AIMS For a better birth...

Premature babies: Avoidable deaths

by Jean Robinson

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The latest CESDI report[1] has some very revealing things to teach us all about the care of premature babies, AIMS Research Officer Jean Robinson reports

We are summarising the latest CESDI report in full because it raises questions not just about the care of premature babies, but about the quality of maternity care in general. We also hope our summary and comments will be helpful to the many parents who contact us who have had premature babies. It may give them more confidence to ask the questions we know many of them have.

Prematurity kills babies. It is the most common single cause of baby deaths. There is little doctors can do at present to prevent this huge problem. They can only give the mother in premature labour drugs (tocolytics) to try to delay the birth and other drugs (corticosteroids) to reduce damage to babies' lungs.

Just how premature the babies are makes a huge difference to their chances of survival. A 1997 report showed that only 5 per cent of those born at 24 weeks survived, but every extra day in the womb increases maturity and, by 28 weeks, most will live.

The latest Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) report concentrates on the survival of babies born at 27-28 weeks. The enquiry compared the care of 352 babies who died with that of 371 premature babies who survived. Most of the babies (97 per cent) were born in hospital- almost all in a consultant unit-and most of the women had regularly attended for antenatal care (95 per cent). In fact, the bereaved mothers tended to book earlier.

AIMS comments:

As the figures show, neither prematurity nor death of a premature baby was caused by mothers failing to go for antenatal care. The report suggests- though there is no evidence-that the bereaved mothers booked early because they might already have had problems, such as early bleeding. This is a reasonable, but unproven, hypothesis. However, it is also possible that, because they happened to book earlier, these women had more vaginal scans, for which there is no evidence of safety to the embryo or fetus. Although most mothers (95 per cent and 93 per cent, respectively, of bereaved and non-bereaved) were scanned "before 20 weeks", we didn't know whether these took place earlier in pregnancy in the fatal group, whether they had more early scans or whether they were more likely to have vaginal scans where, as the scanner gets nearer the baby, it is exposed to a higher ultrasound dose.

More boys die

Women who had premature babies were more likely to smoke than women in the population as a whole. They were also more likely to be African or Asian. So, both smoking and ethnic group are related to the risk of prematurity.

The babies who died were more likely to be boys (64 per cent), and more likely to be lighter in weight at birth and to be born under worse conditions than the survivors, with lower Apgar scores, so they were, in fact, more at risk. Among the babies who died, 9 per cent were born with no heart rate compared with 1 per cent of the controls. Their mothers were not more likely to have any known severe lifestyle problems or a poor relationship with staff.

Risks of early PROM

Premature rupture of membranes (PROM) tended to occur earlier in the women whose babies died. Nearly 14 per cent had a rupture before 20 weeks compared with less than 1 per cent of surviving babies. By 26 weeks, almost 43 per cent had ruptured membranes compared with 24 per cent of controls. Clearly, early PROM is bad news. When membranes ruptured in mothers of surviving babies, it was more likely to happen after 26 weeks, and they were more likely to go into spontaneous labour. Only 51 per cent of bereaved mothers went into labour compared with 61 per cent of those whose babies survived.

Infection

Surprisingly, mothers of dead babies were only half as likely to have infected urine (bacteriuria) on tests than mothers of survivors. However, if they did get it, they were more likely to have symptoms. They were also slightly less likely to have chorioamnionitis (infection of the amniotic fluid surrounding the baby). Again, this is surprising. Infection in the womb is known to raise the risk of death or damage to the baby.

When the panel looked at management, there were, in fact, more criticisms of care of surviving babies, particularly a delay in giving antibiotics or simply not giving them.

Tests in pregnancy

Doctors were twice as likely to suspect fetal growth retardation in the babies who died (32 per cent) vs those who lived (16 per cent). It is, therefore, not surprising that 47 per cent (vs 36 per cent) of those babies had undergone a Doppler scan (to measure blood flow in the arteries supplying the baby) before birth.

Doctors not only made more mistakes in pregnancy checks for the babies who died, but they were also more likely to make wrong decisions as to the action they should take - 26 per cent of the dead babies had inadequate assessments compared with 18 per cent of survivors, and 14 per cent of dead babies had tests wrongly interpreted compared with only 9 per cent of those who survived.

