

1. Alderson P, Stacey M (1998) The right to know. *Nursing Standard* 48: 24-25.

## **WHEN A CHILD DIES: A CONCERN FOR US ALL**

**Priscilla Alderson and Margaret Stacey**

This article was triggered by a recent meeting between the authors, parents from different areas of Britain and a consultant paediatrician. All the parents had experienced the death of a child in hospital where medical mistakes seem to have been made - some many years ago, others more recently. None had received explanations which satisfied them about why their child had died. Some felt that their concerns that their child was seriously ill had not been listened to. All had later tried to get adequate explanations - through the complaints machinery or the courts. The actions of some parents had led to changes - in a drug data sheet, in General Medical Council (GMC) guidance to doctors. All had experienced great isolation, and were initially unaware of any others in a similar situation. Those parents (and no doubt others we don't know of) say that doctors' refusals to explain stop them from being able to recover from their intense grief about their child's death.

We salute the parents we met for their fortitude and determination in their struggle to find out why their child died and to try to ensure that what they suffered shall not befall others. We salute those nurses and doctors who when they believe things are going wrong have spoken out at considerable personal cost. We recognize the sadness doctors and nurses experience, but may be afraid to show, when death occurs and also the fear and suffering of professionals against whom allegations are made (1) (2).

The GMC in the past silenced doctors and stressed the importance of doctors supporting each other over their duty to patients. This began to change around 1983. In June 1998 the GMC has made it a responsibility of a doctor to tell parents of the reasons for and the circumstances surrounding a child's death. It is a long way from the GMC to the ward or surgery where tragedy may strike. This article considers some of the problems which must be resolved before nurses and doctors have the understanding and support routinely to take parents and relatives into their confidence.

All health professions are rethinking what they must do to retain public confidence and the privilege of self-regulation. The turmoil following the Bristol cases contains the danger of increased professional defensiveness, of turning away from the developing culture of openness; importantly it also provides an opportunity to take stock, to work to transform the situation. This is what this article seeks to begin.

### **Shared care**

Children's hospital treatment is organized through complex team work shared between medical, surgical, nursing, technical and other support staff. The composition of these teams varies as to whether the treatment is entirely medical or also surgical. Treatment includes sharing information and decision-making with the patient and/or parents and respecting their informed consent to or refusal of interventions, although in many cases of routine and minor treatments consent is assumed. Consent can affect treatment results, in that it involves the exchanges of vital information which enables both doctors and patients to make more informed and committed decisions. Practitioners require quiet spaces and time in which to communicate with the family

and with one another to coordinate information as new evidence emerges. Managers play a key part in making space and time available.

Information on the condition, treatment and risks mainly comes from the most experienced doctors, although it is informed by evidence from the family and other staff. Yet the nurses and junior doctors provide most of the details and support to families. They may have to prepare families for the possibility of deterioration or death after the treatment as well as for the hoped-for improvement. Their task is strongly affected by their trust in the senior staff, who have to combine confidence with critical reflection, caution with the courage to take high risks. Trust is tested by the inevitable failures in high risk specialties.

When the risks of treatment are high, nurses' and doctors' efforts to be honest yet also to sustain the hope and confidence of the family, become more complicated. It is still harder for them to do this with integrity, if they are not confident about the expertise in their centre, or the information they are giving. Nurses and junior doctors are in an untenable position if they consider they are expected to give misleading information, and that no senior staff will listen to, respect or act on their concerns.

### **When treatment fails**

Continuing care is important whether the treatment succeeds or the child deteriorates and dies. After failures, parents need to talk again through their previous information and decisions, to be assured that every effort was made for their child, and that they consented to the best possible, or least harmful, decision in their child's best interests. This can begin to relieve their guilt and distress. It enables practitioners to show respect for the child, and to help the parents to feel they are fulfilling their remaining obligations to their child. Bereaved parents tend to talk of desperately needing clear explanations, some expression of regret from the staff, and assurance that careful review will help to prevent any similar and avoidable events in the future.

Treatment can only be successfully undertaken if there had previously been an open culture in the ward and the parents really felt that their point of view had been fully listened to and that they were treated with respect by both nursing and medical staff. Parents after all know their child in the round in a way that no professional, highly trained in particular aspects of treatment can match. Of course parents do not have the professionals' sophisticated knowledge and experience, on this they must trust. Research evidence shows that sometimes parents or patients are stereotyped in ways which prevent the professionals from hearing what they are saying. Research which one of us was involved in indicated that a mother of a child in hospital was categorized as either a careless parent (who had not presented her child soon enough) or an anxious Mum who fussed too much. An analogous research finding about adult patients was that they are both too deferential and too assertive.(1)

If the child's death could have been avoided, and in cases of medical negligence, the bereaved parents we have talked with say they would prefer honest explanations and apology to litigation and financial compensation. They add that nothing can compensate for their loss. A recent legal review concluded that there is no firm evidence to support British doctors' beliefs in the soaring rates of litigation.(3) Relatively few bereaved families sue or officially complain. Yet when Trust managers and lawyers and Medical Defence Union officials warn doctors not to inform bereaved parents, they may be more likely to incite angry criticism than to prevent it. It seems that many

parents whose child has died in hospital consider that they have not been clearly informed, or that they have been misinformed, about the cause of death. Many feel isolated and completely unsupported.

