normally should be respected, if the cause of death is unknown, the legal right to perform it remains intact despite opposition from the relatives (58). The importance of high-standard maternal autopsies are emphasised in the latest UK maternal mortality report, and the recommendation is that maternal autopsies should be centralised to develop national centres of expertise (25).

As mentioned earlier, suicides are not included in the current WHO classification of maternal deaths. The WHO Working Group on Maternal Mortality and Morbidity Classifications suggests that in coming classification, antenatal suicides and suicides related to chronic psychiatric disorders will be classified as an indirect maternal death, whereas postpartum suicides due to postpartum depression or psychosis, as well as postpartum suicides for which associations to psychiatric disorder is unknown, will be classified as direct maternal deaths (Lale Say, personal communication, October 27 2009). While we can expect it to not always be easy to assign a suicide as a direct or an indirect maternal deaths, this change in the classification acknowledges the associations between pregnancy, psychiatric disease and death as a result of suicide, which is a great progress. Surveillance will hopefully be simplified, and the knowledge gap filled about the contribution of psychiatric disorders to the global burden of maternal mortality.
Maternal death and country of birth

The composition of the population of women of reproductive age has changed dramatically in Sweden during the last 25 years. The multi-cultural population adds new dimensions to the challenges of providing good health and good care on equal terms to the whole population (104). Although our hypothesis suggesting that women from LICs would continue to be the most vulnerable group with regard to mortality after migration seems to be true, there seem to be more complex associations between country of birth and death in women of reproductive age from MICs and HICs.

The six- to seven-fold increase in risk of death due to complications of pregnancy and childbirth among women born in LICs, as reported in Study I, was based on the underlying cause of death only. However, the additional deaths identified in Study II were proportionally distributed between Swedish- and foreign-born women. This means that after also correcting for underreporting, the risk of maternal death among women born in LICs seems to be several times higher than that for Swedish-born women. Such differences in maternal mortality have earlier been reported in other European settings (14, 18, 20-29). However, ours is the first study confirming a corresponding difference in Sweden. We set out in Study III to find explanations for this difference.

Medical factors

One hypothesis for explaining the increased risk of maternal death among immigrant women could be that they bring with them medical conditions originating in their country of birth. Study I reported a substantial increase in risk of dying from infectious diseases, and especially HIV/AIDS, for women born in LICs in comparison to Swedish-born women of reproductive age. However, among the maternal deaths in Study III we identified only one foreign-born HIV-positive woman, and she died of a rheumatic heart disease and not from the HIV infection. Two foreign-born women died of complications caused by tuberculosis (TB), but the number of women who died of sepsis was too small to enable analysis of risk related to country of birth. National guidelines for antenatal care advocated generous HIV testing (143, 144), and it is less likely that pregnant women may have been missed.

Four women in total, who were born in LICs, primarily sub-Saharan Africa, died of diseases not usually seen in Sweden. In all four cases we found a limited professional insight into those diseases. This finding illustrates the importance of improving knowledge about rare diseases complicating pregnancies, such as TB, rheumatic heart disease and severe anaemia, which have lately returned to European obstetrics (85-87, 90, 92). Furthermore,
other premorbid risk factors, such as hypertension, type 2 diabetes and obesity, may increase the risk of severe pregnancy complications in some groups of immigrant women (168). The prevalence of hypertensive diseases of pregnancy has been found to be increased among sub-Saharan African women in France (72) and among African-American women (169), which may imply a higher risk of severe complications such as eclampsia, HELLP, DIC, cardio- and cerebrovascular diseases (25, 50, 168). Limited care provider insight may also conflict with women’s limited insight into identifying potential risks to her pregnancy (114). Health care providers need increased skills not only in recognising but also in interpreting symptoms experienced by immigrant women and should appreciate that immigrant women have other medical needs than those expected for native-born women. Education of health care professionals should not stereotype women’s care needs based upon presumed sociocultural barriers (112). If the care provider’s focus relies too much on presumed cultural factors, the appropriate obstetric needs might be obscured by the interjection of culture-based misperceptions. Further, over-emphasising the culture behind a health issue might ultimately hand the problem over to the patient as a private matter and neglects the fact that women simply want to receive competent care (112).