CTGs (cardiotocographs), which check the fetal heart, were criticised as being of poor quality and too brief. An important finding was that doctors decided to deliver some of these babies too soon-three times as often in the case of dead babies as in survivors (6 vs 2 per cent), so some need not have been as premature as they were. It is also interesting that mothers of babies who died were significantly more likely to have a consultant rather than a junior doctor involved in the decision to deliver (79 vs 69 per cent). A decision not to deliver the baby soon enough was made equally often in both groups, in about 3 per cent of cases.

AIMS comments

What mothers do not realise is that tests are not in themselves protective. They may carry risks of their own (as in the case of ultrasound); they may be misinterpreted, and the decisions taken as a result can be wrong-even when taken by the most senior doctors. In only 7 and 5 per cent of dead and living babies was there thought to be a lack of consultant involvement.

The dead babies had more Doppler scans of umbilical arteries (47 vs 36 per cent in survivors), though the report only tells us whether they were used, not whether the fatal group also had them more frequently. This type of scan has been shown in randomised trials to be linked with lower fetal growth and, in one study, more neonatal deaths. Although undoubtedly a useful and necessary investigation for checking whether there is a problem with the baby's blood supply, there are unresolved questions as to their safety for the baby. There is also the faint possibility that they could be a contributing causal factor. We are raising this issue with CESDI.

Protecting the lungs

If there is time before the birth,giving the mother corticosteroids between 24 hours and seven days beforehand reduces the baby's risk of respiratory distress, and death, by a third. Fewer of the mothers of dead babies received such treatment at the right time (49 vs 56 per cent)-in fact, there was less time for them to receive it. However, in 16 per cent of dead babies compared with 11 per cent of survivors, the panel thought that not enough of an effort had been made to give corticosteroids. The main problem was

that doctors did not appreciate they were needed.

AIMS comments:

We often have complaints from mothers that midwives and others disbelieved them when they claimed to be in labour, and this is one reason for delay.

We also need to remember that there is still a big question mark over the safety of repeated doses of corticosteroids. If the mother does not go into labour after she has had a course, another course is usually given if she threatens labour again.

Repeated courses may increase the risk of infection or other problems.

Delaying labour

If imminent, labour can be prevented by tocolytic drugs, and this will buy time for the mother to have a course of corticosteroids to help the baby's lungs, or to be transferred to a unit with better facilities. Management of this care was criicised more often for the mothers of surviving than dead babies (14 vs 17 per cent), so this was not a factor in causing deaths. Steroids should not have been used if labour is too far advanced, or if there was infection or haemorrhage. In other cases, they were not used when they should have been.

Vaginal examinations

The report mentions the risk of vaginal examinations, after membranes have ruptured, increasing the risk of infection and expediting delivery. CESDI says they should be avoided unless there are specific indications.

AIMS comments:

Hurrah! We know of lots of mothers who stay at home just to avoid VEs, particularly as it is often so difficult to refuse.

Staff relationships

CESDI comments that "resistance to medical help is due to the woman or her partner feeling coerced into decisions that will affect their lives". The report recommends acquiring good are well-informed and feel a part of the decision- making process, and that any problems should be documented.

AIMS comments:

CESDI gets top Brownie points for recognising and referring to the coercion. We may not have been wasting our time lobbying them and the DoH for all these years. But this "making them feel part of the decision-making process" is too often interpreted as 'start being a bit more subtle and skilled about the manipulation so they don't cotton on to what you're doing'. However, women are not fools. They know

what is being done and they resent it. They may say nothing, but they go away seething- and phone us! We receive a steady stream of complaints of bossy, authoritarian and rigid paediatric staff of both sexes and all ages. Sadly, this tendency seems to be getting more, not less, common.

The birth

Most babies in both groups were born by caesarean section-70 per cent of those who died and 63 per cent of those who survived. More than half the mothers went into spontaneous labour, but only 29 per cent and 36 per cent, respectively, of each group were born vaginally. The most common indication for delivery was presumed fetal compromise which, not surprisingly, was more common in the fatal group.

Difficulties in extracting the baby were more common with sections than with vaginal delivery. These problems were more common in the fatal group-15 vs 10 per cent in the survivors. Nearly twice as many mothers of dead babies had an incision in the upper part of the uterus (11 vs 6 per cent). These scars significantly increase risk in any subsequent pregnancy. CESDI says that a cut in the lower part of the uterus is often possible, and there is a need to look at this kind of delivery.

The babies who died were more likely to have a consultant present at the birth (41 vs 40 per cent).

AIMS comments:

This does not necessarily mean, of course, that the consultant actually did the operation-or all of it.)

