



## Research Roundup

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#### **Problems after preterm birth**

Newer, apparently better, care for premature babies may not have improved abilities in the survivors.

Many studies have shown that babies born too soon are more likely to have health problems as children—the earlier they were born, the greater the problems. Ten to fifteen per cent have major disabilities (like cerebral palsy) and difficulties with sight or hearing. Even those who can go to ordinary schools are likely to have learning and behavioural difficulties or motor problems, like clumsiness, developmental coordination disorder (DCD) and attention-deficit and hyperactivity disorder (ADHD). Doctors have hoped that new treatments—giving antenatal steroids to the mother, surfactants to line the babies' lungs to prevent breathing problems and better nutrition for the baby after birth—would improve outcomes for very premature babies.

A new study from Liverpool has looked at seven- and eight-year-olds born before 32 weeks who had survived and were well enough to attend mainstream school. They were compared with similar-age full-term children in their class at school. These children would have been born after new treatments for premature babies were introduced.

Testing the abilities of such children is not easy since disabilities can be both subtle and numerous. A number of tests are available, each of which may identify different aspects, so a range of tests was used.

The preterm children had a high incidence of motor impairment compared with children who had been born fullterm, and this affected how well they did at school even when their intelligence was normal.

Over 30 per cent had DCD compared with only 6 per cent in the control group. The preterm children were significantly more likely to be overactive, easily distractible, impulsive, disorganised and lacking in persistence, and to overestimate their ability; 8.9 per cent of the preterm and 2 per cent of the fullterm children had ADHD.

The children who had been the most premature were not necessarily those with the lowest scores, which shows that degree of prematurity alone is not the explanation. A most interesting finding was that, although major disabilities have been reduced, the levels of disability tested here did not seem lower than those found in children born 10 or 20 years earlier, despite changes in care of the newborn.

#### **AIMS comments**

Yet again, a report reminds us of the importance of preventing prematurity if we can. Little progress has been made, and it is necessary to look at primary causes, such as poverty and social stress. We are reminded of the difficulties some of these children born too soon may experience in their lives as well as the needs of their parents, and the problems faced by schools and teachers in the classroom. The study also shows that there are children who are born full-term who have similar difficulties—even if the percentages are much smaller. I wonder what happened during their birth and neonatal care?

#### **Reference**

- Moulder-Hughes LA. Motor, cognitive and behavioural disorders in children born very preterm. *Dev Med Child Neurol*, 2003; 45: 97-103

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#### **Making decisions in preterm labour**

Parents faced with the premature arrival of their expected baby are often given complex information at a time when it is especially difficult to concentrate and make decisions.

A Canadian study has looked at communication between doctors and parents in these circumstances. At McMaster Centre in Hamilton, Ontario, 49 pregnant women in preterm labour at 23-30 weeks, and their partners, were afterwards given questionnaires about what they had been told as well as questions to measure their level of anxiety at the time. The doctors were also asked what they had said. There were considerable differences between what parents remembered being told, and what doctors reported

telling them.

The standard practice at the hospital is for mothers to be 'counselled' on the complications of the pregnancy, the outlook for mother and baby, and what the options are for care of the baby after it is born. This is done initially by the admitting obstetrician and later by neonatal doctors.

Parents answered the questionnaire 24 hours after being given this information. If both parents were present, they were asked to fill it in together. Not surprisingly, mothers who had high anxiety scores were less likely to agree with the doctors' memory of what information had been given (it is well known that anxiety can affect recall).

There was good agreement between parents' and doctors' recall of the pregnancy complications discussed. But there were a number of cases where doctors remembered discussing complications with parents, but the parents did not agree, and other cases where doctors did not report talking about complications, but parents said they had. For example, on the growth of the baby, a quarter of the doctors said they had discussed it, but parents said they weren't told, while a quarter of parents remembered it being discussed, but doctors said it had not. In 37 per cent of cases, parents said no plan had been made for management of the baby, but doctors said they had discussed it. In 34 per cent, doctors said they had described possible difficulties in feeding and holding the baby, but parents did not recall it.

Women were asked whether they would prefer having the doctor advise them on what to do about the pregnancy or whether they should be asked to decide. Only 27 per cent of parents thought they would prefer the doctor to take the lead, yet doctors thought 79 per cent of parents would prefer them to advise. In nearly half the cases where this assessment was made, the parents had the opposite view.

The authors want better means to be developed of improving communication and decision-making when a premature baby is on the way.

### AIMS comments

Neonatal care, and questions about consent for the stream of interventions these tiny babies have, is an increasing problem in our postbag, so we were particularly interested in this study.

The sample is small, but it is one of a growing number of papers showing that doctors' statements on their actions are not verified by patients' recall. There is, however, a dearth of studies that tape-record and/or video the communication that actually went on. The two quoted by the authors found inaccurate memories among both doctors and patients. We need more studies where audio/video-recording of communication is included.