Parents who believe that they are kept in ignorance or deceived can feel stuck for years in intense irresolvable grief. Some regard any information as therapeutic, and silence as cruel. 'We need information, however painful, to start the healing process.' Their suffering suggests that there should be some research into the assumption that silence is a better professional policy than admitting difficulties and failures of care. Robert Powell's parents rejected an offer of £80,000 compensation because they wanted to know the cause of his death. They have spent thousands of pounds on court cases, where doctors advised by their defence union refused to participate. Eventually they got to the House of Lords, where judges decided that parents have no right to know and doctors no legal duty to tell. When their case brought this interpretation of the law to light, two MPs raised the matter in Parliament, and their case led the General Medical Council to revise its guidelines. In cases of serious harm, doctors are advised, "You should act immediately to put matters rights, if that is possible. You should explain fully to the patient what has happened ... when appropriate you should offer an apology." If a child has died "you must explain, to the best of your knowledge, the reasons for, and the circumstances of, the death to those with parental responsibility."(4)

Some managers and clinicians believe that the best way to benefit the great majority of patients is to avoid saying or writing anything which might attract adverse publicity or litigation that could undermine public confidence and waste public funds. But there is no firm evidence to support these assumptions. It is possible that greater accountability and transparency will increase public confidence and reduce wasteful complaints procedures. Many Trusts are moving towards this position, encouraged and increasingly pressured by official bodies to do so. The quality of care and information for patients and families throughout the course of treatment depends on practitioners' skills and attitudes, and also on the kinds of support, which managers and advisers to Trusts such as lawyers, ensure that they have.

The BMA, the Academy of Medical Royal Colleges and post-graduate and under-graduate deans have recently sent a joint report to Ministers **Making Self Regulation Work at a Local Level**. The report argues for a culture of openness and of critical self-appraisal which would make whistle blowing obsolete - if whistle blowing should still be necessary, the whistle blower should not only be protected but supported they say.

This is a step in the right direction, but more is needed. The report is predicated on professional self regulation. But parents and patients need to be taken more into all aspects of the process if the 'them and us' culture is to be broken down. And that itself is needed if professional self regulation is to survive so that nurses and doctors may continue to have some say over their standards and conditions of work.

There are issues about the state of the law, how well or badly the new complaints system is working, what the coroner's job is, whether the Ombudsman system is effective, deleting gagging clauses from contracts. All these will have to be returned to later. In the meantime we have the following suggestions towards a culture of greater openness and humanity.

- \* Routine oral and written information to children and/or parents before, during, and when necessary after, the child's treatment.
- \* Better training and support to help all staff to discuss problems with patients or relatives
- \* Greater practical partnership and information-exchanges between professionals, patients and parents
- \* Prompt attention by managers in response to the serious concerns of their staff about sub-standard care, with remedial actions where necessary, so that there is no need to 'whistle-blow' to outside agencies.
- \* Greater support from the UKCC for nurses who want to express responsible concerns about inadequate care.

### **References**

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2. Mulcahy, L. (1996) From fear to fraternity: Doctor's construction of accounts of complaints. *Journal of Social Welfare and Family Law*, 397-412.
3. Montgomery, J. (1997) *Health care law*. Oxford University Press
4. General Medical Council. (1998) *Good Medical Practice*. London: GMC.

Some of these issues will be discussed at the next meeting of the UK Forum for Health Care, Ethics and Law, in central London on 23 July. Details from Dr Bobbie Farsides, Centre for Law and Medical Ethics, King's College, London WC2R 2LS. [Bobbie.farsides@kcl.ac.uk](mailto:Bobbie.farsides@kcl.ac.uk)

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The cases of children's heart surgery at Bristol tend to be discussed as if the surgeons alone control the outcome of life or death. Yet the responsibilities for patients' recovery are much more widely shared, as we review in this article. We consider the importance of informed consent, and managers' and nurses' contributions to standards of treatment. We list ways to encourage more open sharing of information as therapeutic in itself, as a means of raising standards of care and of protecting staff who try to give honest information..

### **Shared care**

Children's hospital treatment is organised through complex team work shared between medical, surgical, nursing, technical and other support staff. In many cases, treatment plans are discussed at formal meetings, where the records of previous similar conditions may be reviewed, and short and longer term outcomes discussed when evaluating the risks. Physicians as well as surgeons may be very much responsible for surgery results, through the selection of the patients, and decisions about the timing and type of surgery.

