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Essén, Birgitta; Bödker, Birgit; Sjöberg, Nils-Otto; Langhoff-Roos, Jens; Greisen, Gorm;  
Gudmundsson, Saemundur; Östergren, Per-Olof

*Published in:*  
BJOG: An International Journal of Obstetrics & Gynaecology

*DOI:*  
[10.1111/j.1471-0528.2002.01077.x](https://doi.org/10.1111/j.1471-0528.2002.01077.x)

2002

[Link to publication](#)

*Citation for published version (APA):*

Essén, B., Bödker, B., Sjöberg, N.-O., Langhoff-Roos, J., Greisen, G., Gudmundsson, S., & Östergren, P.-O. (2002). Are some perinatal deaths in immigrant groups linked to sub-optimal perinatal care services? Perinatal audit of infants to women from Africa's Horn delivered in Sweden 1990-96. *BJOG: An International Journal of Obstetrics & Gynaecology*, 109(6), 677-682. <https://doi.org/10.1111/j.1471-0528.2002.01077.x>

*Total number of authors:*

7

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PO Box 117  
221 00 Lund  
+46 46-222 00 00

III

## **Are some perinatal deaths in immigrant groups linked to sub-optimal perinatal care services?**

### **Perinatal audit of infants to women from Africa's Horn delivered in Sweden, 1990-96**

*Authors, titles, and institutes where the work was conducted:*

Birgitta Essén, MD<sup>1</sup>

Birgit Bödker, MD<sup>3</sup>

N-O Sjöberg, Professor<sup>1</sup>

Jens Langhoff-Roos, Senior Lecturer<sup>3</sup>

Gorm Greisen, Professor<sup>4</sup>

Saemundur Gudmundsson, Senior Lecturer<sup>1</sup>

P-O Östergren, Senior Lecturer<sup>2</sup>

<sup>1</sup> Department of Obstetrics and Gynaecology, Malmö University Hospital, Lund University, Malmö, Sweden

<sup>2</sup> Department of Community Medicine, Malmö University Hospital, Lund University, Malmö, Sweden

<sup>3</sup> Department of Obstetrics and Gynaecology, University of Copenhagen, Copenhagen, Denmark

<sup>4</sup> Department of Neonatology, Rigshospitalet, University of Copenhagen, Copenhagen, Denmark

*Corresponding author:*

Birgitta Essén, MD

Department of Obstetrics and Gynaecology

Lund University

University Hospital MAS

S-205 02 Malmö, Sweden

[Birgitta.Essen@obst.mas.lu.se](mailto:Birgitta.Essen@obst.mas.lu.se)

Telephone +46-40-331000 (x 7192)

Fax +46-40-962600

*Running head:* Perinatal death in immigrant groups and sub-optimal care factors

## **ABSTRACT**

*Objective:* To test the hypothesis that sub-optimal factors in perinatal care services resulting in perinatal deaths were more common among immigrant mothers from the Horn of Africa, as compared to Swedish mothers.

*Design:* A perinatal audit, comparing cases of perinatal deaths among children of African immigrants residing in Sweden, with a stratified sample of cases among native Swedish women.

*Setting:* Sixty-three cases of perinatal deaths among immigrant east African women delivered in Swedish hospitals in 1990–1996, and 126 cases of perinatal deaths among native Swedish women. Time of death and type of hospital were stratified.

*Main outcome measures:* Sub-optimal factors in perinatal care services, categorised as maternal, medical care, and communication.

*Results:* The rate of sub-optimal factors likely to result in potentially avoidable perinatal death was significantly higher among African immigrants. In the group of antenatal deaths, the OR was 6.2 (CI 1.9-20); the OR for intrapartal deaths was 13 (CI 1.1-166); and the OR for neonatal deaths was 18 (CI 3.3-100), when compared with Swedish mothers. The most common factors were delay in seeking health care, mothers refusing caesarean sections, insufficient surveillance of IUGR (intrauterine growth restriction), inadequate medication, misinterpretation of CTG (cardiotocography), and interpersonal miscommunication.

