Lessons Learned From The Bristol Heart Scandal And The 2001 Kennedy Inquiry – Part 2

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The Inquiry and the Duty of Candour

The Kennedy report found serious, systemic failures at a unit that had clothed itself in a 'club culture' of wilful blindness to safety concerns and poor practice, with staff closing ranks to protect their colleagues. On the eve of publication of the Kennedy report, which documented the lethal consequences of a toxic culture of denial within the collusive community operating at Bristol, the Chief Medical Officer at the time demanded that doctors should admit to patients when an error in their surgery had occurred.

The need for a duty of candour became obvious after Bristol: a duty on doctors and hospitals to report untoward incidents and to raise concerns. They should also, the report recommended, feel able if necessary to blow the whistle on failings and incompetence of colleagues or systemic issues within their hospitals, with proper legal safeguards to protect them from dismissal or victimisation if they have cause to take action.

My experience of acting for parents of these very sick children has shown that they have a heightened awareness and a desperate desire to place their children in the safest possible hands to give them the best chance of achieving a successful outcome. They want to know the truth before and after surgery. They want to know that the surgeon and medical team have the necessary resources and expertise in the procedure they are to carry out. As occurred at Bristol in the 90s, and as repeated across the country since, parents have little option but to place their trust in the surgeons and in the cardiologists who diagnose their children's conditions and refer them for their life-saving surgery.

Patients and families seek information and explanations if treatment has failed. This isn't 'hospital complaint' territory. It shouldn't be left for us as lawyers, after obtaining expensive expert reports, to have to explain to grieving parents what really happened to their child. In many cases, sadly, this was how they learned the truth.

I have misgivings as to whether patients and families in the context of high risk surgery where much depends on the experience of a unit or surgical team will benefit significantly from the duty of candour introduced for NHS healthcare providers in 2014. Children's heart surgery has unique features, in that it is carried out at a number of specialist units across the country. One unit may have a specific expertise or superior safety record in a particular procedure, less so in another. A classic example from Bristol in the 90s was the truncus arteriosus operation. Although on any level this is a highly complicated procedure, parents were not informed that the unit had a significantly higher mortality rate than comparable units in this same operation. It was revealed in a BBC Newsnight programme in October 1998 that, prior to a truncus arteriosus procedure Wisheart performed on a child in 1993, he had performed 11 of these operations in which nine children had suffered 'early' deaths. The patient in the 1993 operation sustained catastrophic brain damage. Clearly his chances of surviving without injury would have been significantly increased, and the NHS would not have had to pay substantial damages for those injuries and his future care needs, if he had been referred to another unit with a superior safety record. Would this explanation - to me, a full and meaningful explanation that I would want - be given to parents today with the duty of candour in place? I doubt it.

Those who sought explanations after their children died received limited explanations from the surgeons. In most cases, parents only came forward in response to the news reports around the time of the GMC hearings in 1998 and the Public Inquiry that began in 1999. Many of the operations had been carried out three or four years previously. Letters to parents from the Trust's new Chief Executive were written in sympathetic, compassionate tones but, as he was relying on medical and surgical staff still at the hospital for his information, they were of little benefit. The hospital sought to explain that the surgeons had encountered unexpected presentations of the children's particular defects or abnormal anatomies that could not have been foreseen. I do not recall any letter accepting that the surgeons or cardiologists or other members of the team had been in any way to blame.

Parents were given no insight into the experience of the surgeons and their medical support team. Before surgery, the surgeons had given highly optimistic assessments of the likelihood of survival, often quoting 80 or 90% survival but with no warning of the risk of surviving with brain damage – a risk inherent in the best hands in these open-heart operations requiring cardio pulmonary bypass (CPB). Parents had been given optimistic success rates in the various procedures, which reflected national but not local experience. They were not given the choice of a second opinion or a referral to another centre with a superior safety record. None of the 25-30 sets of parents of children who had suffered permanent neurological injury over the 10-year time span covered by the Inquiry were, to my knowledge, offered any explanation, even though they had to return to Bristol for their children's continuing cardiology care. We referred to these unfortunate parents and children as the 'forgotten families. I pursued an unsuccessful judicial review of the GMC's decision to limit the charges to mortality rates, excluding consideration of the unit's non-fatal morbidity record, in a narrow category of operations.

All of the brain damage cases from Bristol in the 1990s were litigated and contested to the fullest extent in spite of the findings of the GMC and Public Inquiry. The financial cost to the NHS of these claims was enormous. The cost in damaged human lives was incalculable.

A generation later, how have developments in the law of consent and the introduction of the duty of candour affected the position?

In many ways, little has changed in children's heart surgery since the 1990s. Parents of a child with the extremely complex Hypoplastic Left Heart Syndrome, for example, may not know, but should be told, that a particular unit is pre-eminent as the leading centre for corrective surgery on this defect. Inevitably, units with a greater degree of expertise in these immensely difficult procedures achieve better outcomes in terms of lower mortality rates and a lower incidence of, and ability to cope with, post-operative complications. Units with this leading national expertise should of course be appropriately resourced by the NHS so that they can admit these children.

