

Priscilla Alderson (1998) **When things go wrong, what should be said?** Report of UK Forum on Health Care, Ethics and Law, 23 July, Meeting at Institute of Education, London  
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Chairs: Bobbie Farsides, Centre for Medical Law and Ethics, King's College London  
and Heather Draper, Centre for Biomedical Ethics, University of Birmingham

This meeting on communication and truth telling was planned while the hearings at the General Medical Council (GMC) about the Bristol heart cases were being publicised. The Forum holds meetings to bring a range of professionals and academics together and, this time, people who have personal experience, to see what can be learned in order to raise standards in future. The government has responded to the GMC hearings by issuing a report and setting up a committee of enquiry to be chaired by Professor Ian Kennedy.

### **Informed consent: processes and cycles**

Priscilla Alderson, Institute of Education, University of London

Traditionally, information, consent and treatment are seen as three separate stages. In practice, they are constantly interwoven, from explaining and consenting to tests and planning treatment near the beginning, through to consenting to follow up checks after treatment. Consent could be said to be the part which lasts longest, the state we live with through the future, content that the right decision was made, or regretful or remorseful that the wrong decision was made, or that we felt deceived.

Besides seeing information, consent and treatment as interweaving strands through time, they can be seen as cycles. Assessment and audit after treatment can lead to new clinical information. With a new operation, doctors, nurses and other support staff can all refine their skills and develop better methods. The success rates may improve, the risks fall, and this leads to new information being shared between doctors and given to future patients. When clinicians publish their findings, they can affect the consent cycles in other hospitals around the world.

Knowledge is also gained, refined and passed between patients and parents. In a paediatric cardiac unit, for example, some children return several times for treatment, the family come to know the staff well and become very knowledgeable. Children are usually admitted into the children's ward, go for surgery, stay in intensive care, then return to the general ward, and staff and parents pass knowledge round this cycle, for example about risk, or about the kinds of care which most benefit the children.

Short and long term follow up review may lead to changes in decisions about the type of treatment. An operation with good short term success rates may be associated with poor health after five or ten years. Review of these longer term results may lead doctors to try another method which turns out to have much better long term effects. Yet more patients may die or not do well shortly after this surgery. Current failures have to be balanced against future uncertainties and later definite knowledge. Assessments of the benefits of surgery involve patients' own estimations of their health, and their knowledge contributes to the agreed information which doctors eventually give routinely while discussing consent with future patients. The importance of the cycle of information, consent, treatment and follow up review, in which clinicians, patients and relatives share their knowledge is illustrated in the Bristol cases

recently reviewed by the GMC. At Bristol, the cycle was broken, when the children went to separate hospitals for assessment and referral and for surgery and intensive care and the clinical teams were separated by the split site. The meticulous analysis of the outcomes for each type of condition and treatment which is usually conducted in children's heart centres was not possible.

Children can also join in the cycles of gaining, using and refining knowledge. Some children as young as four or five years who have experienced months of serious treatment make major decisions about whether to accept or refuse further treatment and their views are respected (C Irwin 1996 Samantha's wish. *Nursing Times*,92,36:30-31). It is very hard to force children to accept surgery or courses of medication, and even very young children seem to understand the need for treatment and to cooperate. Yet when a child deeply knows that "things have gone wrong", such as when their problem is almost certainly incurable, honesty between the health professionals and the family is essential, if the child's views are to be listened to and respected. Increasingly, paediatric staff attend to parents as experts in their child's needs and responses to treatment, and many staff also take serious account of children's own views (Alderson P 1993 *Children's consent to surgery*. Open University Press).