*Conclusions:* Sub-optimal factors in perinatal care likely to result in perinatal death were significantly more common among east African than native Swedish mothers, affording insight into socio-cultural differences in pregnancy strategies, but also the sub-optimal performance of certain health-care routines in the Swedish perinatal care system.

## INTRODUCTION

Sweden exhibits one of the lowest perinatal mortality rates in the world. A decrease in recent decades has been attributed to both socio-economic improvements and better perinatal care. However, the increasingly multi-ethnic composition of the Swedish population presents a challenge to existing Swedish perinatal care services. Studies over the last few decades have not accounted for the higher perinatal mortality in Sweden among women born abroad.<sup>1,2</sup> A recent investigation has shown that women in Sweden who immigrated from sub-Saharan Africa (predominantly Somalia) represent an ethnic group with increased perinatal mortality.<sup>3</sup> One hypothesis put forward to explain this observation is that culturally determined strategies of handling pregnancy and childbirth by this particular ethnic group affect perinatal outcomes.<sup>4</sup> In order to gain an increased understanding of these phenomena, a medical and anthropological study was undertaken. It was determined from Somali women residing in Sweden that they had particular pregnancy strategies in seeking to achieve a safe birth. For instance, due to fear of caesarean section—in their perception a life-threatening event—these women reduced their food intake to prevent dystocia due to the size of the baby. It was hypothesized that the various maternal strategies of these women unintentionally resulted in sub-optimal perinatal care, which, in turn, may have led to a higher perinatal mortality rate in this group.

Perinatal mortality is traditionally considered an indicator of the level of perinatal care. Quality assessment can, therefore, be carried out by a perinatal audit, identifying sub-optimal (i.e., potentially avoidable) perinatal care factors in cases which resulted in perinatal death.<sup>5</sup> The Nordic-Baltic perinatal death classification, introduced in 1995, identifies three stages at which fatalities are potentially avoidable with improved care: antenatal, neonatal, and intrapartum surveillance.<sup>6</sup>

The aim of this study was to test the hypothesis that sub-optimal factors in perinatal care services are more likely to result in potentially avoidable perinatal death among immigrant mothers from the Horn of Africa, than among native-born Swedish mothers.

## METHODS

A perinatal audit based on medical records was made of 183 perinatal deaths in Sweden from 1990 to 1996. These represented the full cohort of pregnant women from the Horn of Africa and a stratified sample of native-born Swedish women who delivered in Swedish hospitals during this period. Perinatal death was defined as stillbirth after 28 weeks of gestation, or death within the first week of life. Using the national Swedish Medical Birth Register, all 63 perinatal deaths of children born in Sweden to women originating from Ethiopia, Somalia, or Eritrea (hereafter referred to as ESE) were identified. For each case deriving from ESE mothers, two perinatal deaths of infants born to Swedish women at the same hospital, and matched by time of death (ante-, intra- or postpartum), were selected at random. Records could not be found in two of the 126 Swedish instances. One ESE and 11 Swedish perinatal deaths listed in the Medical Birth Register did not match the records and were excluded. Consequently, 11 of the ESE cases were only matched by a single Swedish case.

Narratives based on individual records were written for each birth. They contained in-depth descriptions of relevant time-related events, including such elements as medical history, social conditions, communication, surveillance, interventions, and outcome. The narratives limited themselves solely to data obtained from the records, noting if pertinent information was missing.

### Audit Procedure

An expert panel of three obstetricians and one neonatologist was convened to review the 175 cases. Panellists were blind as to the country of origin of each woman studied. The panel

worked with the case narratives to identify sub-optimal factors which were likely to have contributed to perinatal death. Primary criteria (explicit and primarily evidence-based) for identifying sub-optimal factors were adopted from the EuroNatal study of perinatal mortality in Europe.<sup>7</sup>

Other sub-optimal factors identified during the audit were categorised as secondary criteria (Table 2). Sub-optimal factors were assigned to one of three categories: maternal factors (which the mother did not realize were detrimental), medical care, or communication.