Care-seeking

Sub-optimal factors related to care-seeking, such as late-booking and non-compliance, were more common among foreign-born than Swedish-born women, and in six cases such factors were assessed as major. However, it is difficult to reconstruct a woman’s decision-making processes around her choices to seek care. The medical records can only document her registered contacts with a care centre, which become the perspective of the care provider, and from these we can presume whether or not a woman chose to comply. Socio-cultural explanations for delays to care-seeking have been theorised as the ‘maternal migration effect’, describing how factors related to the pre-migration experience, have the potential to influence women’s obstetric choices after migration to a new setting (114). Other factors delaying care-seeking and utilisation of maternal care include mutual broken trust between the woman and the care giver during the care encounter, which is also exhibited as women’s non-compliance/limited adherence to treatment advice and refusal of care, as well as care provider frustration at not being able to impart quality care as a matter of course (111, 115). These negative influences on care-seeking have the potential to delay the provision of optimal preventive advice as well as timely referral. All patients receiving care in Sweden have the right to decline care (104). However, limited guidelines exist for helping professionals to manage situations when this occurs (116).
It is worth noting that for three of the Swedish-born referents, but in none of the foreign-born cases, substance abuse was assessed as a major suboptimal care-seeking factor.

Accessibility of services
In rural low-income settings, delays to accessing the health care facility occur regularly due to such absolute factors as cost and poor transportation infrastructure. In our HIC material, there was one occasion when an ambulance was delayed, but this was due to language problems, assessed as a minor suboptimal factor. All other patients reached the health care facility without transport-related delays. Accessibility problems arose once they came into care. The ‘migration three delays’ framework offers the ability to model how language discordance acts as a negative influence to accessing optimal care. Despite both persons being present during a care encounter, the care provider cannot access the medical history, a component which is essential to make the right diagnosis, whereas the patient cannot access the knowledge and advice from the medical expertise because she cannot interpret or sufficiently describe her symptomatic history. Limited language congruence was assessed as a contributory factor in 13 out of the 25 foreign-born women, and in three of these as a major factor, that is, assessed as actually contributing to the death.

It seems as if the legal right to professional interpretation for non-native speaking persons (104, 113) is not always incorporated in the care management strategies. In one of the reviewed medical records, the midwife responsible documented that she had difficulties in understanding an English-speaking woman, which reminds us about the reciprocity of the language barrier. Optimally, there should be no need to call attention to the impossibility of taking a proper medical history from a person who does not speak the same language, but unfortunately it is, apparently, not a matter of course (25, 106, 112).

Maternal death and quality of care
In total, major or minor suboptimal factors were associated with two-thirds of the maternal deaths, and more commonly among foreign- than Swedish-born women. In nearly half the deaths we found at least one major suboptimal factor. Hence these deaths were assessed as potentially preventable. Suboptimal quality-of-care factors (Phase 3) were the most commonly occurring.
Suboptimal outcome does not necessarily imply suboptimal care and suboptimal care does not always result in suboptimal outcome. Two Swedish case-control studies showing associations between intrapartum substandard care and metabolic acidosis and low Apgar score respectively, also showed that substandard care was present in up to 40% of the controls (170, 171). The field of obstetrics is characterised by the possible need for urgent interventions. Some maternal deaths are truly sudden and catastrophic, in the sense that they could not have been predicted or prevented, and the course of events is too rapid to enable interventions to save the woman’s life (172). However, a majority of the deaths are preceded by warning signs and a period of instability during which timely interventions may have helped to avoid the disaster. Interventions averting severe maternal complications usually require more than individual care providers’ medical knowledge and necessary technological equipment, but also a well-functioning surrounding infrastructure. Adverse events usually result from several coincidental factors and mistakes that occur on several levels of the organisation (173) which underscores that patient safety work needs to involve health care professionals, as well as organisations, and the patients, to build a strong safety culture (121, 174).

Among the Phase 3 facility-based delays, the most common suboptimal factors were grouped under the heading ‘inadequate care’, and delayed treatment or misdiagnosis was the most commonly occurring event. In some cases, evidence-based treatment for hypertensive disorders or sepsis was delayed or inadequate. This finding is consistent with substandard care reported from other European countries (25, 130, 131), and illustrates that insufficient knowledge about current guidelines may occur, or that action is delayed for some reason. Early warning systems, such as the modified early obstetric warning system (MEOWS) which recently has been introduced at maternity wards in Sweden, provide support in identifying emerging complications (22, 175) although further validation is claimed to be needed (176).