I will ride my hobbyhorse again to criticise the authors' use of the word 'counselling' (the most misused word in the English language) when what they appear to mean is 'giving information'. The trouble is, so

many doctors think they are 'counselling' when they are doing nothing of the kind.

Nevertheless, this is a useful addition to the scientific literature as it shows once again how difficult it is for a mother in premature labour, and her partner, to take in information and make decisions about the care of the coming infant.

One lesson they need to learn: doctors may be far too ready to assume you want them to 'advise' you on what to do when, in fact, you want to make your own decisions. Does the finding that 79 per cent of doctors thought parents wanted to be "advised what to do" indicate just more ignorance and misunderstanding, or does it suggest wishful thinking and their basic belief that they should be in control?

## Reference

- Zupancic J et al. Characterising doctor-parent communication in counselling for impending preterm delivery. *Arch Dis Child Fetal Neonatal Ed*, 2002; 87: F113-7

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## Breast damage from baby care

The steps taken to save a baby's life in intensive care can sometimes cause later problems and often leave permanent scars of the invasive treatment.

A report from Austria shows pictures of deformed breasts in adolescent girls as a result of tubes put in their chests when they were babies in intensive care. The girls were upset by this and had corrective surgery.

As premature babies, these girls had been subjected to multiple draining of pneumothorax (when air in the chest outside of the lungs causes the lungs to collapse). This had affected the tissue that would later develop into breasts.

The authors examined breast tissue in babies that had died to measure how far it extended, and found it extends from the third to the sixth rib. This means they can give guidance on how to avoid breast tissue when inserting chest drains.

## Reference

- Rainer C et al. Breast deformity in adolescence as a result of pneumothorax drainage during neonatal intensive care. *Pediatrics*, 2003; 1121: 80-3

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### Stroke in young children

Paediatric neurologists from three London hospitals have published a paper on stroke in young children soon after having had a mild, accidental head injury. For example, a one-year-old fell from a low sofa onto a thinly carpeted floor, and a four-year-old also fell off a low sofa and bumped her head. Two of the five children had had recent chickenpox infection, which could have made them more vulnerable. Three children recovered completely, and two were left with some damage. This is not the first report of such cases.

### AIMS comments

Obviously, bumps and falls in toddlers are common, and strokes are rare. Each year, only one child in 20,000 has a stroke, and most of these are not caused by a fall. The reason we mention this in our journal is not to worry parents, but to draw attention to yet another situation where accusations of child abuse could have been made. In these cases, it had been accepted that the initial injury was minor and that it was accidental. But in how many other cases could the outcome have been different?

### Reference

- Shaffer L et al. Can mild head injury cause ischaemic stroke? *Arch Dis Child*, 2003; 88: 267-9

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### Eat more fish for healthy babies

Mothers who never eat fish have more than three times the risk of delivering a preterm baby compared with those who eat it at least once a week.

Over 8000 women in Denmark were asked to fill in questionnaires when they were 16-30 weeks pregnant asking how often they ate fish. In mothers who never ate fish, 7.1 per cent of the babies were born preterm whereas in those who ate only one fish meal a week, the preterm rate was 4.1 per cent; the rate fell progressively to 2.1 per cent in those who ate fish often. Low birthweight and intrauterine growth retardation were also more common in those who did not eat fish.

## AIMS comments

This is the latest in a series of studies showing that the "long-chain fatty acids" in fish are important in the development of the baby, and this one looks particularly at earlier pregnancy. The exact dose is not yet known. While women are being urged to take folic acid before they become pregnant, too few of them are being advised to eat fish. However, we think there should also be some specific advice about the damaging heavy metals in some fish (for example, the recent warning about mercury in shark and swordfish) and the pesticides used in farmed fish.

## Reference

- Olsen SF, Secher NJ. Low consumption of seafood in early pregnancy as a risk factor for preterm delivery: prospective cohort study. *BMJ*, 2002; 324: 447-50

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## How dangerous is seafood?

The US Food and Drug Administration has recommended that pregnant women, women of childbearing age and young children should avoid eating shark, swordfish, mackerel and tilefish because they are likely to contain high levels of mercury. They can, however, eat up to 12 oz/week of other kinds of fish, including shellfish, canned fish, smaller seafish or farmed fish.<sup>1</sup>

Mercury is a toxic metal that is particularly dangerous to the central nervous system. Mercury vapour is released into the atmosphere and returns to the earth as rain, and is present in nearly all large bodies of water, such as seas and lakes. The metal is taken up by tiny creatures like plankton, which are eaten by larger fish, and so on up the food chain. This organic mercury-methylmercury-binds to fish muscle and is not excreted, so its concentrations in long-lived fish that prey on smaller fish can be a million times the concentration in the water they swim in.

