

CESDI

Confidential Enquiry into Stillbirths and Deaths in Infancy

Executive Summary

of the
5th
Annual
Report

Focusing on:

Second Pass Panels

Sudden Unexpected Deaths in Infancy
- The Explained Group

Antepartum Term Stillbirths

Focus Group - Place of Delivery

Focus Group - Ruptured Uterus

Focus Group - Shoulder Dystocia

The 5th Report of the national Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) reflects the wide variety of work undertaken by CESDI since its commencement in 1992.

Rapid Report Form Returns - 1996

The Rapid Report Form (RRF) is the notification system used by CESDI since 1993. In 1996 10,487 deaths were notified: 1102 legal abortions, 1659 late fetal deaths, 3688 stillbirths, 2785 neonatal deaths, and 1253 postneonatal deaths.

Ascertainment is assessed using data from the Office for National Statistics (ONS) as the 'gold standard'. This is based on Death Notifications collected by the Registrar of Births and Deaths. The proportion of ONS deaths reported by CESDI has improved from 93% in 1993 to 99% in 1996. Postneonatal deaths remain the most difficult category to collect, but this too has improved from 86% in 1993 to 91% in 1996.

The stillbirth rate (5.4/1000 total births), neonatal death rate (4.1/1000 live births) and postneonatal death rate (1.9/1000 live births) are all stable over the last 4 years. The combined (stillbirth, neonatal and postneonatal) death rate is 11.3/1000 total births. Combined death rates range from 9.6 in East Anglia to 12.7 in the West Midlands. These crude mortality rates are not indications of standards of care and should therefore be interpreted with caution.

CESDI is the only system which collects information on late fetal loss (after 20 completed weeks but before 24 weeks). Late fetal loss rates (as expressed per 1000 late fetal losses and total births) show greater regional variation (2.2 in Trent to 5.2 in Northern) than death rates at later stages of pregnancy and infancy. In the absence of validating data it is not possible to assess the degree to which this variation is artefactual or real.

Postmortem Rates

The postmortem rate for England, Wales and Northern Ireland was 57%, ranging from 44% in NE Thames to 69% in South Western. Late fetal losses were most likely to have a postmortem (64%) and neonatal deaths least likely (44%).

Validation of the panel method for Enquiry

All Enquiry Reports, including those on maternal mortality and peri-operative deaths, are based on professional opinion. The format used by CESDI is a peer review of anonymised

case notes in which care is discussed, and the degree of any suboptimal care is graded. Each region addresses its tasks independently. To assess consistency of opinions, every fifth enquiry in 1995 was reviewed by a second panel in another region. Three quarters of panels (85/113) agreed to within one grade of each other. A comparison of the comments was made in the 97 cases graded 2 or 3 by one of the panels. Forty-four were in agreement; 19 in partial agreement and 34 not in agreement. As a result of this study the future enquiry programme will use a more directed and structured approach.

'Explained' sudden unexpected deaths in infancy - 60 potentially avoidable deaths yearly

In conjunction with the Foundation for the Study of Infant Deaths CESDI has undertaken the largest study of sudden unexpected deaths in infancy (SUDI). This involved 5 Regions and 456 sudden unexpected deaths between 1993 and 1996. A case control approach was adopted, utilising medical records and parental interviews. Enquiries and centralised pathology were undertaken on the deaths. Although most (363, 80%) were categorised as sudden infant death syndrome (SIDS), a sizeable proportion (93, 20%) had a specific explanation. The commonest cause of death was infection (35/93, 38%). By extrapolation, it is estimated that there are approximately 120 such 'explained' deaths in England and Wales annually. The epidemiological profile is similar to SIDS: peak incidence in December; lower birth weight and gestational age; the mothers younger and more likely to have smoked; parents more likely to be unemployed and in receipt of Income Support. However, these babies died at an earlier age (most commonly in the first month of life) compared with SIDS where deaths are uncommon in the first month of life. It was notable that half showed illness severe enough to warrant medical attention in the 24 hours before death.

Sixty-seven of the explained SUDI cases were subjected to confidential enquiry. Suboptimal care was judged to have occurred in 35 cases i.e. half of these deaths might have been avoided if professionals or carers had behaved differently. A professional was involved in 20 and a carer in 23 of these 35 cases.

The General Practitioner was the professional most frequently mentioned (probably reflecting the degree of involvement) and the commonest

problem was failing to recognise the severity of illness. However, many examples of suboptimal care occurred in hospital where poor clinical management was commonly cited. The need to review the training and Continuing Medical Education requirements of all doctors assuming responsibility for the emergency care of infants is recommended.

Carers were as likely as professionals to have contributed to the outcome: health support services should be targeted to vulnerable populations.

Study of Antepartum Term Stillbirths

The unexpected loss of a baby at term or weighing above 2.5kg prior to labour accounts for nearly an eighth of all fetal deaths. The underlying cause of these losses is often unknown. CESDI commissioned a pilot study of antepartum term stillbirths (SATS). This comprised a case control study (medical records, blood tests and parental interviews); confidential enquiries (cases and controls); and pathological review. The Report summarised the findings on the 86 cases and 172 controls.