So, what can parents expect from the Duty of Candour if their child has undergone surgery at a unit that lacked expertise in this procedure? They may be given a frank explanation of why their child died, or why he or she suffered complications, but in the same way that they should have been informed of the facts before surgery, surely they should be informed that there may have been a quite different outcome if their child had been operated on at another centre with a superior safety record?

Data

"Comparative data" - performance of comparable units

Kennedy called for greater transparency in data recording so that no hospital could allow poor outcomes to go unscrutinised.

These features of the children's cardiac specialty raise a number of points. How can the outcomes and competence of a surgeon or unit be measured and how can a patient be advised of the risks if the surgeon doesn't know what other surgeons and units are achieving and how his outcomes compare with those of other units? How can a surgeon fulfil the requirement of a genuine consent process before surgery or of a meaningful duty of candour when explaining why surgery has failed without knowing how his or the unit's outcomes compare with similar units?

A recent article in the World Journal for Paediatric and Congenital Heart Surgery (reference below) in the context of how parents of children with a life-threatening congenital heart defect interpret and perceive risk. 8 in every 1000 babies are born with a cardiac anomaly. Pre-surgery discussions as to risk are difficult for clinician and parent. Many parents are too anxious (if not terrified) to take in Montgomery options. A number of the sets of 106 parents who participated in this UK study felt that the decision to operate or not should rest with the clinician, not the parents. Parents simply want to know that they are placing their child in the hands of a competent, experienced surgeon in a well-performing unit, giving their child the best chance of surviving with a successful repair. The availability of readily understandable data to enable these comparisons to be made and units to monitor their performance becomes a crucial element in both consent and candour.

Although the Public Inquiry concluded that, between 1990 and 1995, up to 35 children and babies had died as a result of poor care at Bristol, we calculated by extrapolation from the data that in fact as many as 170 might have survived if they had been treated elsewhere. We never knew the numbers of how many children had survived surgery but suffered brain damage and other serious injury. The Trust denied that it held data to establish this. Even now, accurate, informative data can be difficult to locate and there is still no centralised collection of data on cardiac morbidity. So, a generation later, we have no measure of success or failure of a surgeon or unit other than 30-day mortality rates – if a child survives for a month he is regarded as a statistical success, even if he has suffered injury in the process. In reality, rates of mortality should provide an alert system only.

Families choosing a cardiac centre often struggle to interpret the data to make properly informed decisions about units and surgeons. The availability of readily understandable data is surely a facet of a meaningful duty of candour across the wider NHS. Reflecting this, Great Ormond Street hospital announced in 2016 that they were leading an ambitious National Institute for Health Research (NIHR) funded joint project to achieve a better understanding and categorisation of the non-fatal complications that can occur in children after heart surgery.

Despite cardiac surgery leading the way in the publication of data after Bristol, serious problems relating to reporting in this field have persisted. Operations at the children's cardiac unit at Leeds were controversially suspended in 2013 after NHS Medical Director Sir Bruce Keogh announced he wasn't satisfied with incomplete data disclosed by the unit in response to concerns that were reported to have been brought to his attention. The unit was soon reopened but it became difficult to establish whether and if so to what extent there really were problems at Leeds because the available data was so hard to interpret and allow comparisons to be made with the performance of other units.

In March 2016, following reports of long-standing problems at the adult cardiac unit at Queen Elizabeth Hospital, Birmingham, an editorial in the Guardian referred to the unit's 'disdain for the data' and the fact that, two decades on from the Bristol Scandal, the NHS 'continues to harbour some dangerously defensive instincts'.

More transparency is needed but the recommendation in the recently published Paterson report (see below) that every surgeon's expertise and experience should be published on a website may too simplistic. Paediatric cardiac surgery in particular is a 'team sport' involving a wide range of specialisms and this would not reveal the full picture.

Many of the Kennedy recommendations remain unresolved.

Whistleblowing

Sadly, whistleblowing in the NHS continues to be career suicide for medical staff. It is inexplicable that this is still the case given the cost to the NHS of ignoring warnings over dangerous practices that could have been addressed if the concerns of a whistleblowing doctor or nurse had been investigated. Every scandal that has emerged over the years since Bristol seems to have involved whistle-blowers who have been ignored or worse, suppressed , and intimidated.

