Retaining trust

The debate over the retention of organs in hospitals in the UK has been dominated by those whose children have died. It is hard to disagree without some understanding of what these parents have experienced. I have seen the business of necropsy from both sides. As a doctor I have asked for consent for necropsies many times; in many cases the result helped relatives come to terms with a death when a necropsy confirmed the ante-mortem diagnosis. When the diagnosis had been wrong, I and my colleagues learned. As a parent I signed consent for a necropsy on my stillborn daughter. The necropsy was unhelpful. It was superficial; no reason for the death was forthcoming—because, said the obstetrician, “we did not know what we were looking for”.

The press headlines in the UK about organs retained after necropsy, and about children’s thymus sold for research by The Royal Liverpool Children’s Hospital (Alder Hey), are creating an atmosphere of public mistrust in doctors that will have serious implications for the future of medicine in general, and pathology in particular. The stories imply that the medical profession is populated by incompetent, uncaring doctors who take body parts for either their own interests, or for profit, and who do necropsies for their own ends. There have clearly been rogue practices at Alder Hey (see page 365), but these are not the norm. For doctors to regain the trust of the public, they need to defend themselves against these charges, and insist that not all doctors have behaved beyond the pale.

Most doctors wish to heal their patients, and when they fail they want to know why. These sentiments are also those of patients and their relatives. Why then is there such a gulf between doctors and patients? There are many technically advanced diagnostic tests that can be done during life, but the ultimate test in medicine is the necropsy. A lack of appreciation of the value of this procedure is central to the current public misconceptions of medicine. No-one who has done or attended a necropsy can seriously suggest that the procedure is done for trivial reasons. The retention of tissue is integral to the necropsy—for immediate further tests, for research, or for teaching. For many years body parts removed from cadavers have contributed directly to the medical education of every doctor. What has changed to make necropsy so appalling to non-doctors?

People have started to take a far more active interest in how their health and illnesses are managed. They are offered many more chances to make decisions about their health, and that of their children, ranging from those on prenatal screening to those on terminal illness. However, to make informed decisions, all the facts are needed. In the past these facts were kept from patients for two main reasons. First, for some patients medical tests can be hard to make sense of. This point has been borne out by the difficulty many women have in understanding the results of prenatal screening tests. Tests that help epidemiologists make decisions at a population level do not help a woman understand the degree of risk for her unborn child. Second, doctors believe that patients do not want to know the gruesome details of all that happens to them. Not giving patients all the facts has been interpreted as paternalism. The failure to communicate with patients is the real cause of all the anguish over retained organs, and if doctors are to blame for this anguish, the reason is generally a desire to spare already grieving relatives from more distress. Admittedly, doctors also find it distressing to have to confront relatives with the realities of death, and have tended to gloss over the details for everyone’s sake. The interim report or the inquiry into paediatric heart surgery at Bristol Royal Infirmary put it thus: “There is a price to be paid for being informed”.

In the desire to comfort the families of children who died at Bristol and Alder Hey, there is a danger that the contribution of necropsies and medical research will be lost. These contributions ultimately benefit the public. Between 1984 and 1998 the number of hospital necropsies requested for non-legal reasons decreased from 19 367 to 3335 per year.1 The remains of the dead should be treated with respect, but contributing to learning is compatible with this principle. Every blood sample, every histological specimen, does not by its removal diminish a child. The recommendations from the Alder Hey inquiry include a very detailed consent form for necropsies and the disposal of tissue. Doctors must be honest with patients and relatives, but is this principle to be carried to the point of unkindness. Will parents want to read a long list of exactly what is done at necropsy, what is taken out, and where the tissue goes?

Consent is essential for necropsies (and has been common practice for many years), but the right balance must be struck. If doctors become too scared to ask for necropsies, or relatives so horrified by the minutiae that they refuse all requests, then all will be the losers. Necropsies are vital for good medical practice. If doctors do not look for answers, patients are right to lose trust in them.

Virginia Barbour
The Lancet. London WC1X 8RR, UK


Habituation technique in study of development of fetal behaviour

The technique of dynamic ultrasonography is enabling both obstetricians and psychologists to improve their assessment of health of the fetus, including quality and activity of the fetal central nervous system. It is now known from dynamic ultrasonography that healthy human fetuses make movements from 7 weeks of gestation onward, and that 15 distinct patterns of movement (eg, breathing, swallowing, sucking) emerge at between 8 and 15 weeks.1 Fetal behavioral states develop gradually from around 28 weeks of gestation and are fully developed at about 36 weeks.2 Deviations from these trends suggest an abnormality. For example, fetuses of mothers with type 1 diabetes show a 1–2 week delay in the emergence of almost all movement patterns, poorer concordance among indices of behavioral state (such as heart rate, body movements, and eye movements), more frequent asynchronous and disrupted transitions between behavioral states, and shorter rest-activity cycles than comparably aged fetuses of nondiabetic mothers.3

