

Consent to neonatal research

I am writing this during the Christmas holidays, and one of the papers in this issue brings to mind the extraordinary serenity and peace of mind with which Joseph and Mary dealt with the strange happenings surrounding the birth of their first son, baby Jesus, who according to the *Bible* was a N=1 experiment. The paper by Nathan *et al* studies parental decision-making in relation to neonatal research (*see page 106*). They used the MacArthur competence assessment tool for clinical research (MacCAT-CR) to assess parental competence in parents of neonates undergoing cardiac surgery. The parents were asked for permission to enrol the neonates in one of three non-therapeutic studies before the surgery. The study shows that parents in this situation in general had similar MacCAT-CR scores to previously sampled normal control populations, indicating good competence to decide.

This finding seems to contradict previous research on consent to neonatal research, which has found that parents often have difficulties in processing the information they are given about the research. One possible explanation is that the parents in the present study were asked about research that did not interfere with or involve changes in the treatment of their child and that this situation does not create the same psychological tension as a situation where you have to decide to

let your child be randomised to radically different treatment arms.

Rationing in healthcare—what do patient's want to know?

When baby Jesus was born, he was met with a surfeit of gifts, gold, frankincense and myrrh, but the patient in today's healthcare system is more likely to be met by rationing and efficiency drives. The paper by Owen-Smith *et al* uses a qualitative interview approach to study whether (1) patients want to know whether there had been any rationing decisions in relation to their care and (2) whether UK doctors routinely give this information to patients (*see page 88*). They found that nearly all patients wanted to know about rationing, but that doctors did not always understand that that was what the patients wanted. The research further showed that patients use a wide range of sources to search for treatment options for their condition and that they become worried/suspicious when doctors leave out treatment options without explanation.

Forensic autopsy and information to the family

Forensic autopsy takes place to investigate the cause and manner of potentially unnatural deaths. In Japan, families have traditionally been told little about the purpose of forensic autopsy, the reasons

that it is being performed in the specific case, and the results of the autopsy. Ito *et al* studied the results of this restrictive policy in relation to information (*see page 103*). The response rate to their questionnaire was not great, only just over 30% of the families contacted responded, but the results are nevertheless thought-provoking in their bleakness. They show that the information received from the police before the autopsy was deemed as insufficient or poor by more than 80% of families and that, among the 65% who receive some information after the autopsy, 70% feel that this information is insufficient. The research also, not surprisingly, shows that there is a link between the perceived quality of information and the families' feelings about the autopsy.

JME moving to 'Online first' publication model

The JME is moving to an Online first publication model. This means that papers will be sent for technical editing as soon as they are finally accepted and that they will be published online in their final form with a doi as soon as they have been technically edited and the proofs have been accepted by the author(s). All accepted papers will still be published in the paper journal as well, but moving to the Online first model means that we can get your ideas into the public domain faster.