Registration of Births and Deaths in Europe: The Challenges

Ashna Mohangoo and Jennifer Zeitlin
Content

- Euro-Peristat versus WHO criteria
- Variation in mortality rates
- Registration of live and stillbirths
- Inclusion of TOP
- Exclusion of early preterm births and deaths
- Euro-Peristat’s challenges and discussion
Euro-Peristat collects data on births and deaths from 22 completed weeks of gestation
WHO definition

- The WHO defines the perinatal period by gestational age
- starting from the 22nd completed week of pregnancy
- but recommends that countries collect data on stillbirths based on birth weight
A stillbirth is defined as death of a fetus that has reached a birth weight of 500 grams if the birth weight is unavailable; a gestational age of 22 completed weeks or a crown-to-heel length of 25 cm is used.
The first EPHR showed wide variability in perinatal mortality rates.

The highest mortality rates were approximately 3.5 times higher than the lowest.
Variability between European countries?

▷ Real differences or artefacts?
▷ Registration-related differences?
▷ Differences in population characteristics?
▷ Differences in health care services?
▷ Differences in policies towards screening and terminations of pregnancy?
Gestational Age Patterns of Fetal and Neonatal Mortality in Europe: Results from the Euro-Peristat Project

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Abstract

**Background:** The first European Perinatal Health Report showed wide variability between European countries in fetal (2.6–9.1%) and neonatal (1.6–5.7%) mortality rates in 2004. We investigated gestational age patterns of fetal and neonatal mortality to improve our understanding of the differences between countries with low and high mortality.

**Methodology/Principal Findings:** Data on 29 countries/regions participating in the Euro-Peristat project were analyzed. Most European countries had no limits for the registration of live births, but substantial variations in limits for registration of stillbirths before 28 weeks of gestation existed. Country rankings changed markedly after excluding deaths most likely to be affected by registration differences (22–23 weeks for neonatal mortality and 22–27 weeks for fetal mortality). Countries with high fetal mortality ≥28 weeks had on average higher proportions of fetal deaths at and near term (≥37 weeks), while proportions of fetal deaths at earlier gestational ages (28–31 and 32–36 weeks) were higher in low fetal mortality countries. Countries with high neonatal mortality rates ≥24 weeks, all new member states of the European Union, had high gestational age-specific neonatal mortality rates for all gestational-age subgroups; they also had high fetal mortality, as well as high early and late neonatal mortality. In contrast, other countries with similar levels of neonatal mortality had varying levels of fetal mortality, and among these countries early and late neonatal mortality were negatively correlated.

**Conclusions:** For valid European comparisons, all countries should register births and deaths from at least 22 weeks of gestation and should be able to distinguish late terminations of pregnancy from stillbirths. After excluding deaths most likely to be influenced by existing registration differences, important variations in both levels and patterns of fetal and neonatal mortality rates were found. These disparities raise questions for future research about the effectiveness of medical policies and care in European countries.

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### Table 1. Criteria for registration of live births and stillbirths and inclusion of terminations of pregnancy in Europe in 2004.

<table>
<thead>
<tr>
<th>Country</th>
<th>Live births</th>
<th>Stillbirths</th>
<th>TOP included</th>
<th>TOP included in a separate data system</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>No limit</td>
<td>≥500 grams</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>BE: Brussels</td>
<td>No limit</td>
<td>≥22 weeks or ≥500 grams</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>BE: Flanders</td>
<td>No limit</td>
<td>≥500 grams</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Cyprus</td>
<td>No limit</td>
<td>No data available</td>
<td>No data available</td>
<td>No data available</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>≥500 grams or any birth weight surviving the first 24 hours</td>
<td>≥22 weeks</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Denmark</td>
<td>No limit</td>
<td>≥22 weeks</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Estonia</td>
<td>No limit</td>
<td>≥22 weeks or ≥500 grams</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Finland</td>
<td>No limit</td>
<td>≥22 weeks or ≥500 grams</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>France</td>
<td>≥22 weeks or ≥500 grams</td>
<td>≥22 weeks or ≥500 grams</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Germany</td>
<td>No limit</td>
<td>≥500 grams</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Greece</td>
<td>No limit</td>
<td>legal limit of ≥28 weeks</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Hungary</td>
<td>No limit</td>
<td>≥24 weeks or ≥500 grams</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Ireland</td>
<td>No limit</td>
<td>≥24 weeks or ≥500 grams</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Italy</td>
<td>No limit</td>
<td>≥500 grams</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Latvia</td>
<td>No limit</td>
<td>≥22 weeks</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Lithuania</td>
<td>≥22 weeks</td>
<td>≥22 weeks</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>No limit</td>
<td>≥22 weeks or ≥500 grams</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Malta</td>
<td>No limit</td>
<td>≥22 weeks or ≥500 grams</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>≥22 weeks or ≥500 grams</td>
<td>≥24 weeks for civil registration</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Norway</td>
<td>≥12 weeks</td>
<td>≥24 weeks for perinatal registry</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Poland</td>
<td>≥500 grams</td>
<td>≥24 weeks</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Portugal</td>
<td>≥24 weeks</td>
<td>≥500 grams</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Slovakia</td>
<td>No limit</td>
<td>≥22 weeks or ≥500 grams</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Slovenia</td>
<td>≥500 grams</td>
<td>≥500 grams</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Spain</td>
<td>No limit</td>
<td>≥26 weeks (national) or ≥22 weeks (region Valencia)</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Sweden</td>
<td>No limit</td>
<td>≥26 weeks</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>UK: England and Wales</td>
<td>No limit</td>
<td>legal limit of ≥24 weeks voluntary notification at 22–23 weeks</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>UK: Northern Ireland</td>
<td>No limit</td>
<td>legal limit of ≥24 weeks voluntary notification at 22–23 weeks</td>
<td>TOP is not legal*</td>
<td>No</td>
</tr>
<tr>
<td>UK: Scotland</td>
<td>No limit</td>
<td>legal limit of ≥24 weeks voluntary notification at 22–23 weeks</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

