Perinatal pathology in 2001

Paediatricians will not need to be convinced of the value of the necropsy examination. Necropsies have received extensive adverse coverage in the press during the last year, the main issue being the retention of organs without the knowledge of the family of the deceased.

However, patients in the United Kingdom have been receiving a standard of service in perinatal pathology that is unequalled elsewhere in Europe. It is an important facet of reproductive health care, both at an individual level and also for the community. The importance of good perinatal pathology has repeatedly been recognised by bodies such as the confidential inquiry into stillbirth and death in infancy (CESDI), whose remit is to identify ways of reducing fetal and infant deaths. The current controversy is seriously damaging perinatal pathology—there are currently 10 unfilled consultant posts (of a total of less than 40), with only a single trainee in post. The current adverse publicity does nothing to aid recruitment to a discipline that already requires highly specialised diagnostic skills. Perinatal necropsy rates are generally down and thus many parents are not receiving the information they need to make informed reproductive choices. Research output has also suffered.

If we are to recover this lost ground, pathologists and other professionals involved in counselling families about perinatal necropsies need to work hard to reassure parents and explain the importance of the postmortem examination to their future reproductive health.

In recent years, the majority of consented necropsies (that is, those not performed for the coroner) in the United Kingdom have been perinatal cases. The practice of perinatal pathology is concerned with investigating perinatal deaths, miscarriages, early pregnancy losses, and congenital abnormalities diagnosed prenatally. Paediatric pathologists also examine infant and childhood deaths for both natural and unnatural causes.

Perinatal pathology is based on the necropsy examination of the infant or fetus. Where this is performed to a high standard, the information it yields can have a major influence on the way the parents are counselled with regard to the risk of a recurrence in a future pregnancy and what options they have for early diagnosis or treatment. Much of this information cannot be obtained in any other way. Various studies in recent years have shown that from 14 to 46 per cent of perinatal necropsies provide significant new information, and around one in 10 lead to the diagnosis being changed.1–5 Other research has shown the importance of expertise when performing perinatal necropsies, the quality of information being much greater when a specialist perinatal pathologist performs the examination.1–4,6,7

A full necropsy requires a careful examination of the external appearance and internal organs of the baby. The fetal and infant brain is a very delicate organ that requires fixation before it can be properly examined. Formalin fixation takes a few days for a small fetus and a week or two for an infant; thus for the maximum information to be obtained it is necessary for the brain to be held for this time. It is also essential that histology be performed, and thus small samples of tissue need to be taken and processed for microscopy. The resulting paraffin blocks and slides are archived in the same way as the patient notes, for future reference.

The present controversy over the retention of organs at necropsy has been heightened by the question of what has been done with those parts of retained organs and tissues which are not selected for histology. Usual practice in pathology laboratories has been to destroy this tissue once the necropsy report was completed. No special distinction has been given to whole organs.

Selective organ retention, as indicated by the clinical circumstances, is regarded as good practice, especially for examination of the brain, and pathologists have not attempted to conceal this. Most doctors will have been aware of this practice, indeed most descriptive research in the field of neuropathology is entirely based on tissue from such retained organs. There has been no suggestion until recently that specific consent was legally required, and this appears still to be the case across the rest of Europe and North America. Although patients’ families were clearly not told specifically and in detail what the examination entailed by the doctor requesting consent for the necropsy, this was undoubtedly felt to be an act of compassion and not one of concealment. Pathologists have rarely been involved in the process of requesting an necropsy.

The attitudes of society have changed. Patients are no longer happy to accept a paternalistic medical profession providing care as they see best. Understandably, in this age of information, patients expect to make informed choices about health care, and pathology is no exception. By today’s standards the traditional consent procedure for necropsy examination has been less than ideal. The recent guidelines from the Royal College of Pathologists8 go a long way to addressing this issue of informed consent, and practices for obtaining consent are being revised throughout the country. In particular, the wishes of the patients’ relatives regarding the disposal of retained tissues and organs are being included in consent forms. The amendment to the Cremation Regulations9 issued early in 2000 has helped to clarify the position for disposal of residual tissues by formal cremation. We cannot, however, change what happened 5, 10, or 20 years ago and cannot bring back tissue that has been already disposed of. There is a danger that further national inquiries will cause additional distress to parents who have lost babies in the past, by making them revisit their grief and raising doubts, which will not be answerable, years after the event.

Addendum
Since this article was written, the official report of the Alder Hey inquiry has been published. As a result, trusts with perinatal or paediatric pathology departments have each received between 100 and 1000 calls from worried parents.

The task of tracing all tissues, blocks, and slides from the babies concerned is now under way. This has had, and continues to have, a considerable impact on the time of the staff involved, to the detriment of their ability to provide a pathology service. However, the tracing process and resultant counselling of families will be completed over the next
few months. What is less clear is what the future of perinatal pathology will be thereafter.

Even if parents are made aware of the importance of a necropsy examination to their future reproductive health, there may be no pathologist in their region of residence with the necessary experience to perform the examination. A great deal of effort will be necessary from everyone concerned, if this country’s excellent perinatal pathology service is to be maintained.

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