In fact, the surviving babies were more likely to be delivered by someone who was too junior (17 vs 11 per cent). Quite rightly, consultants were more likely to be present at the riskier births, and CESDI points out that the percentage at which they are present has increased. Yet, despite the greater likelihood of senior doctors being involved, there were nearly twice as many critical comments on the conduct of the delivery of babies who died than of the survivors (3 vs 2 per cent).

However, there is also concern over the grade below them-specialist registrars- who, in fact, performed the majority of deliveries. The report points out a wide variety of seniority and experience in this group and, in each case, the consultant should decide whether the registrar should operate unsupervised.

Difficulties with vaginal birth arose for breeches, which occurred in eight fatal cases and two survivors.

AIMS comments:

In both groups combined, 73 babies were vaginal breeches. Clearly, there would have been more but for the high section rate. Doctors nowadays have less training in breech births because most mothers are given caesareans. Beverley Beech, until recently AIMS' representative on the RCOG Consumers' Forum, has been patiently working away to get them to involve experienced and skilled midwives, who can do these with minimum risk, in doctors' training. So far, progress at the Royal College is very slow.

Anaesthetics

Mothers whose babies died were more likely to have had a general anaesthetic - nearly half of them. Criticism of pain relief or anaesthetic management (10 per cent or so) was similar in both groups. The report suggests that recognising premature labour early could reduce the number of general anaesthetics given, and 15 mothers were thought to have had a general anaesthetic unnecessarily.

There were criticisms of cases of inadequate pain relief-10 fatal and four non-fatal cases; in two cases, this is attributed to a language problem. Says CESDI: ". . . the emotional impact on the mother should not be underestimated." It calls for a 24-hour interpreting service for ethnic minorities.

AIMS comments:

Recovering from a caesarean-particularly one with a general anaesthetic-is a problem for many mothers who wish to see and bond with their babies in the same hospital, let alone for those whose babies have been transferred.

Fluid balance

Although the report gives no details, it mentions concern about fluid balance management (see also 'Blood pressure' below). When mothers are having fluids dripped in for different purposes (corticosteroids, tocolytics, nerve blocks), they can have a fluid overload, so it is essential to monitor fluid balance.

AIMS comments:

This is important. A Confidential Enquiry into Maternal Deaths showed that a number of deaths of women with preeclampsia was probably caused not by the condition itself, but by fluid overload. These women are having intravenous fluids ordered by different doctors for different purposes, and there is no one keeping an eye on the overall fluid input and output.

Resuscitation

The main problem here was the timely attendance of skilled staff. Most babies in both groups had to be resuscitated at birth. Ten years ago, the British Paediatric Association standard required paediatric staff of at least intermediate grade to be present. This standard was achieved in only just over half of all babies (54 per cent and 56 per cent). A crucial question for measuring care of the high-risk baby at birth is therefore: Who was present at the delivery? That information was missing in the cases of 150 babies. In nearly 5 per cent of births, only a midwife was present, and the senior house officer in only 14 per cent. Babies who died were twice as likely to have information missing.

Also missing in many cases was information about who arrived later to help, and when. By the available data, a senior or intermediate doctor arrived later for 29 per cent of the dead, and 16 per cent of the

surviving, babies.

AIMS comments:

Because a number of past reports have shown too few paediatricians with too little experience in providing immediate care, a number of official reports have made criticisms and set standards. Clearly, we still have a major problem in this country with providing adequately trained and experienced personnel to be present at high-risk births. The problems highlighted in this section appear frequently in our postbag- the arrival of a very sick baby, but no experienced person present to resuscitate, and sometimes long delays in getting someone. The gaps in the records also tally with our mothers' experiences.

Quality of resuscitation

The Enquiry found that babies who died were more likely to have deficiencies in care-failures in intubation or multiple attempts, delayed or no cardiac massage, poorer care to maintain temperature, resuscitation stopped too soon (5 cases vs 0) and the wrong doses of drugs (9 cases vs 0).

Although paediatric training has been improved, intubation is still a major problem partly because of the difficulty for staff to gain experience (there are now more trainees needing babies to practice on), and for them to do it often enough to maintain skill.

Keeping baby warm

Premature babies lose heat quickly, and hypothermia can kill or damage them. The temperature should be above 36 when admitted to the neonatal unit: that was the standard set in 1992. Most of the babies in the study did not reach this standard, and those who went on to die had lower average temperatures than did the survivors. In the report, 47 per cent of the dead and 37 per cent of the survivors were considered to have deficient thermal care. Both resuscitation and routine procedures can cause falls in temperature, especially if the room is not warm enough.

