

Leading article

Reflecting on Redfern: What can we learn from the Alder Hey story?

In 1998 the General Medical Council (GMC) charged two Bristol surgeons and their medical director with misconduct on the grounds that they had failed to recognise and act upon their poor outcome results.¹ In September 1999, the enquiry set up to investigate the events at Bristol heard evidence from Professor Robert Anderson. He told the panel that a collection of hearts was housed at the Alder Hey Hospital in Liverpool and that many other hospitals had collections of organs for research purposes. His purpose was to explain how these had improved the results of paediatric cardiac surgery,² but the Liverpool Echo and the national press picked up the story and presented it as a scandal. The Alder Hey Hospital was overwhelmed with enquiries from anxious and angry parents. Accounts of post mortem organ removal, examination and retention, which the medical profession had considered normal practice, rapidly became intertwined with the unprofessional and unacceptable behaviour of one Alder Hey pathologist, Professor van Velzen. The Secretary of State for health then ordered an enquiry, which was conducted by a Queen's Counsel (senior trial lawyer), Michael Redfern.

Redfern's report contains many important messages about job descriptions, management and the responsibilities of coroners.³ It is not just an account of an overzealous and dysfunctional pathologist. Nevertheless, the detailed descriptions of how parents felt they had been deceived and let down by doctors make disturbing reading. These, together with media phrases such as "ghoulish malpractice and gross mismanagement", "organs systematically stripped", and "return of the body snatchers"⁴ have left the profession hurt and bemused. Politicians are accused of talking up the story for their own ends. This was clearly a systems failure,⁵ yet the doctors involved have been reported to the General Medical Council. Apologies have been offered on behalf of all health professionals by the Royal College of Pathologists and the Royal College of Paediatrics and Child Health.

Is this just another doctor-bashing story? Many of us may have thought so at first but Alder Hey is probably as cataclysmic an event in British medicine as the Bristol case.¹ Alder Hey represents the culmination and, perhaps, the final demise of what we have thought of as benign medical paternalism, intended to protect patients and relatives from distressing details. Others have diagnosed our paternalism as arrogance, secrecy, dissimulation, and deception.⁶ In her evidence presented to the Chief Medical Officer's summit meeting on 11 January 2001, Dr Ruth Richardson outlined a historical perspective and explained why she thinks that Alder Hey was a scandal "waiting to happen for at least a generation". She saw it as "a product of cultural baggage which predates the establishment of the NHS". This is strong stuff. Do we deserve it?

The care of the body after death, though differing widely according to culture and religion, has always been recognised to be important for the mourners and often for the wellbeing of the departed in the afterlife. In the debate on the Human Tissue Act 1961, Lord Balniel referred to "... instincts that say the human body, once life has been extinguished from it, should be treated with the utmost dignity and respect . . . and left in peace. These instincts are

felt by most persons whatever religious—or indeed irreligious—beliefs they may have".³

Henry VIII recognised these instincts and introduced dissection as an additional post mortem punishment for criminals, thus providing a supply of bodies for study by barber-surgeons. As the demands of anatomists and pathologists increased, body snatching and grave robbery emerged, outraging public opinion. In 1832 the Anatomy Act attempted to resolve the problem by requisitioning the bodies of the poor, who could not afford funerals. The Victorians were understandably desperate to avoid burial as a pauper and this resulted in massive growth of the funeral insurance business.

Perhaps this history explains why it was widely believed by our profession that "specimens" could be collected and retained, without the relatives being informed or consent being given. It was part of accepted professional behaviour. For me, as for most medical students of my generation, attendance in the dissection room and the post mortem room was not just part of one's education but also a form of initiation into the profession. This view persisted more or less unchallenged in the collective medical consciousness until Alder Hey forced a re-examination of the legal and ethical issues.

The precise legal position with regard to the ownership of bodies and body parts, the appropriate approach to disposal and the right to retain items for research or study is still "complex, uncertain and obscure".⁷ The relevant legislation includes the Anatomy Act, the Human Tissue Act, the Polkinghorne Report on the use of fetal tissue, and a body of case law. The health care professions, funeral directors, and the public would welcome clarification.

