

From the Editor-in-Chief

Arrogance born of indifference?

AMONGST PAEDIATRIC CARDIOLOGISTS AND CARDIAC surgeons working in the United Kingdom, one of the major topics of conversation over the last twelve months or so has been the so-called “Bristol Affair”. The source of discussion is the less than adequate results of cardiac surgery undertaken in infants and children at Bristol Royal Infirmary over the period 1984 through 1995. This culminated in the two cardiac surgeons involved, along with the chief executive of the United Bristol Healthcare Trust, being struck from the medical register of the United Kingdom subsequent to a hearing conducted by its General Medical Council. Until recently, the implications of this affair have largely been parochial, although the surgical aspects have been addressed in the broader context.¹ Subsequent to the disciplinary hearings organised by the General Medical Council, there has been an extensive public inquiry convened and funded by the government. Established in June, 1998, its terms of reference were “To inquire into the management of the care of children receiving complex cardiac surgical services at the Bristol Royal Infirmary between 1984 and 1995 and relevant related issues; to make findings as to the adequacy of the services provided; to establish what action was taken both within and outside the hospital to deal with concerns raised about the surgery and to identify any failure to take appropriate action promptly; to reach conclusions from these events and to make recommendations which could help secure high quality care across the National Health Service.” A panel of four experts, chaired by Professor Ian Kennedy, and supported by a formidable team of barristers, solicitors, and civil servants, heard 95 days of oral evidence, in addition to receiving many additional formal written statements. The transcript of the oral hearings is available in full on the website of the inquiry at www.bristol-inquiry.org.uk. The final report from the inquiry will appear in a few months. The inquiry has just published, however, an interim report,² and the full text is also available from the inquiry website. This report is of significance for all involved with cardiology in the young. It is concerned with “Removal and retention of human material”. Constructed in four parts, comprising 193 paragraphs, making 69 recommendations, and having two annexes, its findings are far reaching. They could, and should, inform the actions of all those who seek to perform autopsies in infants and children dying with congenitally malformed hearts, particularly with regard to the

nature of consent. Although the legal aspects surrounding the practice of postmortem examinations will vary from country to country, the principles and philosophy expressed in the report deserve universal attention. The problem addressed is well stated in paragraph 4: “The issue of concern was that, without the realisation of parents, tissue had, over a long period of time, been systematically taken at or after post-mortems on children who had died following paediatric cardiac surgery ...”. Although the report is concerned specifically with the happenings at Bristol, subsequent events showed that similar activities had taken place throughout the United Kingdom. It is likely that they have occurred elsewhere. If so, then the same problems need to be addressed.

As the report describes (paragraph 5), “When the practice of tissue retention came to light in Bristol, there was, both in Bristol and elsewhere, an outcry from parents. They sought information about whether tissue had been removed from their children”. The report then goes on to describe the “considerable publicity” which was attracted by my own evidence to the inquiry, in which I publicised the “various collections of tissue which existed around the country”. My purpose in giving this evidence was to highlight the huge advantages which, in my opinion, had accrued from the availability of the post-mortem material held in these collections. It had been access to the extensive collection held at the Royal Liverpool Children’s Hospital which had kindled my own interest in the structure of congenitally malformed hearts, and which had permitted us to help clarify the course of the conduction tissue in malformations such as congenitally corrected transposition,^{3,4} double inlet left ventricle,⁵ and isomerism of the atrial appendages.⁶ As is explained in paragraph 101, it is my belief that those responsible for making the various collection of hearts had been unaware of the fact that, in many instances, parents had not been informed that the organs of their children were to be retained. As is also explained in the next paragraph, Professor Michael Green, Emeritus Professor of Forensic Pathology at the University of Sheffield, told the inquiry that, at the time, “... it was felt that if organs were to be retained, relatives should not be further distressed by being presented with a list of organs that might be retained”. Irrespective of the reasons, it rapidly became evident from public opinion that we, in the medical profession, had misjudged to a large extent the wishes and desires of a significant proportion of parents. The major reason for

our wishing to retain the organs, of course, was our desire to use them to increase our knowledge, and hopefully improve our strategies for future diagnosis and treatment. We failed to recognise the need to do this in partnership with the bereaved parents. As was stated succinctly by one of the parents giving evidence (paragraph 27) "I know I felt if another baby could be helped by the retention and, if that was the reason, then we would have said yes; but the fact that they were kept without our knowledge ... came as a very, very big shock". There is no suitable response to this justified criticism.

The situation had not been helped in the United Kingdom, however, by ignorance concerning the legal situation of autopsies carried out on behalf of the coroner, who has legal responsibility for establishing the cause of death, and the ambiguity which continues to surround these activities. The background to these problems is admirably summarised in paragraphs 12 through 25 of the report. In essence, during the period examined by the inquiry, the majority of post-mortem examinations undertaken in children dying with congenital cardiac malformations were done so at the behest of the coroner. In these circumstances, it was the duty for those making the examination to "... make provisions, so far as possible, for the preservation of material which in his opinion bears upon the cause of death for such period as the coroner thinks fit". In my own experience, this was interpreted as being necessary to retain the heart, and to the best of my knowledge, we were never specifically advised that material should be returned to parents when we had satisfied the coroner as to the cause of death. In the case of those autopsies performed with the permission of parents, it had always been my assumption that parents had properly been informed that organs were to be retained, although we subsequently became aware that counselling had rarely been specific. But, as the interim report recognises fully, it is of little value to dwell on the past. "The task we have is a task for the future. It is to ensure that parents are respected *and* that medical care is developed, not least through the appropriate use of post-mortems" (paragraph 57).

The recommendations of the inquiry, as set out in part IV of the report, will facilitate and direct this process within the United Kingdom. Already, as far as I am aware, the forms used in obtaining consent for autopsy have been modified in all centres dealing with diagnosis and treatment of congenital cardiac malformations, and already fulfil the recommendations. As yet, the proposals are no more than recommendations. Almost certainly, when acted upon by the chief medical officer and the government, for whom they are prepared, they will be enshrined in the legal framework of the United Kingdom. And this can only be for the good. We might argue with the wording of one or two

of the paragraphs. For example, in paragraph 32, it is suggested that "There was, in essence, a professional arrogance, justified by the recourse to traditional paternalism, that parents, on this view, are best kept from the details but would be thankful if they knew what was being done". In my own opinion, the actions of those obtaining consent for autopsy were dictated by compassion rather than arrogance, a view endorsed by the president of our Royal College of Pathologists.⁷ Argumentation of this kind, nonetheless, is unlikely to assuage those parents who feel wronged and abused. We now hope that the recommendations of the report will prevent any recurrence of these activities, whilst preserving and emphasising the need to obtain and retain cardiac material for the purposes of future research, training, and education. The Bristol Inquiry, to date, has been of interest primarily to those working in the United Kingdom. The practices highlighted in the interim report, nonetheless, have probably been replicated throughout the world. I have studied personally autopsied hearts in centres in many countries, and have been privileged to be granted access to several outstanding collections. I have never questioned the way in which the collections were assembled, nor whether the material had been retained with the proper permission of bereaved parents. Perhaps I should have. For the future, it will be essential that those responsible for these collections do ask these questions, and respond to the needs of parents just as we are beginning to do in the United Kingdom. They cannot do better than follow the excellent recommendations set out in the interim report.

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References

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