Professor Sir Ian Kennedy carried out a detailed, robust review of disgraced breast surgeon Ian Paterson's NHS activities in 2013 and found that whistle-blowers had repeatedly been ignored. He said this was "a blight on the NHS and is one of the principal areas where lessons must be learned"

Twenty years after Kennedy's Bristol report NHS Trusts still go to astonishing lengths to suppress whistle-blowers, spending significant sums defending cases brought by employees who have blown the whistle. Whistle-blowers are still gagged as part of pay-off deals. Investigative journalist Tommy Greene made a number of FOI requests and revealed in a Telegraph report in January 2020 that NHS Trusts had spent £20m over a 4-year period battling whistle-blowers and contesting discrimination claims (see reference). So much for a learning culture we wanted to see in the NHS after Bristol

Reorganisation of children's heart units: Reconfiguration

Reconfiguration of our children's heart units, intended to concentrate expertise in a smaller network of national centres, was never completed as originally envisaged in the 2001 Kennedy report. The Government tried unsuccessfully to force through what became a long-delayed programme of national reorganisation and closure of units first proposed by Kennedy. The Safe and Sustainable Review, established in the wake of the Inquiry, brought about the suspension of operations at the John Radcliffe unit, Oxford in 2010, over which there had been worrying issues ever since the time of the Kennedy report. Even then, it was several years before action was taken.

Although there was a will to progress this in the early years, reconfiguration became a highly controversial issue. Local populations and their MPs became involved in campaigns to resist closure; Leeds enlisted the support of the Archbishop of York. NHS medical director Professor Sir Bruce Keogh later described the delay in implementing this Kennedy recommendation as a 'stain on the soul of the specialty.' A generation on demographics has changed – the solution was ...

"Forgotten Inquiries"

When the report into the long-running scandal at Mid Staffs hospital was published in 2013 Dr Phil Hammond suggested in Private Eye that many of Sir Robert Francis QC's 290 recommendations could have been cut and pasted from Kennedy's 198 recommendations in the 2001 Bristol report. Dr Hammond made a similar 'cut and paste' observation in February this year regarding the recommendations in Bishop Graham James' Paterson report. The Paterson scandal which had its roots as far back as 2003 when colleagues first raised concerns involved a rogue surgeon carrying out unnecessary and inappropriate operations and inflicting life-changing harm on patients over a 14 year period before he was eventually stopped. The "culture of avoidance and denial" in a "dysfunctional" healthcare system where there was "wilful blindness" to his actions identified in the report sounded all too familiar. The Inquiry recommended that 11,000 former Paterson patients should be recalled for their surgery to be assessed.

Incredibly there were problems again in Bristol in the years 2012 to 2014. Following a series of deaths at the children's heart unit Professor Sir Ian Kennedy was called in again after families tweeted their concerns to NHS Medical Director Sir Bruce Keogh who appointed Eleanor Grey QC to carry out the New Bristol Review for NHS England with Kennedy as Consultant Adviser. The CQC had issued a Warning Notice in 2012 after Inspectors noted a lack of sufficiently experienced staff to meet the needs of children requiring high dependency care. We represented 10 families at inquests into deaths over the period covered by the Review. The report, published in June 2016 (which parents described as 'inexcusably weak'), found that much of the care was good but the treatment of 27 children raised particular concerns. Bristol's 30-day mortality was found to be the 6th lowest in the UK out of 13 units. The report included 32 recommendations including the need for a national review of paediatric intensive care units.

The call for a public inquiry so that scandals can be scrutinized and for lessons to be learned has become the inevitable and wholly understandable reaction of governments since Bristol and before that the 1969 inquiry into the abuse of patients at Ely Hospital , Cardiff. Many similar recommendations had been made even earlier than that in the Platt Report into the Welfare of Children in Hospital published in 1959. The problem is the failure of governments to follow up Inquiries and introduce a statutory mechanism making it mandatory to review and ensure implementation of recommendations of these hugely expensive investigations.

So, have the lessons of the Bristol Scandal of the 1990s been learned? Sadly, many of the issues investigated by the Kennedy Report still arise today. Some of the systemic, cultural failures at Bristol in the 90s have been repeated more than a generation later.

Much is rightly made of the need for a learning rather than a blame culture but with scandals including those that have emerged in Shrewsbury & Telford – described as the biggest in maternity services in the history of the NHS – and East Kent which involves reports of over 300 babies suffering brain damage as a result of oxygen deprivation during birth over a 4 year period - steps have to be taken to make doctors and managers accountable. This seems to be unavoidable. Sadly it is a case of the bad apples spoiling it for the overwhelming majority of doctors who are dedicated and conscientious but the medical profession seems collectively to have turned a blind eye and allowed these problems to grow from manageable failings into major scandals. The NHS simply can't afford these scandals. A dangerous state of affairs which exposes patients to a real risk of avoidable harm of which senior staff and management are aware but have failed to address exposes the NHS to negligence claims which it will find difficult to defend.

What is the solution? Listening to concerns raised by medical staff on the ground is crucial. Whistleblowing, like litigation, a blunt instrument to correct errant behaviour, drive up safety standards and achieve a measure of accountability, but why not impose a duty on managers to ensure that whistle-blowers in their organisations are encouraged and protected and their concerns properly investigated. What's the harm? I can't think of any whistle-blowers whose concerns over patient safety have not eventually been vindicated.