The final determination of the existence of sub-optimal factors was based on the consensus of the panel. The expert opinion of the neonatologist was decisive in matters of neonatal care, while the three obstetricians determined antenatal and intrapartum issues. In cases of divergent opinions, the most experienced obstetrician was given the final word.

For purposes of categorising perinatal deaths to ascertain which were potentially avoidable, we used a modified version of the Nordic-Baltic perinatal death classification scheme.<sup>6</sup> According to this system, all cases involving fetal malformation are assigned to a common category, regardless of time of death, since they are almost always unavoidable. The remaining mortalities are grouped in mutually exclusive categories, based upon four variables: (a) time of death in relation to delivery (antenatal, intrapartum, and neonatal), (b) small for gestational age (SGA with birth weight < mean – 2 Standard Deviations),<sup>8</sup> (c) gestational age (< 28, 28–33, or > 33 weeks), and (d) neonatal distress (Apgar score < 7 at 5 min). In a previous study, a large proportion of SGA-antenatal deaths, intrapartum deaths, and neonatal deaths of infants > 33 weeks were considered potentially avoidable by improved care.<sup>9</sup>

As the stratified sample of the Swedish women was not a full cohort, they were compared to a full national cohort of perinatal deaths, classified by the same Nordic-Baltic categories, in order to see whether they were representative of the full cohort, even though all analyses were confined to the described strata.<sup>6</sup>

Statistical analyses were performed by means of SPSS (Norusis, 1990). A difference was considered statistically significant if  $p < 0.05$ . The relative risk was estimated by means of odds ratios (OR), applying 95 % confidence intervals (CI). A multivariate analysis was performed by means of conditional logistic regression, where variables were selected on the basis of the univariate analysis of risk factors.

## RESULTS

Ninety-eight per cent of the ESE women and 96% of the Swedish women studied were between 19 and 40 years old; they were nullipara in 34% and 50% of the cases, respectively. Every third Swedish woman was a smoker in early pregnancy, as compared to only one of all the ESE women. The total number of twin pregnancies was nine (one ESE woman and eight Swedish women). In only 12% of the ESE mothers with SGA-infants was the *absence* of fetal movements reported within 24 hours, as compared to 71% for the Swedish women.

Table 1 presents the risk factors found in the ESE versus the Swedish group by antenatal, intrapartum, and neonatal death. The ESE mothers were more likely to give birth to SGA-infants and to suffer from chronic disease.

Sub-optimal factors likely to have contributed to potentially avoidable perinatal death are shown in Table 2. All categories of such factors were more common among the ESE group, except death in placenta abruption among children of smoking mothers and undetected IUGR (intrauterine growth restriction).

The odds of sub-optimal factors were higher in the ESE group as compared to the Swedish group in all three strata of time of death in relation to delivery (Table 3). In a multivariate analysis, an adjustment for the two risk factors that were significantly higher among the ESE women was made in order to assess how much of the higher risk could be explained by these factors. In comparing ESE and Swedish mothers, the inclusion of SGA as a covariate changed

the OR for sub-optimal factors likely to contribute to antenatal deaths to 1.4 (CI 0.5-3.9), whereas factoring in maternal disease did not affect the unadjusted estimate.

Table 4 shows the distribution of deaths among ESE and Swedish women in the cohort of this study, in comparison with the distribution of perinatal deaths in the full national birth cohort in Sweden in 1991—again using the Nordic-Baltic perinatal death classification scheme.<sup>6</sup> No major differences in the pattern of perinatal death were found between our stratified sample of Swedish women, and the full national cohort of Swedish women giving birth in 1991.