Clinical decision-making is a complex process, and several of the cases in which the diagnosis was delayed or missed suggest cognitive errors of the care providers. The most evident was ‘search satisfying’, which is when the care provider becomes satisfied with an investigation once a single diagnosis is identified, even if it is not the root cause of the problem (177). ‘Anchoring’ and ‘diagnosis momentum’, terms meaning that a diagnosis is put too early in the diagnostic process and that once diagnostic label is attached to a patient it tends to remain there, even though additional data contradicts the given diagnosis, could also be identified. ‘Omission bias’, that is, the tendency toward inaction rooted in the principle of non-maleficence, resulted in some cases in delays labelled as ‘appropriate care,
but too late’. The awareness of cognitive errors and strategies to minimise them have gained increasing attention in the literature during the last decade, but have not been sufficiently recognised in clinical training (177, 178).

Delays in consultation and referral occurred in one-third of the women, and could be described as a problem on both individual and structural levels. There were examples of cases admitted at a university hospital, where all necessary resources were available, but due to insufficient communication and dubious prioritisation, the right specialist did not investigate the patient, or the patient did not reach, for example, the intensive care unit, in time. In the larger cities we identified delays in care for a few women who were moved between hospitals, due to the fact that different medical specialities were available at different hospitals.

Communication between health care providers failed and contributed to the suboptimal care management of nine of the reviewed maternal deaths. Communication failures were associated with other delays and over-lapping may have occurred with factors described as, for example, delayed referral and limited use/priority of resources (179). In one of the cases, the obstetrician and the two anaesthesiologists spoke different Nordic languages and did not completely understand each other, which created misunderstanding based on an actual language barrier. In the other cases the health care providers all spoke Swedish. Teamwork training is known to improve patient outcomes (180-182). However, less is known about how to optimise team performance when the team may include varying professionals from different disciplines that may change over time (183), which sometimes occurred among the reviewed maternal deaths. A striking finding was that anaesthesiologists’ documentation was often missing from the medical records, despite their known active involvement in many obstetric emergencies.

Greenberg et al. have studied how communication breakdowns pose a threat to surgical safety (184). The most common occurrence involved ‘information never transmitted’ and ‘information was communicated but inaccurately received’. Frequent risk situations were handoffs and transfers of patients, and ambiguity about roles, responsibilities, and leadership were contributing factors. Our result supports that Greenberg’s findings may be also valid for obstetric care. Standardising the content and format of communication activities and handoffs, such as using the concept of SBAR communication (Situation, Background, Assessment, and Recommendation) (185), is suggested to increase patient safety (182, 186), and has recently been introduced at Swedish hospitals (187, 188).
Suicides

In parallel with other studies, a majority of the women who died as a result of suicide during and after pregnancy had previously received specialist psychiatric care, and we found psychiatric morbidity prior to pregnancy common (25, 142). Although very few of all women presenting with psychiatric symptoms will die as a result of suicide, Study III shows that antenatal care has failed to take a proper psychiatric history in one-fifth of the women who died as a result of suicide. Taking psychiatric history at antenatal care is a challenge because women with psychiatric disorders may not be willing to share such events of their history with the health care provider. It is important that the health care providers have enough knowledge to identify severe psychiatric disorders and to improve their skills on interviewing women about this sensitive issue (143, 189). Serious psychiatric illness in the last few weeks of pregnancy and the first few weeks following childbirth have a tendency for sudden onset and rapid deterioration, and perinatal psychiatrists in the UK recommend that those at risk should be proactively managed (25, 190). Despite the well-known risk of many psychiatric disorders to deteriorate after delivery, only a minority of the women with psychiatric disorders prior to or during pregnancy had a documented follow-up plan at discharge from the maternity ward. Such follow-up plans are recommended by the SFOG guidelines from 2009 (189). The collaboration between psychiatry and maternal care was often deficient or non-existing. A suicide attempt constitutes a life-long risk factor for suicide (138). Our findings suggest a potential for improvement in taking psychiatric history in maternal care. The common use of violent methods in postpartum suicide has been noted earlier (13, 25, 140, 142). However, the differences in both pre-pregnancy psychiatric morbidity and method of suicide between women who died as a result of suicide within 6 months and from 6 to 12 months of delivery suggest that they have different risk profiles.