Nevertheless, we do not need to wait for new legislation to learn and apply the main lessons from Alder Hey. Of course, the most urgent is that we need proper consent procedures for post mortem examinations. The Royal College of Pathologists is taking the lead in developing these and they will show the profession's commitment to change. But better consent procedures are not enough. We need to change our thinking at a more fundamental level. There was always a risk that professional self interest could be disguised as paternalism, but in an era where the ignorance of the profession was only slightly less than that of the laity, it might have been defensible. That is no longer the case. Richardson refers to "a change of perception . . . that the public be seen as intelligent collaborators in the project of improving the nation's health and the development of medical science".⁶

The second lesson is that many parents indicated that, had they been asked, they would probably have been willing for their child's organs to be used for research. Though some perceive that Western people are more selfish and more socially isolated than ever before⁸ the continuing generous donation of blood, bone marrow, and organs as well as bodies for dissection suggests that altruism is alive and well.⁹ More detailed information about what happens at necropsies may in the short term result in fewer being done and a fall in organ donation for transplant, but perhaps in the long run the effect will be the opposite. Lord Balniel put it elegantly when he said "there is something infinitely

wonderful in the thought that medical science now allows men to use the tissues and organs from a dead body in order to bring health and happiness to the living . . . to create something approaching the immortality of the living cell".³

Parents who have lost a child seem often to agree with Lord Balniel. The donation of an organ or the use of some part of the body for medical teaching or research might offer that immortality for their child, helping them to make sense of their personal tragedy. Perhaps their anger over the retained organs issue relates to the lack of information about post mortem procedures, which deprived them of the opportunity freely to make that gift.

What should we do next? It is vital to clarify the law and to introduce acceptable procedures for obtaining consent to necropsy. We must listen to what parent organisations are telling us about the need for clarity and honesty about necropsies and for time to make what are often very difficult decisions.¹⁰ We must introduce those lessons into our training programmes. The possibilities of carrying out limited necropsies to answer specific questions ought to be explored using—for example, imaging and guided biopsies. It is a matter of urgency to improve recruitment into paediatric pathology and to ensure that when necropsies are essential, the examination is done to a high standard and that all necessary investigations are completed and reported to the parents. The Government's response to Redfern should include an overhaul of the coroners' regulations, so that these expectations can be met.

Perhaps it is reassuring that a recent opinion poll commissioned by the British Medical Association showed a high level of trust in doctors, notwithstanding recent events. But we dare not be complacent. Can we do anything further to restore public confidence in doctors? Better education in schools about science, the human body, and the responsibilities of individuals in society might help in the long term, but will not resolve the immediate loss of confidence in our profession.¹¹ I am attracted by an idea put forward by Richardson in her evidence. She proposes a public act of thanksgiving for the selfless actions of all those who donate blood, organs, tissues, or whole bodies to medicine and science. That might be the ideal opportunity for our profession not only to say "Sorry" for our slowness to adapt to the expectations of our society but, more importantly, to show that we really have learned the lesson of collaboration.

Perhaps we should now all be asking ourselves what else we might be doing that seems routine and normal to us but might suddenly become the focus of public attention.

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Commentary

Hall's article provides useful balm to the inflamed topic of organ retention. It is helpful as we enter the repair and rebuilding phase following the biggest public outcry against the medical profession in recent years. His analysis of why and how it happened is fair, and Ruth Richardson's "cultural baggage predating the NHS" is probably true, although most histopathologists would say they were simply doing what they had been taught and believed to be good professional practice. As Hall says, for generations of medical students the dissecting room and mortuary were a rite of passage that gave them a perspective on dead bodies which their future patients would not share. I use the past tense, because, such is the modern curriculum, many students today have never seen a necropsy. Although that might give us pause for thought, at least it means they are more easily able to understand the current public disquiet than their teachers.

The solution to regaining public confidence is not just simply to redesign a consent form, or even to focus solely on consent. It is about information and understanding. It must be remembered that the majority of necropsies (>90%) are requested by the coroner (or procurator fiscal in Scotland) and do not require consent; but it is only common courtesy and compassion to let the relatives know what is going on, to explain to them what needs to be retained by the coroner, and if anything is sought for teaching or research, to ensure that their permission is obtained. Exactly how this is achieved is relatively unimportant.

The English and Scottish Health Departments have made several recommendations to their respective governments and the same will happen in Wales and Northern Ireland. There will be new codes of practice, the breaching of which will be a disciplinary offence in the NHS. Primary legislation will be reviewed, as will the processes behind medicolegal necropsies. The Westminster team has set up a Commission on Retained Organs, which has the job of ensuring that all hospitals and universities catalogue their tissue archives and, for a limited time, respond to queries from the general public in a constructive, honest, and helpful manner. The cataloguing is proving less than straightforward and there is a crackle of static over the topic, but all that will pass and ultimately a new equilibrium will be achieved. Histopathologists, too few in number, overworked and demoralised, will recover eventually. Paediatric pathology as a viable subspecialty is in a particularly parlous state at present, though it too will re-emerge in time. But for a while the service will struggle. So has any good come from all this?

The legacy of Alder Hey will undoubtedly be a major change in the way necropsies are carried out, but more importantly, as Hall implies, I believe it will be longer remembered as a watershed on the road to the wider medical profession's acceptance of the need to abandon paternalism. Before Redfern, many realised this, but after Redfern the many became most and the tide of professional opinion has turned. It is a pity that this could not have been achieved without so much pain and distress to bereaved parents, other relatives, histopathologists, hospital managers, and university staff.

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