Methylmercury is particularly dangerous because 95 per cent of it is absorbed by the digestive system and stays in the body a long time, especially the brain. By the time it is excreted, or the problem is diagnosed, the damage is done. It easily crosses the placenta, and levels of mercury that do not affect the mother may cause physical and mental damage to the baby.

In the Faroe Islands, where people eat a lot of whale meat, the children of mothers with higher levels of mercury in their hair were found to have problems with hand-eye coordination, language, memory for verbal information and eye-space judgment.

Around Hong Kong, the sea is contaminated with heavy metals, and fish is a major part of the local diet. A recent study there found that mercury causes infertility.<sup>2</sup> Researchers knew that the more often people ate fish, the higher the concentration of mercury in their hair, and it is known that mercury can cause abnormalities in sperm. This time, they measured mercury levels in blood and found that 35 per cent of infertile men had abnormally high levels that were significantly higher than those of a control group of fertile people. Among women, 23 per cent with unexplained infertility also had abnormally high blood mercury concentrations, and this was also significantly more common than in the control group. Subjects were asked how often they ate fish, and this was found to be positively linked with their mercury levels.

### AIMS comments

This makes for depressing reading especially now that we know of the health benefits of those lovely essential fatty acids in oily fish. Personally, I am sticking to a fish-oil capsule from one of the brands recommended by the Consumers Association as having low contamination, the occasional tin of sardines in olive oil and topping up my fatty acids with flaxseed-oil capsules. All suggestions will be gratefully received.

### Reference

1. Evans E. The FDA recommendations on fish intake during pregnancy. *J Obstet Gynecol Neonatal Nurs*, 2002; 31: 715-9
2. Choy C et al. Infertility, blood mercury concentrations and dietary seafood consumption: a case-control study. *Br J Obstet Gynaecol*, 2002; 109: 1121-5

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### No consent, no publication...

The American Journal of Obstetrics and Gynecology recently received a paper describing a prospective, randomised, clinical trial in which the subjects had not consented to take part. The authors admitted this and gave reasons why they thought it was justified.

The journal refused to publish the report because it is in breach of their ethical standards, and have instead produced a short article reminding doctors that publishers, as well as researchers, have ethical obligations. They say, "By refusing to submit the article for peer review, the Journal is refusing to accept, condone or encourage the unethical conduct of research."

## AIMS comments

Three cheers for the ACOG. They are, of course, simply upholding a standard that is generally accepted by all major medical journals. Nevertheless, we are writing to let them know that they have our support.

## Reference

- Cohn F, Manetta A. A teachable moment: Research ethics revisited. *Am J Obstet Gynecol*, 2003; 188: 2

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### ...Except in England?

A major British paediatric journal has just published a paper-from Glenfield Hospital in Leicester-on cooling babies, on research that was done five years ago. (Cooling all or part of the body is currently of considerable interest as doctors hope it might reduce brain damage in babies who have suffered a lack of oxygen.)

In 1988, 15 babies in the intensive care unit who were extremely ill and receiving ECMO (extracorporeal membrane oxygenation)-a sort of lung bypass-had their temperature lowered for 12 hours. The first five infants had temperatures lowered by one degree, the second group of five by two degrees and the final group by three degrees. This was not done as a form of treatment for the babies, but solely to study the feasibility of the procedure-in other words, it was nontherapeutic research.

The authors comment: "Such children, by definition, are in extremis, and undue delay in establishing ECMO could not be justified. As a result, it seemed inappropriate to seek consent from parents as soon as they arrived in Leicester anxious and with little or no understanding of ECMO. The work was therefore treated as a modification of our normal clinical protocol: however, we provided all parents with an information sheet about the work and sought assent. As a separate safeguard, we established an independent data-monitoring committee, who were informed of patients recruited on a case by case basis."

The Leicestershire Health Authority Ethics Committee approved the study.

## AIMS comments

Whether or not there was a data-monitoring committee is, of course, irrelevant to the consent issue.

Data-monitoring committees are usually set up for large, randomised trials so that they can be stopped if one treatment emerges clearly as better. With small numbers of trial subjects, though, by the time any shortterm risks are apparent, there would not be enough subjects to show whether this was significant before the trial was finished. The need to start ECMO urgently is not in dispute—that's what the babies were there for. Many had been referred from other units. But the need to start ECMO promptly does not mean that the limb cooling had to start at the same time, with no time allowed for explanations.

As a former member of three research ethics committees, I have strong reservations about this piece of research being allowed on these babies at all—with or without consent.