Before, during and after the operation, clearly the quality of nursing care can be crucial, and anaesthetists and technicians also contribute to helping children to survive, and preventing problems such as brain damage. Managers give, or withhold, further vital support in budgeting for sufficient highly trained staff, appropriate equipment, and reasonable working conditions which enable the staff to spend enough time on treating and reviewing each patient. All these factors can affect surgery success rates.

### **Talking as part of treatment**

Treatment includes sharing information and decision making with the patient and/or parents, and respecting their informed consent or refusal. Consent can affect treatment results, in that it involves the exchange of vital information which enables both doctors and patients to make more informed and committed decisions. Except in emergencies, consent is a process of absorbing knowledge and of gradual understanding. The process is emotional as well as intellectual, when fear of proposed treatment is gradually overtaken by fear of the untreated condition, mixed with increasing trust in the clinical team. Discussions in wards, out-patient clinics and GP surgeries aid this process. Practitioners require quiet spaces and time in which to communicate with the family, and with one another to coordinate information as new evidence emerges. Managers play a key part in making time and space available.

### **Risk**

Talk of risk percentages helps to sustain the firmer trust which includes acceptance of the risk of failure. However, the complications of calculating surgery risks are well known. Should calculations be based on results in leading units or the centre in question, on the performance of individual surgeons or their collective average, on certain types of operation only and, if so, which ones? Over what period will results be reviewed, as success rates rise or fall? In measuring mortality, how long a period after surgery should be set as the limit? How can morbidities be measured precisely? Should a procedure with high early success rates but poor longer term outcomes be replaced by one with a higher early mortality but better overall survival? When a promising new procedure is attempted but fails initially, for how long should attempts to

introduce it continue? How much should families be informed about the experimental nature of some treatments?

If several patients die in succession, it can be harder to remember that overall success rates may still remain high. Percentages need to be seen in context. For example, some surgeons attempt to rescue very sick children where others might refuse to try. Despite these difficulties, quality control managers should pay more attention to outcome audits and records which show whether patients are getting actually better.

### **Cycles of information**

Information flows through cycles as it is gained, shared and revised before, during and after surgery. For example, it may be found that certain kinds of post-surgery care work better, or perhaps one type of operation is more successful in younger babies, as it is gradually tried at earlier stages of life and the long term effects are observed. This refining of knowledge depends on close liaison between different teams of staff, and on learning from children and parents, treating them as expert partners, and respecting their observations. A major problem at Bristol was that the split sites for heart surgery services blocked this cycle of learning, and prevented proper multi-disciplinary care and review. When doctors and nurses do not see through the whole course of treatment, they cannot inform patients adequately. The geography, and its vital influence on success rates, are managerial rather than clinical responsibilities.

In practice, the consent process continues after surgery, as people receive further information and follow up treatment, and come to terms with the results. As a method of making doctors formally accountable to patients, the consent process contributes towards clarifying and raising standards of care. Doctors have to be very well informed in order to be able to inform patients and/or parents adequately about every stage from preparation to longer term effects.

### **When treatment fails**

We end by reviewing some of these important levels of policy, management and practice, and the new approaches, already practised in some centres and urgently to be developed in others.

and changes in any contracts of employment which limit practitioners' ability to speak honestly  
\* more open and positive, thorough and prompt complaints procedures about maladministration, incompetence or negligence, designed with help from patients and parents who have experienced problems

\* autopsies of children to be conducted by paediatric pathologists

\* a prompt independent statutory inquiry after every paediatric death or case of severe injury from treatment, with protections for staff who speak freely to the inquiry, but also a clear final report to the relatives

\* attention to remedying any causes of harmful events revealed by inquiries, such as, faulty equipment, incompetence, negligence, a professional's tiredness or stress, illness or heavy workload, with measures to prevent any repetition, such as by retraining staff or moving them to other duties

\* changes to seriously inefficient structures in services (like split sites)

\* greater public representation on the GMC, the UKCC and other regulatory professional bodies, and the right to appeal against GMC procedures and decisions

\* a committee which is accountable to the public to oversee investigations in the NHS and also those enquiries by the Health Ombudsman

- \* a radical improvement in coroners' inquest procedures, with legal aid granted to families who contest the coroners' findings
- \* greater promotion of the GMC Good Medical Practice standards of doctors' responsibilities to respond to complaints, to inform patients and parents about any harm they have caused them, and to volunteer information at coroners' inquests
- \* greater publicity about the Medical Defence Union's advice that doctors apologise when something has gone wrong and give a full candid explanation of events
- \* changes in the current state of the law, by granting bereaved parents the right to know the circumstances surrounding their child's death in hospital and to see the medical records.

1. J Montgomery 1997 *Health care law*. Oxford University Press
2. General Medical Council 1987 *Good Medical Practice*. London: GMC.