Now scientists have started to look at fetal learning and memory. These studies use a habituation technique that focuses on the decrease and eventual cessation of an organism’s response to a harmless repeated stimulus. The habituation response pattern is considered an adaptive function that is dependent on early learning mechanisms. A quicker response decrement to the same
stimulus presented at a later time (eg, 24 h after initial exposure) is evidence of memory. For example, van Heteren and colleagues have recently reported that 17 of 19 healthy term fetuses, to whom a stimulus was applied repeatedly, exhibited habituation (defined as no trunk movements within 1 s of four consecutive stimulus presentations) at the initial test as well as at 10 min and 24 h later. Moreover, compared with their initial performance, 16 of 19 fetuses showed more rapid habituation at 10 min and at 24 h, which suggests that short-term and long-term memory functions are intact before birth.

These experimental studies of fetal learning and memory not only extend knowledge of early human capacities and development, but they may also provide the basis for early and more sensitive assessments of the integrity of the fetal central nervous system and ultimately help elucidate the developmental mechanisms underlying behavioural teratogenesis. Researchers have reported long-range correlations between an environmental aberration (eg, malnutrition, drug exposure) during critical periods in brain development and subsequent low-par neuropsychologic functioning in the offspring. For example, measures of maternal lipid and glucose metabolism in the second and third trimesters of diabetic pregnancies correlate inversely with subsequent intelligence quotient in childhood, after the effects of family socioeconomic status and race or ethnic origin have been controlled for. The implication is that these early aberrations may directly affect concurrent developmental processes (especially the development of brain structure and function) and the trajectory for subsequent development. Thus Nicola Doherty and Peter Hepper have found that fetuses of mothers with type 1 diabetes were slower to habituate at 28 and 32 weeks of gestation than were fetuses of non-diabetic mothers. Group differences were not significant at 36 weeks of gestation possibly because the fetuses most affected by poorer metabolic control had been delivered by this time.

Studies of fetal habituation are informed and bolstered by the more established infant research. In the first year of life, performance on habituation—and on a complementary procedure called novelty responsiveness (also called recognition memory) that focuses on the recovery response upon presentation of a novel stimulus—correlates significantly with later intelligence quotient. This correlation is substantial (median raw correlation of 0.45) given the low reliability of infant measures; does not depend on the inclusion of high-risk infants; and is higher than for standardised infant tests. Future research should establish and improve the reliability of the fetal habituation technique by standardising procedures and constructing an assessment battery (for example, by using multiple trials with different stimulus properties, and by adapting the novelty responsiveness procedure). Research should also try to establish the correlations between fetal habituation and concurrent assessments of fetal health and behaviour, and between fetal habituation and measures of infant habituation and later child development.

Thomas Rizzo
851 Washington St, Elmhurst, IL 60126, USA
(e-mail: trizzo@medisonet.net)


New cells from old

In the UK, the House of Commons, and now the House of Lords, have voted to legalise research involving stem cells derived from cloned human embryos. Cloning entails the transferring of nuclei from differentiated cells into enucleated human ova (somatic-cell nuclear transfer), and the generation and growing of embryos, which may then be used as a source of stem cells. A surfeit of advice was offered, the bulk in favour of legalisation. Yvette Cooper, the Public Health Minister, articulating Government support, said that it "could prove the Holy Grail in finding treatments for cancer, Parkinson's disease, diabetes, osteoporosis, spinal cord injuries, Alzheimer's disease, leukaemia and multiple sclerosis . . . transform[ing] the lives of hundreds of thousands of people". The widespread view seems to be that research using human embryos is the only available approach to the development of stem-cell therapies, and that objecting to such research is to "deny sufferers of devastating illnesses the chance of a cure".

This view has been based not least on the serious contributions of the Royal Society, the Medical Research Council, the Wellcome Trust, and the British Medical Association, as well as the Chief Medical Officer's report (Donaldson report). All agree that the human embryo has "special status", but all take the view that this status may be over-ridden in the interests of therapeutic research.

But is the matter so straightforward? Two important points seem to underlie the Government's stance. The first is that embryo-derived stem cells are poised to unleash imminently their "huge power to end suffering". The second is that there is no realistic alternative.

Most clinical scientists would agree that stem-cell research does have enormous potential, but they would also agree with that part of the Donaldson Report (on which the proposed legislation is based) that repeatedly emphasises that stem-cell research is "basic research which . . . would precede by many years any application to treatment". Despite the high profile that this topic rightly enjoys, animal studies exploring the potential benefits of stem-cell transplantation are few, and still in their infancy. Many clinicians and, some scientists too, consequently consider that even the small amount of stem-cell clinical-trial work now underway is premature. Although definite tumour formation has not been reported, sufficient long-term experiments have not been done to allay concerns about this serious hypothetical hazard. The potential adverse effects are well illustrated...