## DISCUSSION

Our investigation shows that, to a significant degree, sub-optimal factors in perinatal care such as can be linked to perinatal death were more often observed in all three stages—antenatal, delivery, and neonatal—among ESE mothers than Swedish mothers. Potentially avoidable deaths in the ESE group may be related to maternal pregnancy strategies, deficiencies in medical care, and verbal miscommunication.

The present results may have been biased by misclassification or confounding. Autopsies were only conducted in 36% of the ESE versus 70% of the Swedish cases, leading to a possible underestimation of the number of cases in the ESE group classified as “fetal malformation”, i.e., non-avoidable.

The stratification we performed in the sample of perinatal deaths among children born to Swedish women did not introduce any major differences in the types of perinatal deaths, when compared with the full national cohort of perinatal deaths in Sweden in 1991. This decreases the likelihood of selection bias regarding the Swedish cases.

Theoretically, dependent misclassification might originate by using information taken from medical records which were completed *after* a fatal outcome was known. Care providers who were aware of such an outcome had the responsibility of supplying some of the written information. This knowledge could have biased the provider to focus on sub-optimal *maternal*, rather than on inadequate *medical care* factors, resulting in an overestimation of the importance of such factors for potentially avoidable perinatal death. Still, provided that the propensity toward such misclassification was the same for both ethnic groups, no difference between ESE and Swedish mothers should have resulted. In addition, despite the attempt to maintain a blind cohort, certain information in the narratives may have indirectly disclosed the ethnic affiliation of the some cases under review to the expert panel, as when mention of severe communication problems was cited in the record.

In order to reduce the risk of personal idiosyncrasies affecting the results of the audit, explicit primary criteria for the definition of sub-optimal factors were established in advance, and secondary criteria were discussed thoroughly prior to consensus.<sup>10</sup>

### (a) Avoidable perinatal deaths related to maternal pregnancy strategies

SGA related antenatal deaths, and those related to a pregnant woman’s failure to report the absence of fetal movements, were more common among children of ESE women. Mothers from ESE often did not participate in routines of IUGR surveillance. This again reflects a strategy among some ESE women for keeping the fetus small in order to avoid obstructed delivery. From the point of view of these women, a doctor’s recommendation that they undergo surveillance to avoid IUGR seems inappropriate. Their reluctance is not because they are neglectful mothers, but because they wish to have a small baby, not comprehending that IUGR puts mother and child at greater risk for death.<sup>4</sup> In addition, ESE women were more frequently late in booking antenatal care, and were less inclined to schedule routine ultrasound estimations of gestational age—factors which might impede the detection of IUGR.

Sixty-three per cent of the ESE cases, which resulted in intrapartum death were classified as potentially avoidable, as compared with only 11% of the corresponding Swedish group. A comparison can be made with other studies in which 30% to 55% of intrapartum deaths were regarded as potentially avoidable.<sup>11,12</sup> Elevated intrapartum mortality may be associated with a low rate of interventions during delivery. However, all of the ESE cases were emergency caesarean sections, and national figures show that ESE immigrants run the highest risk of caesarean section in Sweden.<sup>13</sup> Thus, the caesarean sections seem to have been performed too late. This is supported by the finding that ESE mothers often refused or delayed emergency caesarean section, even when experiencing grave symptoms, such as haemorrhage. Fear of severe complications or even death may cause this group of immigrant women to avoid seeking medical care, or to refuse interventions potentially involving caesarean section. Their apprehensiveness seems to be primarily grounded on memories of the situation prevailing in their countries of origin, where there was a high risk of maternal mortality. The notion among these ESE women seems to be that caesarean section causes death, rather than viewing the procedure as an attempt to avoid a fatal outcome.<sup>4</sup>

The Swedish antenatal care programme has, heretofore, lacked appropriate measures to meet the pregnancy strategies of this immigrant group. As a matter of public policy, it would appear to be important that ESE women in Sweden be informed about perinatal health issues, be encouraged to book antenatal care early, attend clinical sessions regularly, and be trained to seek immediate health care when certain symptoms appear.