It appears from this that, although the parents were told what was happening, they were not told it was research-and non-therapeutic research at that. It is unclear whether the parents understood that they could refuse hypothermia, and still get the ECMO. We have written to Professor Field, professor of child health at the University of Leicester and the named correspondent for the study, asking for details of the information parents were given. We shall be following up in the next issue of this journal. It so happens that obtaining consent for research from parents whose children were involved in the original ECMO trial in this country has been looked at in some detail. We were among the consumer organisations helping the National Perinatal Epidemiology Unit design the information leaflet parents were given before giving their consent. The NPEU did a follow-up study of parents to find out what their difficulties had been in understanding and consenting to research at such a difficult time. Their findings have been of great value.

## Reference

- Ichiba S et al. Pilot investigation of hypothermia in neonates receiving extracorporeal membrane oxygenation. *Arch Dis Child Fetal Neonatal Ed*, 2003; 88: F128-33

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## The worst care in Europe?

An important study has been published comparing avoidable baby deaths throughout Europe, using a method similar to that of the UK's CESDI (Confidential Enquiry into Stillbirths and Deaths in Infancy).

Anonymised case notes were reviewed by a panel that did not know which country they came from. Cases were graded according to whether there were suboptimal aspects of care that might have contributed to death (grade 2) and aspects that were likely to have contributed to death (grade 3). The problems in care were considered 'maternal/social', 'infrastructure/ service organisation' or 'professional care delivery'. England does not come out well, having the highest percentage of avoidable cases: 53.4 per cent graded as 2 or 3. Greece did slightly better with 51.4 per cent, Denmark 51.2 per cent, Belgium 51.1 per cent, Scotland 50.6 per cent and South Holland 48.4 per cent. Finland did best, with only 31.9

per cent graded 2 or 3, followed by Sweden at 35.7 per cent and Spain (Valencia) at 44.1 per cent.

Two major common factors that emerged were failure to detect severe intrauterine growth retardation (IUGR, where babies are small for dates in the womb) and mothers smoking, which can cause both IUGR and placental abruption.

### AIMS comments

As we never tire of saying, case notes do not tell the whole story in quality of care, and a true review can only take place when parents' stories are included.

As we know, mothers' smoking does affect babies' growth and health (so do fathers who smoke) but, as we have pointed out, stress can affect growth as much as smoking, and the two often go together. Study after study has shown that it is those who are poorer and less educated who smoke. Poverty and shorter schooling are each separately linked to higher mortality in babies. We shall watch carefully to make sure the European audit does not develop into a mother-blaming exercise.

As for IUGR, we see so many examples of false-positive and false-negative cases, together with the anxiety and unnecessary interventions they cause, that we are concerned. Mothers are misled into thinking that ultrasound will accurately tell doctors the size of their baby when it does not.

Although the team list the two major avoidable factors they found, they do not comment on the other aspects they examined. We would be particularly interested to see how organisation of care, which differs widely throughout Europe, affected outcomes.

### Reference

- Richardus J et al. Differences in perinatal mortality and suboptimal care between 10 European regions: results of an international audit. *Br J Obstet Gynaecol*, 2003; 110: 97-105

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### Mouth infections can harm fetus

Harmful bacteria can get into amniotic fluid surrounding the baby from the mother's mouth via the mother's bloodstream. Infection can trigger premature labour even when the membranes are intact.

Six years ago, an article in a dental journal suggested that gum disease in mothers could be related to low birthweights.<sup>1</sup> More recently, doctors at a London dental school looked at bacteria from the mouth in amniotic fluid.<sup>2</sup>

Women who were to have planned caesareans had samples taken from their mouth the day before. Samples of amniotic fluid were taken after the caesarean incision as well as birth samples of chorioamnion (membrane surrounding the fluid). The 48 women came from a deprived population and were of various ethnic backgrounds.

In all cases where the researchers found an organism called *Fusobacterium nucleatum*, the mothers had had one or more previous miscarriages. In 18 of 34 mothers with bacteria, there was a history of problems in previous pregnancies compared with three out of 14 women without such bacteria. The authors suggest that the mouth may provide a reservoir for these harmful pathogens. The fact that they have not been revealed in previous investigations could be because the detection methods then used (bacterial cultures) were not as sensitive as the more modern techniques used here.

### AIMS comments

This is another clue to causes of miscarriage and prematurity. That the culprits were not in the vaginal tract and not the usual bacteria found in amniotic fluid suggest a connection with the mouth. We have to remember how difficult it is for some women to get an NHS dentist nowadays, and poor dental health is often found with poverty, poor diet and social stress. More germs in the mouth and less resistance to them may also be contributory factors. So, if you are planning a pregnancy, get a dental check-up first if you can- and make a fuss if pregnant women don't have access to an NHS dentist in your area.

### Reference

1. Offenbacher S et al. Periodontal disease as a possible risk factor for preterm low birth weight. *J Periodont*, 1996; 67: 1103-13
2. Bearfield C et al. Possible association between amniotic fluid microorganism infection and microflora in the mouth. *Br J Obstet Gynaecol*, 2002; 109: 527-33

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