AIMS For a better birth...

Shaken baby syndrome: Caused by hospital care

by Jean Robinson

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A healthy baby is everyone's goal. Indeed, many practitioners still believe that the mode of birth is irrelevant as long as it produces a healthy baby in the end. But just how healthy are today's babies, and what influence does obstetric care as well as care in the postnatal period have on infant health? In a journal that evolved to focus in part on the health of babies after birth, Jean Robinson leads off by revealing disturbing evidence of harm to premature babies at the hands of doctors and nurses.

We get a number of calls from parents who have been wrongly accused of child abuse, and are threatened with having their children taken away and their babies adopted. Yet, in some cases, the injuries were caused by prematurity, injury at birth, genetic disorders or damage from hospital care. There have been cases where mothers or fathers saw their baby dropped on the floor but, in other cases, the baby is whisked away and fractures are revealed at a later date.

Over the years, we have kept in touch with Rioch Edwards-Brown, who had to fight a long battle to prove she had not injured her son and who now supports other parents facing similar accusations[1]. The following is a salutary reminder of what can happen to babies given the standard hospital care at the time. It also shows the difficulty of identifying causes when new side-effects occur, the complexity of ethical issues and the price the staff may have to pay.

Brain damage In Birmingham

Two doctors recently wrote a brief account of a little-known episode in medical history in a paediatric journal[2]. Between 1988 and 1990, doctors in a neonatal unit in Birmingham were seeing a new kind of serious brain damage in the premature babies they were caring for. It has a tongue-twisting eleven-syllable name - encephaloclastic porencephaly (ECPE) - but don't worry, you don't have to remember it to understand the story.

There were 15 babies, all born at 24-32 weeks, who had extensive necrosis (tissue death) on both sides of the brain. Fourteen died and the one survivor had severe neurological damage. Post-mortem examinations confirmed what they had already seen on the brain scans when the infants were alive.

Six doctors from Birmingham published an article describing their findings in 1992[3]. They reported that no new techniques or procedures were being used in the unit, and concluded: "It seems probable that this represents the effects of an as-yet unidentified postnatal event." However, as we shall see, at least one of

the six authors of the article had a pretty good idea of what might be causing the problem.

Brain damage in Auckland

In 1994, two years after that publication, Dr Jane Harding, a neonatal paediatrician at the National Women's Hospital in Auckland, New Zealand, found herself dealing with a batch of cases just like those described in Birmingham. In December of 1994, their pathologist, Dr David Becroft, contacted Dr Ian Rushton, a neonatal pathologist and one of the Birmingham authors. Rushton told him he thought he knew the cause-the vigorous chest physiotherapy the babies had been given without their heads being properly supported.

He suspected the physio because of the similarity between the brain damage in these babies and that seen in shaken baby syndrome[4]. He had wanted to include this in the paper, but his coauthors disagreed, although he did present his views at a number of scientific meetings. Apparently, there were also fears of possible litigation. In a follow-up letter to Sunderland and Williams's mini- history of the event, Dr Rushton now says he regrets not having insisted because, if this idea had been published, the New Zealand babies may not have died[5].

An interesting aspect of the story is that, although Birmingham was unwilling to publish Rushton's suspicions, they were worried enough to act on them. From then on, they insisted that babies' heads be supported when chest physiotherapy was given. The result was that Rushton saw only one more case by the time he had retired.

New Zealand finds the cause

Auckland realised that their cluster had started after a change in treatment. Whereas chest therapy for premature babies had taken place only during regular working hours, it was now available round the clock. This meant that babies were likely to get more treatments.

The physio was rather vigorous. It was done by tapping on the chest with a small facemask - a technique called cupping. On hearing Rushton's story, Auckland acted promptly. They did not just alter the way physio was done, they stopped it altogether - and they never saw another case.

We should point out that, although chest physiotherapy had been shown to remove more secretions, there was (and is) no proof that it has any long-term benefits to the baby. Moreover, earlier publications had shown risks. A premature baby was found to have multiple rib fractures caused by chest physiotherapy from percussion by hand and vibration from an electric toothbrush.

"Had the fractures of this unintentionally battered neonate first been diagnosed following hospital discharge, he might have been labelled as a case of parental child abuse," wrote paediatricians from Charleston, South Carolina[6].

Another study of chest physiotherapy on newborn babies with respiratory distress syndrome showed

that it could increase brain haemorrhages.[7]

New Zealand then did what Birmingham should have done. There could be another, as yet unknown, reason for the damage. In any case, even if physiotherapy were the true cause, they had to prove it to convince and warn doctors elsewhere. As similar round-the-clock chest physiotherapy was being provided in neonatal units throughout Australia, Auckland did a case-control study to identify any differences between the care of these babies and those who didn't have unusual brain damage.[8]

Thirteen cases were identified from brain ultrasound records and compared with 26 controls born with a similar gestation period (24-27 weeks) and weight (680-1090 g). Obviously, such tiny, early babies are very much at risk of complications anyway. Five of them died and seven of the eight survivors were handicapped, ranging from mild hemiplegia to severe spastic quadriplegia. Only one of the 26 controls died, 35 per cent were normal and 54 per cent were handicapped (details not given).