The dominant sub-optimal maternal criterion among the Swedish mothers in our cohort was smoking (resulting in placental abruption), a well-known avoidable factor.<sup>14</sup>

#### **(b) Avoidable perinatal deaths related to miscommunication**

According to the findings of this study, it appears that some intrapartal and neonatal deaths among children born to ESE mothers could have been avoided if an interpreter had been present during emergency situations. Furthermore, certain cases might also have had a positive outcome if the frightened mother had understood why a caesarean section was imperative, and if the obstetrician had foreknowledge of the woman's reasons for refusing the intervention. Routine use of interpreters, therefore, is highly recommended. To our knowledge, this sub-optimal factor in relation to perinatal death has not previously been described. It would appear that Swedish perinatal care services do not presently meet the communication needs required by a multiethnic population.

#### **(c) Avoidable perinatal death related to sub-optimal medical care**

In antenatal deaths, insufficient monitoring of IUGR was identified as a sub-optimal factor leading to avoidable perinatal deaths. The lack of ESE immigrants receiving such care may be a lingering effect of cutbacks in visits made in the antenatal care program during the 90s.<sup>15,16</sup>

More than 80% of all neonatal deaths in the ESE group were potentially avoidable by adequate medical care, as compared to 28% in the Swedish group. ESE mothers and their infants experienced higher rates of inadequate CTG (cardiotocography) interpretation, late arrival of paediatricians, delayed transferral to neonatal intensive care units (NICU), and greater instances of inadequate medication to mother or premature infant (cortisone or surfactant). A previous study in Sweden has shown that newborns to ESE women were transferred to NICUs less frequently than were the newborns of Swedish women.<sup>3</sup> Health care personnel may also be less experienced in surveillance of mothers of ESE origin and their infants, resulting in a less active and belated management.

## **CONCLUSION**

The higher prevalence of sub-optimal factors in the perinatal care received by children born in Sweden to mothers from the Horn of Africa were likely to result in a higher incidence of potentially avoidable perinatal death than their counterparts born to native Swedish mothers. ESE women received less optimal care due to inappropriate maternal pregnancy strategies, inadequate medical treatment, and miscommunication. It appears clear than an unfortunate interaction exists between specific pregnancy strategies among ESE women in Sweden and the sub-optimal performance of Swedish perinatal care services. However, a greater awareness of these circumstances among all health care professionals involved could effectively change this unfavourable encounter between patient and care provider. Solutions might be sought on the basis of discussions between ESE women and the health care personnel responsible for their care.

## **ACKNOWLEDGEMENTS**

The authors would like to express their appreciation to Dr. Jan Hendrik Richardus, the EuroNatal Study, Rotterdam, Holland, for his cooperation. This study has been supported by grants from the Faculty of Medicine and the Health Research Council, Lund University; the University Hospital MAS, Malmö; and the Foundation Samaritan, Sweden.

## **CONTRIBUTORS**

BE had the original idea for the study, wrote the narratives, and conducted the record survey and, together with JLR and PÖ, is responsible for the study design. The perinatal audit expert group consisted of SG, BB, JLR, and GG. BE is the guarantor; she analysed and wrote the paper in discussion with the multidisciplinary group of authors, among whom especially PO, BB, GG, and JLR had an active part in the writing process.

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**Table 1.** Risk factors for perinatal death of children born to immigrant women from Ethiopia, Somalia, or Eritrea (ESE), versus women of Swedish origin, in Sweden 1990-96

Death in relation to delivery and risk factors	ESE origin (n = 62)	Swedish origin (n = 113)	Odds Ratio (OR) (95% Confidence Interval)
<b>Antenatal</b>			
Malformation	3	7	0.8 (0.2-3.3)
SGA	21	19	3.4 (1.5-7.9)
Preterm	17	26	1.4 (0.6-3.2)
Maternal disease	12	10	2.7 (1.1-7.4)
<b>Intrapartal</b>			
Malformation	0	1	
SGA	3	1	*
Preterm	4	0	*
Maternal disease	5	2	5.8 (0.7-4.9)
<b>Neonatal</b>			
Malformation	4	14	0.4 (0.1-1.6)
SGA	2	10	0.3 (0.1-1.6)
Preterm	6	17	0.5 (0.1-1.8)
Neonatal distress	10	24	0.6 (0.2-2.0)