To our knowledge, an increased suicide risk during pregnancy and postpartum among foreign-born women (born in MICs and LICs) as compared to native-born women, as reported in Study IV, has not been shown previously. The social and psychiatric vulnerability of immigrant women in terms of psychiatric ill-health is well documented (145-147), as is the increased risk of partner violence among immigrant women (191). Since psychiatric vulnerability and experiences of intimate partner violence are known risk factors for death by suicide, these women need special attention. The special needs of immigrant women have been regarded in national guidelines for maternal care (143, 144) published during the study period. Again, we identified deaths of non-Swedish-speaking women for whom no professional interpreter was used at antenatal care, a situation which is unacceptable.
Screening women for depression with EPDS at 6 to 8 weeks postpartum, as recommended in Sweden (151), aims at early detection of women without prior depressive symptoms, which is important for the woman’s well-being and the development of the child (192), although there is no knowledge about whether it reduces the number of suicides. EPDS is today validated for a number of foreign languages (151), although some of the most common languages among immigrants in Sweden are still missing and no recent studies were found on the coverage of the screening (152). However, EPDS is a screening instrument, and should not replace proper risk identification and care management plans for women with symptoms or disorders already identified during pregnancy or postpartum (22).

Strengths and limitations

The study setting is characterised by a homogenous, public, tax-financed health care organisation. The studies of this thesis are national and population-based, based on national registers known for maintaining high international standards of accuracy (193-195). Register linkage was possible through each resident’s personal identification number. Complete medical records were available for a majority of the reviewed deaths. Experienced obstetricians reviewed the medical records, with assistance from specialists in cardiology, infectious diseases, neurology, pathology, psychiatry, and medical anthropology. A conceptual framework based on qualitative research was used for interpreting the suboptimal care of the audit procedure.

The main limitation of the studies in this thesis is the small sample size and the extended time period. However, these unique data are validated by having tracked the deaths nationally and by representing nearly completed record materials. The recruitment of cases represents an extended calendar period, which can be regarded as a limitation because both recording processes and clinical routines evolved during the study period. However, the long inclusion period was necessary in order to gain an utilisable sample size in this small population of Sweden.

We had no information on reasons for migration or number of years spent in Sweden. However, due to the small total sample size it could have been difficult to adjust for these factors. Socioeconomic situation was unknown for both foreign-born and Swedish-born women. We considered various socioeconomic indicators, such as disposable income or level of education, but we found these to be problematic. Because the studied population consisted of women of childbearing age, whose income might have been reduced due to parental leave, part-time work, or illness before their death,
their disposable income may not necessarily have accurately reflected their socioeconomic status. Education was another alternative socioeconomic indicator, but the misclassification of level of education is known to be bigger for foreign-born inhabitants than for Swedish-born and would therefore imply an error that was unevenly distributed between immigrants and native women (196).

The audit method enables determining the presence or absence of suboptimal care and thereby modifiable factors, thus generating new knowledge, especially in the case of rare events such as maternal death. It is, however, essential to be cautious when generalising the findings as true for all maternal care. We have no control group of women whose lives were saved thanks to optimal care or despite suboptimal care, although experiencing similar complications, a critique which also has been posed to confidential enquiries (63). As mentioned in the introduction, implicit reviews have been criticised for being idiosyncratic and reviewer dependent. However, explicit review with pre-defined criteria for suboptimal care was not an option, due to the nature of maternal deaths. Clinical practices evolved during the study period, but the majority of the suboptimal quality of care factors were not dependent on specific treatment strategies, but more often due to factors assessed as less dependent over time, such as delayed diagnosis or referral, and miscommunication. Apart from the development of clinical treatment strategies, the clinical documentation practices evolved over time. Medical records from the latter years of the study were more extensive and comprehensive, but more difficult to get an overview of than the medical records from the first years. Although we did our best in striving to review the care based on what information was available in each moment when a decision was taken, there is a risk of hindsight bias (177), because we knew the tragic outcome.

Access to psychiatric and primary care records would had given a more complete picture of psychiatric care of the women who died as a result of suicide. To assess the quality of psychiatric care was, however, beyond the scope of Study IV, and would have required a different study design. Moreover, Swedish psychiatric health care has been reorganised and decentralised during the 28 years covering study period. To retrieve psychiatric records would therefore have been extremely time-consuming and costly.
Implications and recommendations

For accurate maternal mortality statistics, including differentiating between direct and indirect maternal deaths, the current method for identifying cases is insufficient. Routine register linkage of the CDR and the MBR should be implemented, a policy which is also recommended by the Swedish Society of Obstetrics and Gynaecology Maternal Mortality Group (MM-ARG).