They looked at many possible causes, but the main difference that stood out was the number of physiotherapy treatments given. The cases had received two or three times as many-an average of 79 vs 19 for the controls, a significant difference. The authors concluded that the physio was likely to be the cause, particularly as clusters of cases had stopped after the physio was banned in Auckland and changed in Birmingham.

An official enquiry

The New Zealand Ministry of Health commissioned an enquiry[9]. This gave parents a chance to give evidence, allowing us to hear voices that are usually absent in paediatric journals. They described how worried they had been by what they saw: "banging the baby's chest with the baby shaking like a jelly on a plate. We are told never to shake a baby and, yet, here it was happening in hospital" and "it was like they were on a little trampoline".

The enquiry played videotapes of seven treatments given in 1990, 1992 and 1994. Independent physiotherapists and doctors viewing them thought the 1990 video showed overvigorous treatment, but disagreed on the others. But the intensity of the treatment did not seem to vary over time, so that alone did not explain the risk.

As one of the authors of the New Zealand study, Dr David Knight, now sadly points out, the upshot of all this was that, in Auckland, the hospital which had discovered the likely cause underwent a long public enquiry and lawsuits, with 20 of its staff investigated by their professional bodies. In Birmingham, the hospital that first described the brain damage, but did nothing to find the cause, report its suspicions or tell the parents, experienced none of these problems.[10]

No complete answer

On reading the study from Auckland, my first thought was to ask what other changes, if any, were taking place in rates of death or brain damage to babies in the unit at that time. Recently, a more detailed

analysis has been published, showing that the ECPE cluster was not accompanied by an overall increase in mortality or other brain haemorrhages[11]. Details provided in this report help us to see the complexity of the detective work they were faced with. For instance:

- 1985: Fingertip vibration used for chest physiotherapy; treatment given by physiotherapists from around 15 days of age
- 1996-8: Technique changed to percussion using a soft facemask, five times a day. Treatment began earlier - at around six days old. Average number of treatments increased
- 1989-91: Same type of treatment, but only four times a day because of staff changes. Fewer babies treated and fewer treatments given
- 1992-4 (when ECPE reported): From mid-1993, nurses were trained by the physiotherapists to carry out the chest physio.

Between 1985 and 1994, there were not only changes in the technique and type of staff, but also in three other factors: the percentage of babies treated; the age at which treatment began; and the average number of treatments given to each child. Whereas apparently simple changes may not seem harmful, as new factors are added, there could be interactions that create new risks.

At the beginning, 58 per cent of babies had chest physio. This rose to 66 per cent, then declined with staff shortage to 52 per cent, then rose again to 66 per cent when nurses joined in. From then on, nurses did the nighttime chest physiotherapy and some of the daytime treatments as well. There was concern among nurses over the treatment, including the worry that the treatment was "overly aggressive for the stage of the babies"[12].

Treatment that had originally started when babies were an average of 15 days old now began at around five days of age, then changed again to starting at around eight days of age.

In 1985, the average number of treatments per baby was 121. This was later reduced, but the treatment started when babies were younger. The number of treatments fell further with the staff shortages in 1989-91 to around 37, and stayed at around that level.

So, the authors suggest, the number of treatments given and the technique used cannot explain their cluster in 1992-4 (although the case-control study had shown the one significant difference was that cases had far more physio than controls). The physiotherapy the Auckland babies received was similar to treatments reported elsewhere. In Sydney, babies of similar age were getting about the same number of treatments by the same method.

The problem began around the time the nurses were being trained by physiotherapists to do the treatment. But the first affected baby was not treated by a nurse, and the second and third had only two and five nurse treatments, respectively. (But remember, parents have to shake a much-older baby only once to inflict permanent brain damage.) The other 10 babies had 20-40 per cent of their treatment from nurses, but there was no written protocol for how the treatment was to be done.

Auckland also now brings up a new possible risk factor. One possible cause, they suggest, is the softer bedding introduced in 1992. As in Birmingham, the babies' heads were not supported during treatment, and this a softer bed allowed an unsupported head to move more.

More questions

Were Birmingham and Auckland the only places with ECPE? Given the widespread use of the chest physiotherapy described, it seems unlikely. An AIMS member told us what she saw in another UK special-care baby unit in 1992:

"A nurse would come and give chest physio to a tiny baby in an incubator. She would put a warm towel on his chest and press on it at intervals for several minutes, then turn him over and do the other side. The baby would bounce off the mattress, leaving it entirely. He could not cry because he was on a ventilator, but he would go purple in the face and his face would screw up, showing his distress. Other parents would find this so upsetting to watch, the nurse would put screens round. I was so glad they weren't doing that to my baby."