*The legislation which legalised abortion in the rest of the United Kingdom does not cover Northern Ireland, but TOP are occasionally done there under case law.*
No Limits for Registration of Live Births

★ Exceptions

★ Czech Republic:
  ≥ 500 grams or any birth weight surviving the first 24 hours

★ France and the Netherlands:
  ≥ 22 weeks or ≥ 500 grams

★ Norway:
  ≥ 12 weeks

★ Poland:
  ≥ 500 grams
Substantial Variation in Registration of Stillbirths

- **BW criteria of ≥ 500 grams:**
  - Austria, Flanders, Germany, Poland, Slovenia

- **GA criteria:**
  - ≥ 12 wks in Norway
  - ≥ 16 wks in the Netherlands (Perinatal Registry)
  - ≥ 22 wks Czech Republic, Denmark, Latvia, Lithuania
  - ≥ 24 wks in Portugal and United Kingdom
  - ≥ 180 days in Italy and Luxembourg
  - ≥ 28 wks in Greece and Sweden
Substantial Variation in Registration of Stillbirths

- GA and BW criteria: ≥ 22 wks or ≥ 500 grams
  Brussels, Estonia, Finland, France, Malta, Slovak Republic

- GA and BW criteria: ≥ 24 wks or ≥ 500 grams
  Hungary and Ireland

- Voluntary vs. obligatory registration:
  United Kingdom:
  Legal limits of ≥ 24 wks, but voluntary notification at 22-23 wks
  The Netherlands:
  Civil registration ≥ 24 wks, perinatal registration ≥ 16 wks
Differences in Registration and Inclusion of TOP

› TOP were not included by most countries

› TOP were included
  by France, the Netherlands, England and Wales, Scotland

› TOP were registered in separate system
  Finland and Italy provided additional data on TOP

› TOP were not registered
  by Austria, Brussels, Flanders, Greece, Luxembourg, Portugal
Differences in Registration and Inclusion of TOP

- TOP are illegal and not performed in Malta
- TOP are not legal and not performed in Ireland
- TOP are not legal in Northern Ireland, but are occasionally done under case law
Impact of different inclusion criteria on perinatal mortality rates
Impact of different inclusion criteria on perinatal mortality rates

The exclusion of early preterm births and deaths affects ranking
Figure 3. Correlation between fetal and neonatal mortality rates, after exclusion of deaths most likely influenced by registration differences. High mortality countries are presented in bold. Correlation for fetal and neonatal mortality: $r = 0.646$ ($p < 0.001$).

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Fetal deaths at 22-27 wks and neonatal deaths at 22-23 wks were excluded to minimize the effect of differences in registration requirements and TOP legislation.
Euro-Peristat’s Limitations

- Despite efforts of Euro-Peristat to ensure comparability in definitions
- Euro-Peristat’s lack of knowledge about the extent to which these were applied uniformly in all countries
- Limits Euro-Peristat’s ability to assess real fetal mortality at 22-27 weeks and real neonatal mortality at 22-23 weeks
Euro-Peristat’s Limitations

- A related issue is the registration of TOP, which is managed very differently from one country to another, and TOP are not always included as fetal deaths.

- TOP varied between 3-28% of total fetal deaths in those countries where this proportion could be computed.

- In France, even an larger proportion of early fetal deaths is estimated to be TOP.
Challenges for Euro-Peristat Action

- Collect comparable data on European level
- Assess *real* fetal mortality at 22-27 weeks
- Assess *real* neonatal mortality at 22-23 weeks
- Differentiate between fetal mortality with and without TOP
- Assess the *real* proportion of total fetal deaths that is TOP
If countries were not able to provide data using the Euro-Peristat’s definition
   - local definition was used
   - e.g. different inclusion criteria for registration of stillbirths

To what extent should these countries who provided data using their own definitions be included for international comparisons?
Euro-Peristat’s versus WHO criteria

- Continue data collection on births and deaths based on Euro-Peristat inclusion criteria of 22 completed weeks of gestation?

- Change the inclusion criteria to WHO criteria, which is not solely based on gestational age?
Thank you!