Although root cause analyses nowadays should be carried out after adverse events, the confidential enquiries of MM-ARG play an important role in spreading the knowledge gained from maternal deaths to maternal care providers nationally. The results from this thesis will thus increase the knowledge base of MM-ARG.

Every setting needs to find its own ways to combat suboptimal factors on the road to reducing the number of maternal deaths. The studies of this thesis suggest that it would be possible to further reduce maternal mortality in Sweden, despite already very low numbers.

The majority of maternal deaths are preceded by suboptimal care, both in a health care system approach and individual professional conduct. Cross-disciplinary collaboration, prioritisation of patient safety work, including ensuring good communication with all patients, and between health care providers, is crucial, irrespective of setting. Care providers should be trained in identifying cognitive mistakes and strategies to reduce them. Communication and teamwork skills avoid medical errors and ultimately save lives.

Non-adherence to the Swedish Administrative Act regulating non-Swedish-speaking inhabitants’ right to professional interpretations services is remarkable. Despite the fact that more than ten years have passed since the first report on the associations between language barriers and perinatal adverse outcomes in Sweden, it still happens that maternal care providers try to communicate with non-Swedish-speaking women without a professional interpreter.
Non-compliance is not only the responsibility of the patient. The care provider has a responsibility to gain insight into possible misconceptions behind the behaviour.

During maternal care it is important to take into account that foreign-born women may carry with them health conditions nowadays rarely seen in Sweden. Obtaining a proper medical history includes gathering information related to the woman’s health before, during, and after migration.

As stated in the national guidelines, it is essential to identify women with a psychiatric pre-morbidity at antenatal care. A care management plan for follow-up postpartum should be mandatory for all women with a psychiatric premorbidity and women experiencing psychiatric symptoms during pregnancy. Foreign-born women constitute a vulnerable group in terms of psychiatric morbidity.
In conclusion, the MMR in Sweden was very low, but not really as low as the figure we reported to the WHO. To measure maternal mortality is difficult, but it is possible to acquire more accurate statistics by linking national registers. The risk of maternal death, as well as suicide during pregnancy and a year after delivery, is increased for women who were born in LICs. The elevated risk for maternal death could partly be explained by health conditions arising in the women’s countries of origin, inadequate utilisation of professional interpretation services, and by an increased risk of inadequate medical care. More than half of the women who died as a result of suicide during pregnancy and within a year after delivery had a known psychiatric disorder, although this was not always observed by the antenatal care providers. In one-fourth of the suicides, there were no indications of psychiatric disorders in the medical records or the NPR.

Maternal deaths and suicides associated with pregnancy will continue to occur in Sweden. Some complications are brutally unpredictable and sudden, and will inevitably lead to death. We, who work as health providers in maternal care, will continue to make mistakes, because we are human beings. However, by studying the cases of the women who died, we can illuminate flaws in the health care process, which will hopefully lead to improvements for all pregnant women.
Trots att 99% av alla mödradödsfall sker i låginkomstländer, händer det även i höginkomstländer att unga kvinnor dör på grund av komplikationer till graviditet och förlossning. Mödradödligheten i Europa har gått ned under flera decennier, men studier från flera europeiska länder samt USA har visat att nedgången har stagnerat och att mödradödligheten i vissa länder till och med har visat en svag uppgång. Utlandsfödda, särskilt kvinnor från Afrika söder om Sahara, har visat sig löpa högre risk för mödradöd än kvinnor födda i Europa. Detta har inte enkelt kunnat förklaras av enbart kända obstetriska eller socioekonomiska riskfaktorer.

Mödradöd definieras av WHO som död under graviditet eller inom 42 dagar efter att graviditeten avslutats, oavsett graviditetslängd, av sjukdomar eller komplikationer orsakade eller förvärrade av graviditeten. Däremot räknas inte olyckor och tillfälligt sammanträffande sjukdomar. Ett direkt mödradödsfall orsakas av en graviditets- eller förlossningskomplikation eller en kedja av händelser som startar med en sådan komplikation. Ett indirekt mödradödsfall orsakas av en sjukdom som uppstår före eller under men inte av graviditeten i sig, även om sjukdomens förlopp kan förvärras av de fysiologiska förändringar som graviditet medför. Dödsfall orsakade av förlossningsblödningar, barnsängsfieber och narkoskomplikationer är exempel på direkt mödradöd, medan död orsakad av försämring av en hjärt- eller njursjukdom klassificeras som indirekt. Mödradödlighet brukar mätas som en kvot; antalet mödradödsfall per 100 000 levande födda barn. I Sverige föds varje år omkring 100 000 levande födda barn. Nämnaren kan uppfattas som förvirrande eftersom en del kvinnor avlider utan att ha fött sitt barn, men den används ändå eftersom det är ett stabilt mått och det inte är möjligt att räkna antalet graviditeter.

