



Epidemiology of prematurity — How valid are comparisons of neonatal outcomes?

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KEYWORDS

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Summary Direct comparisons of neonatal outcomes at any level (unit, regional or international), require detailed validation and standardisation to ensure 'like for like' evaluation. Reported variation in neonatal performance may be either real or the result of one or more artefacts of the data collection. These issues need to be understood in order for an accurate interpretation to be made. Such artefacts are a particular feature of national data collection systems and can lead to serious misinterpretation. For example, very preterm deliveries have a major impact on neonatal mortality rates in developed countries with births before 33 weeks of gestation accounting for between 35% and 70% of neonatal deaths. Variation in the rate of very preterm delivery rates and differing practices regarding registration of these infants can have a major effect on the recorded neonatal mortality rate.

At a more local level the validity of neonatal comparisons often depends upon whether the question being raised is appropriately matched to the data obtained to answer it. Problems arise when the question being addressed has been poorly framed or the data used to answer it has been inappropriately chosen. Comparisons using questions based on clearly defined standardised outcome measures and good quality prospective data collection are a much better way to proceed.

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Background

There are two main reasons for carrying out comparisons of neonatal outcomes: (1) as an indicator of the health of mothers and babies in a population allowing for inter-regional and international comparisons, and (2) to monitor the quality of perinatal and neonatal care provision providing information for the performance management of perinatal and neonatal services.

In all countries, monitoring the wellbeing of the population is a key public health activity, which is often devolved to local teams. For example, in the UK this role falls to the Primary Care Trusts who commission care for populations of around 200,000. In relation to perinatal health they require local information to ensure key issues are being addressed, e.g. teenage pregnancy rates and the prevalence of smoking during pregnancy, which have an impact on prematurity rates and, thus, by implication, on neonatal and infant mortality rates. Current UK government health inequality targets include the reduction in reported infant mortality rates by 10% by 2010.¹ Neonatal mortality constitutes approximately 80% of infant mortality

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and it is, therefore, of great importance to establish the accuracy and comparability of the measurement of the reported mortality rates. Direct comparisons of neonatal outcomes at any level (unit, regional, national or international), require detailed validation and standardisation to ensure 'like for like' evaluation. In particular, it is essential that the baseline denominator is clearly defined.

Whilst the routine statistics produced by individual countries may still have relevance to developing countries (where most of the deaths are to mature infants and are associated with infection, poor maternal health and limited care provision), in the developed world these issues are far less important and the majority of deaths are due to very preterm deliveries.^{2,3} The development of more focussed neonatal outcome measures is, therefore, required for comparisons both within and between developed countries. Data collection required for such comparisons needs to be flexible enough to allow for the comparison of different types of populations depending upon the question being asked, e.g. the use of total birth cohorts to investigate issues concerning the health of populations, and all potential live births when issues of the quality of perinatal and neonatal services need to be addressed.

Although, over time, various groups have agreed on the definitions and standards for measuring perinatal and neonatal outcomes,^{4,5} the problems of compliance and reporting variations still occur. General recognition of these problems is, however, still limited and therefore simplistic media headlines are widely quoted by both the public and political parties. There is, therefore, a requirement for the production of outcome data that can be simply interpreted by all interested groups including the lay public. Early steps were made by the World Health Organisation (WHO) towards agreement,⁶ but they were limited by the use of birth weight as the lower cut-off. This was later seen as inappropriate since birth weight is biologically dependent upon both gestational age and fetal growth rate,⁷ whereas gestational age is a biological measure directly related to maturity. The perinatal period is now defined by the WHO as running from 22 completed weeks (154 days) of gestation (when birth weight is normally 500 g) and ending 7 completed days after birth.⁸ The recent European Peristat project⁵ has produced a suggested set of identifiers for monitoring and describing perinatal health. Results from their feasibility study show, however, that variations in the registration of live and stillbirths and the reporting of gestational age across European countries limit the meaningful production of their recommended core indicators for fetal, neonatal and infant mortality.²

Very preterm deliveries have a major impact on neonatal mortality rates in developed countries in particular. Over recent years, as the neonatal mortality rate has shown a steady reduction and technological advances in neonatal intensive care have developed, the impact of very preterm deliveries on such rates has increased. As a result, whilst very preterm births before 33 weeks of gestation constitute less than 2% of all births, they account for between 35% and 60% neonatal deaths.² Thus, one of the first avenues of investigation for a particular developed country or region with a high neonatal mortality rate would be to calculate their very preterm delivery rate and the outcome of these babies. This highlights the importance of the standardised

identification and recording of very preterm births in order to carry out valid comparisons and hence reduce the risk of reporting artefactual variations in mortality rates.

In a competitive health service it is necessary for clinicians to be able to demonstrate the quality of their care provision by using appropriate performance indicators to provide patients with information upon which to base their choices for place of care. Whilst in a regionalised service, such as neonatal intensive care, parental choice is limited as care is provided by a managed network these measures are still required for both service commissioners and managers to ensure equality of provision.

This paper will highlight some of the problems in carrying out comparisons of various perinatal and neonatal outcomes in developed countries, detailing the factors that have a direct effect upon their calculation with particular reference to very preterm births – defined as deliveries of less than 33 weeks' gestational age – in the UK and Europe.

Measurement of neonatal mortality rates

There are a number of factors that have a direct effect upon the measurement of neonatal mortality rates leading to variations in reported rates that may be either real or the result of one or more artefacts in the data collection. These issues need to be investigated in order for an accurate interpretation to be made. Limitations of national data collection systems are such that this cannot easily be achieved and, therefore, misleading results can be unwittingly presented and, subsequently, misinterpreted.

Artefactual issues affecting neonatal mortality rates

Birth registration

Definitions

Clearly one of the major factors that can affect the calculation of perinatal mortality rates is related to differences in definitions for birth registration between countries. These definitions are limited to stillbirths, as any live born infant should be registered as a birth irrespective of the gestational age at delivery and, as such, neonatal mortality rates should not be affected. However, these definitional differences are known to also have an effect on the registration of live births with an under registration of live births at a boundary when a stillbirth would not require reporting,⁹ possibly in a paternalistic effort to relieve parents of the burden of birth registration. Conversely, a stillborn delivery that would not require reporting due to the gestational age may be over-reported as a live birth, at the parents' request, in order to require birth registration.

Whilst the WHO definition of the perinatal period as beginning at 22 weeks' gestation has been adopted by many countries thus minimising these registration differences, there are still exceptions, including the UK (which only registers stillbirths from 24 weeks' gestation), Denmark (which registers stillbirths from 28 weeks' gestation) and Germany (which has a lower birth weight cut-off of 500 g for all births).¹⁰ Direct comparisons of routine neonatal mortality statistics between European countries should,

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