The autopsy: lessons from the National Confidential Enquiry into Perioperative Deaths

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Not long ago, the place of the autopsy in medical practice seemed to be primarily the concern of the medical profession. Then the issue of organ retention came to public attention in the UK following the Bristol Royal Infirmary and Alder Hey Inquiries^{1,2}, and the whole question of keeping organs and other samples from autopsies suddenly became the focus of intense media attention, generally negative, in which the British government was involved^{3,4}. In consequence, there is debate about the future role of the autopsy.

Several government-sponsored reviews of the conduct of the medical profession in regard to autopsies have been proposed. Some of these are currently out to consultation and include national standardized autopsy consent forms, a code of practice for bereavement services⁴, a review of the removal and retention of human organs (including a code of practice for museums, archives and collections of human organs and tissue)⁵ and a Home Office-led review of death certification and the coronial system in England and Wales⁶. A comprehensive review of the Human Tissue Act (1961) is planned. These measures will undoubtedly regulate all aspects of autopsy practice and its contribution to research, education and audit. The National Confidential Enquiry into Perioperative Deaths (NCEPOD) stands to be much affected by such changes but must continue to play a part in informing the debate.

NCEPOD

Since 1987 NCEPOD has sought to improve perioperative care by auditing data on deaths within 30 days of any surgical operation or invasive diagnostic procedure under local or general anaesthesia in England and Wales. The reporting of such cases has been compulsory since April 1999 in line with clinical governance requirements⁷. NCEPOD's remit has recently been extended to include the reporting of all deaths in hospital. The range of topics to be audited will increase, and in many instances review of autopsy data will

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be helpful. Briefly, the procedure is as follows. Local trust reporters send anonymized details of deceased patients to NCEPOD. A proportion of deaths are selected for more detailed analysis by use of standard questionnaires, copies of relevant documents from the patients' case notes being provided. The most recent report (for 1999/2000 cases) concentrated on patients with malignant disease⁸, while the previous year's report (for 1998/1999 cases) selected a random 10% sample⁹. An important part of this process is review of the autopsy report by the pathology advisors against a nationally available 'gold standard'⁹. Attention is paid not just to details of the autopsy findings but also to evidence of good communication between pathologist and clinicians. Any means by which the patient, clinicians, or hospitals could be identified is eliminated from all the documentation, ensuring complete confidentiality for all parties.

UNEXPECTED POST-MORTEM FINDINGS

The experience of NCEPOD is that much can be learnt from examining these deaths, and we agree with others that a properly and respectfully performed autopsy is a crucial part of their investigation^{9–11}. The autopsy often yields findings not suspected in life. In the 1999/2000 NCEPOD report⁸, the pathology advisors identified a major discrepancy between the clinical diagnosis and post-mortem findings in 81 of 346 (23%) autopsies; in 9% a minor discrepancy or interesting incidental finding was recorded. Of the surgeons who received a copy of the autopsy report, 21% indicated that clinically unexpected findings had emerged. The previous year's report⁷ showed similar results: a major discrepancy between the clinical diagnosis and the post-mortem findings was found in 45 of 271 (17%) and a minor discrepancy or interesting incidental finding in 6%. These figures are in line with the many studies which show that unexpected findings continue to be provided by autopsy examination; in particular, there is no indication that there has been any decrease over the years in the proportion of cases in which unexpected findings occur, despite the increasing sophistication of diagnostic procedures¹²⁻¹⁴. Furthermore, there are no known factors that predict which cases are liable to show substantial

differences between the pathological findings and the clinical impression 15 .

A reliable autopsy diagnosis is important for many reasons, of which audit of the type represented by NCEPOD is only one¹⁰. It is also important for the relatives of the deceased; a study, in 1986, of the families of deceased patients showed that 38 (68%) of 56 respondents whose relative underwent autopsy found the results of the autopsy beneficial to the family¹⁶. This view was reiterated in a 1995 study of public perceptions¹⁷.

QUANTITY AND QUALITY

Therefore, we are concerned that an autopsy was performed in only 31% of postoperative deaths in 1999/2000 and 30% of deaths in 1998/1999, in contrast to 41% of deaths in 1988/1989 (the latter was also based on a random 10% sample of submitted cases)^{7,8}. It is possible that the number of autopsies will fall even lower as a result of the recent organ retention issues^{2–4}. Furthermore, relatives may increasingly withhold their consent for retention of tissues or whole organs after autopsy without being fully aware of the benefits of appropriate retention of material, or they may consent to only limited autopsies.

Although there is clear evidence that the autopsy continues to be a valuable tool for diagnosis and audit, there can be problems with the way it is carried out. Despite the publication of guidelines and advice on procedures appropriate to post-mortem investigation^{9,11,18}, NCEPOD classified only 242 (70%) of 346 autopsy reports as satisfactory or better⁸. There are many possible factors that might explain such a high proportion of unsatisfactory reports; one is the potential conflict between the type of investigation needed to fully characterize the disease processes involved in a perioperative death and the constraints of the coroner's autopsy. In the UK, the great majority of post-mortem examinations following perioperative deaths are performed on behalf of the coroner (95% of cases in the 1999/2000 report)⁸. Rule 9 of the Coroners' Rules states that tissue may only be retained for histology if it is needed to ascertain the cause of death; investigations for any other reason require consent from the next of kin. Although histological examination is not essential in every case¹⁹ it should be performed more often than it is⁷. The absence of a histology report was considered to detract significantly from the value of the autopsy in 28% of cases⁸.

COMMUNICATION

Communication between clinicians, relatives and pathologists also needs to be improved. When approaching an autopsy on a complex perioperative case, the pathologist should have full details about events before death, and requires access to the hospital notes. Likewise, the clinicians need timely feedback of the autopsy findings to understand more fully why the patient died and to inform the family accordingly. Only 29% of surgical teams reported that they had been told the time and place of the autopsy and only about half of these attended⁸. The practice in some areas of performing autopsies in mortuaries remote from the hospital where the death occurred exacerbates this problem. Moreover, a copy of the autopsy report was received by only 70% of clinicians; the explanation in some cases is that some coroners still prevent clinicians seeing copies of the autopsy report. It would seem that in too many deaths the audit loop is not being closed. Multidisciplinary mortality meetings to include all interested parties, including the pathologist, should be held (and properly funded) to discuss every perioperative death.

The autopsy needs some positive publicity to counteract the influence of the recent media attention. Truly informed consent is likely if families understand the relevance of the autopsy in modern medical practice, both to themselves and to others. As part of this process, the autopsy findings must be made known to the next of kin. This requires sufficient time for explanations of possibly complex medical matters. There may be a place for pathologists in performing this task²⁰.

CONCLUSION

Clinicians must strive to achieve an audit record for all deaths if professional education, credibility and public support are to be maintained^{7,8}. This process should normally include an autopsy which is appropriate to the problem and which addresses the questions that need to be answered. Since most autopsies are for the coroner, there is a need to emphasize the importance of taking tissue for histology, of pathologists having access to the information they require, and of clinicians and relatives being properly informed of the results.

Note: NC, MB, VS and KM are the pathology advisors for NCEPOD for 2001–2002. CC was the chair of the pathology advisors for the 2000 NCEPOD report.

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