Preterm = < 33 weeks of gestation

SGA = small for gestational age

Neonatal distress = Apgar score < 7.5 minutes

Maternal disease = diabetes, epilepsy, HIV-infection, malaria, cardiac disease

\* Too few cases for meaningful calculation of OR

**Table 2.** Criteria for sub-optimal factors\* likely to have contributed to perinatal death of children born to immigrant women from Ethiopia, Somalia, or Eritrea (ESE), versus women of Swedish origin, in Sweden during 1990-96.

Categories of sub-optimal factors	ESE origin (n = 62)	Swedish origin (n = 113)
<b>Maternal factors</b>		
<i>Primary criteria</i>		
IUGR and absence of fetal movement not reported by mother	7	0
Placental abruption, smoking and/or SGA	0	10
<i>Secondary criteria</i>		
Delay in contact with health care when needed or non-participation in clinical routines	9	0
Mother refusing emergency caesarean section	6	0
<b>Medical care</b>		
<i>Primary criteria</i>		
Insufficient fetal surveillance of suspected IUGR	4	2
Undetected IUGR after 32 wks of gestation and SGA infant	1	3
<i>Secondary criteria</i>		
Inadequately given medication to mother or premature infant	10	6
Misinterpretation of CTG	6	1
Late arrival of paediatrician or late transferral of unstable infant to NICU	4	
Failure to detect operable malformation in unstable infant	1	1
<b>Communication</b>		
Verbal miscommunication in absence of interpreter	5	0

SGA = small for gestational age; IUGR = intrauterine growth restriction; NICU = neonatal intensive care unit; CTG = cardiotocography

\* One case could belong within more than one category

**Table 3.** Relative risk regarding sub-optimal factors likely to contribute to perinatal death of children born to immigrant mothers from Ethiopia, Somalia, or Eritrea (ESE) (n = 62), versus women of Swedish origin (n = 113), 1990-96

<b>Death in relation to delivery</b>	<b>ESE origin (n)</b>	<b>Swedish origin (n)</b>	<b>Odds Ratio</b>	<b>(95% Confidence Interval)</b>
Antenatal	18 (38)	17 (72)	6.2	(1.9-20)
Intrapartal	5 (8)	1 (9)	13	(1.1-166)
Neonatal	13 (16)	9 (32)	18	(3.3-100)

**Table 4.** Perinatal deaths, following the Nordic-Baltic classification, of children born to immigrant mothers from Ethiopia, Somalia, or Eritrea (ESE)<sup>\*</sup>, and to women of Swedish origin, 1990-96<sup>†</sup>, versus the total of perinatal deaths in Sweden, 1991.

<b>Categories of perinatal death</b>	<b>Perinatal deaths in ESE group (n = 62) %</b>	<b>Perinatal deaths in Swedish group (n = 113) %</b>	<b>Total of perinatal deaths in Sweden, 1991 (n = 780) %</b>
I Malformation	6 (10)	22 (19)	179 (23)
II Stillbirth, SGA $\geq$ 28 wks	16 (26)	11 (10)	90 (12)
III Stillbirth, unexplained and -V multiple pregnancy	19 (31)	54 (48)	293 (37)
VI Intrapartum death	8 (13)	8 (7)	23 (3)
VIII Neonatal death $\geq$ 28 wks	10 (16)	6 (5)	81 (11)
-XI			
XII Neonatal death < 28 wks	3 (4)	12 (11)	114 (14)

SGA = small for gestational age; \* Total cohort; † Stratified sample of a total cohort