Lung surfactant

Giving premature babies a lung surfactant to prevent respiratory distress syndrome (RDS) has been the most important factor in reducing their mortality. It should be given to all intubated babies and all those at risk of RDS-and as soon as possible after birth. While most babies in the studies did receive a surfactant, a substantial number (38 per cent and 40 per cent) did not achieve the ideal standard of receiving it within an hour of birth, although 79 per cent in both groups got it within two hours of birth. The report suggests that if any baby dies without receiving a surfactant, there should be a local review.

But the choice of surfactant proved important. At the time (1998-2000), both synthetic and natural surfactants were in use. Most babies in the study- 80 per cent-got a natural surfactant, which is now accepted as having better survival rates. Some were given both types, but the babies who died were

significantly more likely to receive the synthetic version (15 vs 10 per cent).

The fatal cases were more likely to have a failure in surfactant treatment, including delays. Two babies had an overdose, one had an underdose and, in two cases, a surfactant had not been available!

Since some babies who proved to need it had missed out because they were not thought at risk of RDS, the report discusses giving a surfactant automatically to all 27-28-week babies rather than 'waiting and watching'.

AIMS comments:

Surfactant is a success story but, as many mothers tell us and this report confirms, no intervention is risk-free. Also, there was clearly a variation in the rate at which units changed to using the safer, natural form. If it is to be added to treatments given routinely and to babies who may not need it, there will have to be a huge change in neonatal units such that they understand what informed consent means and that informed refusal is not heresy. We already receive far too many complaints from parents that queries or requests for information-let alone a hint of possible refusal-are treated with arrogance and hostility.

Ventilation

Most of these babies need ventilation because of breathing problems, so blood-gas levels need to be monitored and responded to by adjusting ventilation when necessary. The sicker the baby is, the more difficult it is to manage care. Care did not reach the expected standard in 18 per cent of those who died and 7 per cent of survivors. A major problem was lack of a management plan, and failure to respond to danger signs in the blood-gas level. Management of complications was more often found to be at fault in the fatal group.

Blood pressure

It is essential to maintain the baby's blood pressure. If it is too low, this will increase the risk of haemorrhage, brain damage and death. So, blood pressure needs to be continually measured (the report recommends inserting an arterial cannula) and promptly treated where necessary. Treatment involves increasing blood volume (with plasma or saline) and administering drugs such as dopamine.

Since the babies who died were, on average, sicker to begin with, they had lower blood pressure, which would also be more difficult to maintain. But even after allowing for this, more deficiencies were found in their care: there were problems with care of one-third of the dead babies, and one-fifth of the survivors. These problems included failure or delays in giving supportive drugs, inappropriate use of drugs or drug errors, excessive intravenous fluids and failure to give blood transfusions.

Infection

The babies who died were more likely to have germs in their blood than the survivors (15 vs 8 per cent), although the mothers in both groups had similar levels of infection. Fatal cases were considerably more

likely to have Escherichia coli and group B streptococci in particular, both of which are known to cause serious illness. Most premature babies were put on antibiotics soon after they entered the unit. Although there were some criticisms, these were just as common in the case of the survivors as in fatal cases, and the overall standard was considered good.

Organisation

Problems with the organisation of obstetric care were not more common in the group who died, but there were more problems in the organisation of their neonatal care. Organisational difficulties may be more common than the report shows as poor-quality notes can conceal them.

1. The biggest problem was getting access to a neonatal unit before the birth so that the baby could travel in the safest way-inside its mother. Sometimes, mothers or babies had to be transferred from hospitals that had a specialist unit, but which was full up.
2. Staffing levels at the time the mother gave birth-too junior, too few or could not be contacted-were another problem. Inadequate staffing levels in the neonatal unit were linked to 19 dead babies compared with six survivors. Three years ago, a study showed that babies had a 50 per cent greater chance of dying when a unit is working flat out than when it is at half-capacity.
3. The report suggests that access to operating theatres in emergencies could have been partly caused by the increase in caesarean section rates.
4. Finally, there were faulty equipment and missing drugs, flat batteries and empty oxygen cylinders because of a lack of routine checking.