Målet med denna avhandling var att studera aspekter av mödradöd i Sverige såsom förekomst, klassifikation och vårdkvalitet, med fokus på utlandsfödda kvinnor.

Vi fann att mödradödligheten i Sverige 1988–2007 var omkring sex per 100 000 levande födda barn. Med denna siffra hör vi till länderna med den
lägsta mödradödligheten i världen. Jämförelser mellan länder försvåras dock av underrapportering och olika sätt att definiera mödradödsfallet.


I en del fall var förloppet så plötsligt och oundvikligt att inget hade kunnat göras för att rädda kvinnan, men i två tredjedelar (51/73) av mödradödsfallen, fann vi suboptimala faktorer. I hälften av fallen (36/73) förekom minst en betydande suboptimal faktor, vilket betyder att vi bedömde att dessa dödsfall hade kunnat undvikas genom en annan handläggning. Faktorer som relaterade till hur man söker vård, exempelvis att kvinnan skrev in sig sent i mödravården, inte följde läkarens/barnmorskans råd eller inte kom på planerade besök, inträffade både hos svenskfödda och utlandsfödda, men oftare bland de utlandsfödda. Faktorer relaterade till vårdens tillgänglighet omfattar i låginkomstländer oftast försenad transport till sjukhus. I detta material kom kvinnorna fram till vårdföretagen, men tillgängligheten till god vård begränsades av en språkbarriär. Om patient och vårdgivare inte talar samma språk får inte vårdgivaren tillgång till patientens sjukh istoria och patienten får inte tillgång till vårdgivarens kunskap. För att komma över denna barriär krävs professionell tolkning. Suboptimala faktorer relaterade till tillgänglighet förekom enbart bland utlandsfödda kvinnor. I tre fall bedömdes språkbarriären vara en betydande suboptimal faktor, det betyder att döden kan ha kunnat undvikas om väl fungerande tolkning hade funnits på plats, och i tio fall bidrog språkproblemen till förloppet.

De vanligaste suboptimala faktorerna var relaterade till vårdens kvalitet och förekom i 50 fall (i 34 fall minst en betydande faktor och i 16 fall minst en smärre). Bristande vårdkvalitet omfattade att fel diagnos ställdes, att behandlingen fördröjdes, att remittering till annan vårdnivå/specialitet fördröjdes och/eller att kommunikationen brast mellan vårdgivare eller
kliniker. Faktorer som var relaterade till vårdens kvalitet drabbade ofta utlandsfödda än svenskfödda.

Fyra av kvinnorna dog på grund av komplikationer till sjukdomar som inte vanligen förekommer i Sverige, såsom tuberkulos och reumatisk feber. I dessa fall framgick att vårdgivarnas kunskaper om dessa sjukdomar brast.

Den fjärde studien är en beskrivande studie av alla kvinnor som tog sitt liv under graviditet eller inom ett år efter förlossning i Sverige under åren 1980–2007. Vi undersökte registerdata från dödsorsaksregistret, medicinska födelseregistret och patientregistret samt granskade journaler från kvinnornas sista graviditet, förlossning och BB-tid. I genomsnitt dog 3,7 kvinnor per 100 000 levande födda barn på grund av självmord under graviditet eller under första året efter förlossning. Denna kvot var stabil under studieperioden, medan självmord i nästan alla andra grupper i Sverige minskade. Kvinnor födda i låg- och medelinkomstländer löpte en högre risk (6,4 fall per 100 000 levande födda) än svenskfödda kvinnor (3,5 per 100 000 levande födda). Tre fjärder delar (77/103) av kvinnorna som avled hade fått psykiatrisk vård före, under eller efter graviditeten, medan för en fjärdedel (26/103) av kvinnorna fanns inga tecken till psykisk sjukdom noterade i journalen eller i patientregistret. Ett flertal av kvinnorna som tidigare fått psykiatrisk vård fängades inte upp av mödrahälsovården. Trots kunskapen att många psykiska sjukdomar försämras under tiden efter förlossningen hade endast en femtedel av kvinnorna en dokumenterad plan för hur de skulle följas upp avseende sin psykiska hälsa när de skrevs ut från BB. Vi jämförde självmordssätt och psykiatrisk sjuklighet mellan de kvinnor som tog sitt liv under graviditet eller inom sex månader efter förlossning med de som tog sitt liv 6–12 månader efter förlossning. Vi fann att våldsamma självmordssätt var vanligare bland de kvinnor som dog under graviditet eller inom det första halvåret efter förlossning jämfört med de kvinnor som dog under det andra halvåret efter förlossning. Generellt brukar förgiftning, som brukar klassificeras som det icke-våldsamma självmordssättet, vara det vanligaste självmordssättet bland kvinnor. Kvinnorna som tog sitt liv under graviditet eller inom sex månader efter förlossning hade mer sällan en psykiatrisk sjuklighet före graviditeten än de som dog 6–12 månader efter förlossning.