No explanation or associated condition for the cause of death was found in 27 out of 86 cases (31%). The largest associated condition was isolated intra-uterine growth restriction (22 cases).

Panel enquiries of 'normal' controls were curtailed (104/172) because of excessive workload. The cases had an increased frequency of suboptimal care (32/52, 62% grade 2 or 3) compared with the controls (16/104, 15% grade 2 or 3). However, the panel assessments were not blind to the outcome and this may have influenced the judgement.

The limited numbers precluded firm conclusions, but an important finding was the greater proportion of mothers of non-white origin (Odds Ratio 2.6 95% CI 1.4 - 4.9). Ethnic origin has only been recorded routinely in hospital records since April 1995 and there have been substantial technical problems in collecting the data (Hospital Episode Statistics system). Consequently, no appropriate denominator data exist. However, these and other findings have suggested significant differences in death rates.

The parental interviews provided substantial information which was not in the medical

records and which was sometimes at variance with the medical records, for example smoking habits.

Planned home delivery, uterine rupture and shoulder dystocia - associated deaths

The 4th Annual Report concluded that three quarters of intrapartum related deaths might have been averted if alternative management had occurred. CESDI reviewed this area in greater detail in three circumstances: planned home delivery, ruptured uterus and shoulder dystocia. Cases of this type occurring in 1994-1995 formed the basis of Focus Group Reports. These could identify patterns of circumstances and care which would not have been obvious from review of individual cases.

Planned home delivery (22 cases)

Home birth has been a rare event since the 1980s accounting for fewer than 2% of all maternities in England, Wales and Northern Ireland. Between 1994 and 1995 there were 22 deaths of babies weighing 2.5kg or more associated with planned home births at the onset of labour. Recommendations are made concerning: back-up procedures for carers; transfer arrangements to hospital; the immediate availability of equipment in the home and training in its use. In addition, the need for local protocols and for evidence-based information to assist women in their choice of place of delivery is highlighted. The problems of risk assessment due to the lack of denominator data are emphasised.

Ruptured uterus (42 cases)

Of the three clinical areas, ruptured uterus had the largest proportion of cases with suboptimal care. Three quarters involved women with a pre-existing scar; within this group nearly two thirds were induced, suggesting that this is a high risk combination. Prostaglandin was the most frequently used agent. The lack of information on induction using repeated doses of prostaglandin precluded interpretation of the observations but the focus group recommends that repeat doses should only be given with exceptional vigilance. All but three of the 42 cases had some clinical signs of scar rupture, yet in 18 the diagnosis was only made at the time of laparotomy. The need for involvement of senior experienced staff in antenatal and intrapartum management is stressed.

Shoulder dystocia (56 cases)

Shoulder dystocia is a rare and unpredictable

event and when it occurs there is a need for urgent skilled action. The review of 56 fatal cases found that the midwife was usually the professional conducting the delivery and on nearly half of these occasions completed the delivery. No paediatrician was present in a third of the cases. The Focus Group emphasises the need for all birth attendants to be trained to manage this event. Recommendations for practice and initiating the 'fire drill' are given.

Absent denominator - Lack of morbidity data

All three focus groups were limited by the absence of appropriate denominator data. There is a widely held belief and expectation that serious events such as uterine rupture or shoulder dystocia are systematically recorded. This is not the case, and because they are more likely to result in morbidity than death, CESDI has only been able to examine a small proportion. The lack of routine registration of these events limits the provision of information concerning risk.

Communication issues

Good communication is an essential component of health care and becomes increasingly important in situations leading to a poor outcome. In the past, CESDI has cited communication failures in a sixth of the comments. Deficiencies in this area have ranged from illegible and incomplete case-notes to poor relations between professionals, and between the professionals and parents. A literature review is being planned to inform future developments in this area.

The future work programme

The next area of focus by CESDI is babies born at 27 to 28 weeks' gestation. The Office for National Statistics, unfortunately, does not collect gestational age on all live births. The new developments include collection of denominator data (identifying all babies born between 27 and 28 weeks' gestation) and holding enquiries on a random proportion of the survivors in addition to the deaths.

A national audit of the provision of education and training for intrapartum care is planned. An evaluation of the dissemination of CESDI findings is underway.

Changing Practice

Recommendations made by CESDI are often simple and not original. The responses of the Royal Colleges and the other statutory bodies responsible for training and accreditation to the 4th Annual Report are reported and are highly encouraging. The need to continue this process by integrating the findings in both undergraduate and Continuing Medical Education and also within clinical audit contracts is emphasised.

ACKNOWLEDGEMENTS

The advice and guidance of the National Advisory Body and of the Professionals' Steering Group is crucial to the ongoing work of CESDI, and the Consortium wishes to acknowledge the invaluable contributions of the members of both groups. Essential support has also been received from the members of the various working and focus groups.

Particular thanks are also due for the considerable contribution of the district coordinators and the many others based throughout England, Wales and Northern Ireland, who, often without recognition and in their own time, undertake work for CESDI.

A full copy of the 5th Annual Report can be obtained from:

**CESDI Secretariat
Chiltern Court
188 Baker Street
London NW1 5SD**

**Tel: 0171 486 1191
Fax: 0171 486 6543**

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