Transfers

More than a quarter of all the mothers in the study were transferred to another hospital before the birth. In nearly 40 per cent of cases, the hospital sending them on had the right facilities to care for premature babies, but the cots were already full. A fifth of the mothers were already in labour. Journeys took an average of 48 minutes. Failure to transfer the mother before the birth greatly increased the risk of death-24 babies who died were not transferred when they should have been compared with only two of the survivors. On the other hand, there was a small number of cases where mothers were transferred when they should not have been - but this was similar in both groups.

About 10 per cent of both groups of babies were transferred after birth- mostly because of inadequate facilities. In about 17 per cent of cases, it was because their birth hospital had a resource problem. The journeys took around 45 minutes, and six babies were transferred twice.

On occasions, there were problems on the way to another hospital in maintaining temperature or ventilation, or getting the right staff to go with them. Records of what happened on the journey may be inadequate. Quality of care during transfer is crucial.

There were also cases of babies who should have been transferred, but were not. This happened four times as often in the babies who died (13 babies vs 3).

AIMS comments:

These sections highlight how serious the resource problem can be. Some mothers were transferred "on several occasions". But we are delighted that they also mention the problem of parents being separated from their own area and family support, and the delays in getting transferred back to their own hospital because of a lack of a bed. These complaints come up often in our phone calls from parents. But they don't mention the separation from the babies-which particularly happens with post-caesarean mothers.

Post mortems

Post mortems were done on only 36 per cent of the babies. In some cases, the family had apparently not been asked and, in others, an unsuitably junior doctor, like an SHO, made the request.

Three-quarters of these PMs were performed by pathologists specialising in looking at babies. Only 18 per cent of their reports had faults compared with a 60-per-cent fault rate in reports by general pathologists.

The post mortems provided valuable information concerning 45 mistakes in diagnosis: either conditions that had been missed or conditions that had been diagnosed, but did not exist. In many cases, earlier knowledge would not have made a difference to treatment or survival but, in some, it might have done. In any case, good PM information can improve care when it is fed back to the staff.

AIMS comments:

The need to use specialist pathologists has been repeatedly emphasised. Unfortunately, there are not enough of them. Since the retained-organs scandal, parents are more reluctant to agree to PMs and, in talking to bereaved parents, we find they may not realise that they are losing the chance to obtain valuable information to help set their minds at rest or to plan for their next pregnancy. There were three cases in this enquiry where a "congenital anomaly" that had been diagnosed in life was not, in fact, present. Some parents were not even asked to consent to post mortems; in other cases, the request was made by a junior doctor, which is not good practice.

Communication

This section deals with communication between staff and between hospitals as well as with parents. Failure to "inform, explain or listen to parents" was more common in the case of babies who died (36 vs 22 per cent), and these included failure of the neonatal staff to see the mother before the birth, which was strongly criticised. There were five cases relating to clinical trials: "...notable examples where informed consent for clinical trial entry had not been sought or where consideration of clinical trial entry was inappropriate." Quality of records was criticised for 64 per cent of the dead and 53 per cent of the

survivors. Despite strong past recommendations, there is still no standard national design for records.

AIMS comments:

Communication with parents is criticised only on the basis of what is on the records-a totally inadequate measure. Without their voices, a true picture cannot be seen. The information concerning a lack of consent to research is alarming, but it fits the picture we are getting from parents and from articles by paediatricians in professional journals querying whether it is really necessary to obtain such consent.

This report looks only at deaths, and not at the frequency or severity of handicap in the survivors. Yet, records show that the care of the surviving children was often deficient and may well have long-term effects on their ability.

Conclusion

The report also doesn't deal with the quality of life for the newborn in intensive care, an issue parents often raise with us and one especially poignant when a life is so short. Sadly, some of these mothers had the worst of all worlds - a premature labour, a caesarean with a delivery they would not remember because of a general anaesthetic, a dead child and a dangerously scarred uterus which may reduce future chances of successful childbearing.

This CESDI report contains much useful information and we are grateful, but it still has the same basic flaw we have noted and criticised in all of its predecessors and in other confidential enquiries.

The report is based only on the records of the professionals (which, in many cases, are seen to be inadequate), and only occasionally containing their version of mothers' views as recorded in their case notes.

We have been protesting for years that, without the voices of parents, these enquiries are incomplete. Spending public money on such inadequate reports is no longer acceptable.

References:

1. Macintosh M, ed. CESDI (Confidential Enquiry into Stillbirths and Deaths in Infancy), Project 27/28. An enquiry into quality of care and its effect on the survival of babies born at 27-28 weeks. London: TSO, 2003