Sammanfattningsvis var mödradödligheten i Sverige mycket låg, men inte riktigt så låg som den siffra vi rapporterade till WHO. Att mäta mödradödlighet är svårt, men man kan få mer sanningsenlig statistik genom att samköra register. Kvinnor födda i låginkomstländer löpte en högre risikoför mödradöd samt för självmord under graviditet och året efter förlossning. Den förhöjda risken för mödradöd bland de utlandsfödda kvinnorna kunde till en del förklaras av sjukdomar med ursprung i kvinnornas
ursprungsländer, skillnader i hur man söker vård, bristande tolkanväsende samt att de oftare fick bristfällig vård. Mer än hälften av de kvinnor som begick självmord under graviditet och året efter förlorssning hade en känd psykiatrisk sjuklighet, och den hade inte alltid fångats upp av mödravården. I en fjärdedel av självmorden fanns inga signaler till psykisk ohälsa dokumenterade.

Alla mödradödsfall och självmord i samband med graviditet kan inte undvikas, men genom att studera fall med dödlig utgång kan brister i sjukvården belysas och förhoppningsvis leda till förbätttringar i vården.

Rekommendationer

För att statistiken över mödradödligheten i Sverige ska bli så sanningsenlig som möjligt rekommenderas rutinmässig samkörning av dödsorsaksregistret och medicinska födelseregistret.

Studierna i denna avhandling talar för att det skulle gå att minska mödradödligheten ytterligare, från en redan mycket låg nivå. Förutsättningarna för detta är ett nära samarbete mellan de olika specialiteter som kan vara inblandade vid svåra obstetriska komplikationer, samt att prioritera av patientsäkerhetsarbete vilket även omfattar att man säkerställer god kommunikation med alla patienter och mellan vårdgivare.

Enligt Förvaltningslagen har alla personer som inte behärskar svenska rätt till tolk i sjukvården. Mer än tio år har förflutit sedan den första studien publicerades som påvisade samband mellan kommunikationsproblem och ökad risk för perinatal död bland barnen till mödrar från Afrikas horn. Ån idag händer det att man i sjukvården försöker kommunicera med icke-svenskspråkiga patienter utan professionell tolk, vilket är anmärkningsvärt.

Ansvaret för att en patient inte följer vårdgivarens råd bör inte enbart läggas på patienten. Vårdgivaren har ansvar för att försöka förstå om det kan ligga missuppfattningar bakom patientens förhållningssätt.

Mer än var femte kvinna som söker mödrabehälsovården i Sverige idag är född i ett annat land. En fullständig sjukhistoria omfattar att man efterfrågar kvinnans hälsa före, under och efter migration till Sverige. Man bör vara medveten om att utlandsfödda kvinnor kan bära med sig hälsotillstånd som vi inte är vana att se i Sverige idag.

I enlighet med mödrabehälsovårdens nationella riktlinjer är det viktigt att fånga upp kvinnor med psykisk ohälsa, och särskilt viktigt är det att identifiera
kvinnor med svårare psykiatriska tillstånd. Samtliga kvinnor med tidigare psykisk ohälsa och kvinnor som uppvisar sådana symptom under graviditeten bör ha en dokumenterad plan för uppföljning efter förlossningen. Utlandsfödda kvinnor utgör en sårbar grupp avseende psykisk ohälsa.
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