Perhaps other units had odd cases, did not pick up clusters or did not write them up. Whatever our criticisms of Birmingham for telling only part of the story, they did at least recognise a new form of damage, describe it and publish a full description. Unfortunately, they didn't look into any possible changes in treatment at around that time, so we have nothing to compare with the New Zealand data.

Outcomes in Birmingham were worse than in Auckland: almost all their babies died and the survivor was severely affected whereas most of the New Zealand babies survived with varying levels of damage. Why? What, if any, were the differences in the treatment? We shall probably never know.

Ethical decisions

Though we may think Birmingham was too timid - or worse - not to publish their concerns regarding physiotherapy, there are genuine and sensible reasons for not causing unnecessary alarm which could result in a useful treatment being discredited. (Respiratory problems are a major cause of death and long-term illness in premature babies, and chest physio looked promising on small short- term studies, even if the evidence was inadequate.) And even though an outbreak stops when treatment is changed, that doesn't in itself prove cause and effect. But they were, in our view, duty-bound to look further.

An interesting question to ask may be why New Zealand acted rather than why Birmingham did not. Public attitudes affect behaviour in ethical issues, and the National Women's Hospital in Auckland, where the outbreak had occurred, was still recovering from a huge scandal as a result of a government enquiry in 1987-8[13]. Women with signs of early cervical cancer had not been told and, instead of being given appropriate treatment, had been deliberately left untreated for years and followed-up by Professor Herbert Green as part of an experiment. The story was revealed in the press by women's health activists Sandra Coney and Phillida Bunkle in 1987.

It may be that the lessons learned from that appalling story, and the publicity and enquiry which followed, encouraged Auckland doctors and the authorities to be more thorough, more enquiring and more open than they might have been otherwise. We in the UK were to have our cataclysms later, with the enquiry into infant heart surgery at Bristol, and the outcry over the removal and retention of babies' organs at post-mortems without consent at Alder Hey and elsewhere.

Publish - and be damned?

When a résumé of the ECPE story by Williams and Sunderland was published at the end of last year, it was followed by a commentary by two doctors from Alder Hey, who clearly thought the authors should have kept quiet[14]. They also said the explanation of cause was speculative, that chest physiotherapy was useful and safe, and - above all - the article could lead to scapegoating of professionals and encourage "unfounded criticism". (We at AIMS try to ensure that our criticism is 'founded', but they may like that even less.)

Indeed, on the contrary, we believe this story needed to be told. It is not widely known even among neonatal paediatricians and has lessons for us all. In his superb book Retrolental Fibroplasia - A Modern Parable, Professor William Silverman points out that, after an epidemic of blindness due to excess oxygen given to premature babies, there was collective amnesia among the medical profession of the awful tragedy, which means that lessons have not been learned.

The need for audit

Dr Knight, one of the neonatal paediatricians from Auckland, summarises one of those lessons[10]: a treatment generally recognised as being beneficial may not be so, even when it has supposedly passed the test of time. Ongoing audit is needed.

Forty years of reading mothers' letters to AIMS has taught us to be sceptical when doctors assure us that a treatment is 'safe'. We have all learned that whatever uses expensive resources and has become common practice may not be beneficial. Deaths and brain haemorrhages continued to fall at Auckland after chest physiotherapy was abruptly banned - although, to be fair, we have no information on the long-term respiratory health of the survivors.

Protocols should be documented and dated, and any changes to them should be recorded and monitored.

It is also important to have videotapes of treatment in maternity and neonatal care so that there are exact records of what was done and how.

Although the physiotherapists at Auckland were experienced, anyone can understand that the risks could change when treating tinier, younger babies, treating them more often and using nurses, who have entirely different training, who have to learn on the babies and on the job. There could be added risks from extending treatment throughout the night. The babies would get less rest, which is known to affect outcomes, and the many stories we receive from parents make us wary of standards at nighttime, when there is less supervision and fewer experienced staff around.

Who is blaming whom?

Doctor Knight pleads for an atmosphere of learning rather than blame. Can we ask that this apply to parents too? The increasing blaming and policing culture of paediatricians towards parents in this country is damaging trust and making an increasing number of parents afraid to use expert care.

Paediatricians are taking over the authoritarian stance the obstetricians are having to relinquish. We know this is having adverse effects on communication because parents are giving us information they feel unable to give their doctors.

In Auckland, it was the parents and, initially, nurses, using straightforward common sense, who were first concerned by the vigour of the chest physiotherapy being used on tiny premature babies. They were asking the right questions before the paediatricians did, but information is only respected when it comes from powerful voices.

We are alarmed by a growing problem. When parents express concerns about maternity care, neonatal care or paediatric care, the result too often is not a discussion and exchange of ideas, but an immediate threat from paediatricians to obtain a court order to dispense with parental consent. Parents' voices, already muffled by the system, are being silenced altogether. The evidence we have placed before the Department of Health is already causing concern - and there is plenty more on its way.

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