

Invited commentary on Dr Foreman's paper the "Family Rule" by Priscilla Alderson, *Journal of Medical Ethics*, 1999, 25: 491-496.

Abstract

The "family rule" paper by Dr Foreman proposes a way of resolving the present uncertainty about medical law on children's consent and refusal. This commentary reviews how doctors' decisions are already well protected by English law and respected by the courts. The "family rule" appears to be likely only to complicate the already diffuse law on parental consent, and to weaken further the competent minor's position in cases of uncertainty and disagreement. It leaves the difficult questions about defining and assessing children's competence unanswered. This commentary suggests that these questions would be better resolved through professionally determined standards of good practice that respect children and parents, rather than through rules or laws.

Commentary on the "Family Rule"

The "family rule" paper discusses important questions for children, parents, doctors and other health carers. Confusion about the law leads to defensive medicine. It is frequently remarked that children "cannot refuse treatment". Of course they can refuse, no law can stop them. The question is whether doctors should override their refusal, legally or morally. The English two high court cases, re R in 1991 and re W in 1992, which cast doubt on the 1985 Gillick ruling, involved cases of questionable mental health, and therefore of questionable relevance to most minors. They were controversial rulings and were strongly criticised by some lawyers.

To put refusal in perspective, most children and parents accept medical recommendations. Refusal affects only a relatively few cases, and is mainly of three kinds. Firstly, when children are too young, or too ill, or for other reasons are not thought to be competent and adults have to decide for them. Secondly, when fear or confusion prevents a potentially competent child from making an informed decision. Further discussion and time to reflect can often help here. Thirdly, when a child is assessed by the treating doctor as adequately informed and competent, and refuses proposed treatment.

In the third instance, the type of decision is important. If the treatment is not urgent, it could be delayed until the child is ready to consent. Some will recover, in time, without treatment. With much treatment, the aim is to alleviate a problem in order to improve the quality of life, and surely the person who is usually best able to decide how necessary the treatment is will be the person living that life, as many doctors accept. Occasionally, informed children refuse urgent treatment intended to prevent irreparable deterioration, or to sustain or prolong life. Here, "informed" can mean profoundly experienced, when a child with severe chronic illness has had repeated treatments such as chemotherapy. As the Royal College of Paediatrics and Child Health Report (1) discusses, doctors are now more willing to share

these extremely difficult decisions with patients and families and to respect the child's views.

Another important factor is whether the concerned adults' decisions are unanimous, uncertain or controversial. If all the adults unanimously and adamantly disagree with the child, it is hard to see why they cannot reason with and convince a competent child. If they cannot do so, it is likely that either the decision or the child is unreasonable. If the child is judged to be unreasonable, and therefore not competent, the parents have to make the decision. In complex cases of disagreement there may be strong arguments on each side, and then it is likely that some of the adults may have doubts and at least partly sympathise with the child's refusal. When the prognosis is uncertain and involves high risk and uncertain benefit, or when the adults disagree, some will support what they see as the child's competent decision.

The law already gives authority to the treating doctor to proceed on the consent of only one of the relevant people - the minor or any one of the adults with parental responsibility.(2) In English law, the child is currently very well protected (or restricted). The law is also most likely to support doctors who accept a child's refusal against the parents' wishes. All the relevant reported court cases have supported medical opinion either to withhold or to proceed with a child's treatment against the parents' wishes. In the one exception, re R 1997, the young boy whose parents wished to refuse a liver transplant, the child's parents were intensive care nurses, so that the court could be seen here as supporting a professional, not a lay, opinion. The courts also respect doctors' decisions in that judges do not force doctors to treat, and only authorise them to do so.

The case of 11-year-old disabled David Glass (July 1999), whose family failed to get the Court to insist that doctors provide life-saving treatment if David should need it, shows the limitations of any "family rule". The case of M (July 1999), the 15-year-old who refused to accept an emergency heart transplant, shows how Judges appear to be willing to allow doctors to enforce almost any form of treatment, however extreme, on to resisting minors. Because court cases are based on precedents, the Judge might seem to have no other option than once again to follow expert medical opinion and endorse the doctors' decisions. This routine judicial response seems to reduce listening to the resisting child or parents into an empty formality, which disguises the lack of justice in the sense of impartial balancing of two sides. Justice is compromised by the prior assumption of a great imbalance between "expert" medical views and inexpert "lay" ones.

Although media reports compared M's case with enforced feeding of girls with anorexia, the few publicised comments by M showed that she understood that having a new heart was something entirely different and extraordinary. Some paediatric cardiac staff emphasise the time and careful support required while children and parents gradually come to accept that a dreaded heart transplant is preferable to dying of the untreated heart condition.(3) With the shortage of donor organs, clinical staff stress the importance of selecting from among potential recipients those who are most likely to benefit and to willingly cooperate with life-long follow-up treatment. Given a little more time, M may have arrived voluntarily at this crucial acceptance, and she was reported to have done so. The Court ruling appears to underestimate the importance of time and mutual trust in these delicate

professional-patient relationships. The ruling appears to support doctors who wish to over-rule even older teenagers, and to make doctors who do respect these patients more vulnerable to criticism and litigation.

It is therefore unclear what the “family rule” adds to current legal control of minors except, it seems, to complicate matters: to increase adult power over the child; to reduce concern to listen and respectfully negotiate with the child in ways which many doctors regard as part of therapy; potentially to aggravate discord among families who disagree: and to enforce treatment on resisting “children”, it seems up to the age of 18 years.

Dr Foreman’s mention of a “modal” age of consent misreports the research referred to.⁽³⁾ In this descriptive study, the main finding was that children’s competence to consent to a particular decision depends on their own related experience, the type of decision, and the information, support and respect given or withheld by adults, far more than on the child’s age or tested intelligence. As the study showed, adults’ and children’s assessments of competence vary widely, and are coloured by their high or low expectations of children’s abilities. Different samples of young patients are likely to vary too much to provide a generalisable modal age.

The “family” is not defined in the family rule. Does it include step and natural parents, for example? The essence of consent is an explicit, informed, unpressured agreement between reasonably equal partners. This cannot apply to any notion of a baby “consenting” to join a family, which is given as one rationale for the family rule. The concept of the family rule assumes harmonious concern for the sick child’s best interests. When this exists, as in most families, an explicit rule is unnecessary. When there is discord, this essential harmony that validates the family rule is missing. In these difficult cases, the family rule does not address the key questions: What are the child’s best interests? How much information has to be shared with the child to be sufficient? When is a child competent? Are psychiatrists the best qualified judges in these matters? What is good practice with children who consent or refuse, who are judged as competent or incompetent, and how can it be promoted? How can health care professionals be supported in observing high standards, and be protected from litigation? A British Medical Association working group is considering these questions which, as Jonathan Montgomery and I have discussed,⁽⁴⁾ are too subtle for legal solutions which are designed to prevent bad practice but not to promote good practice.

References

- (1) Royal College of Paediatrics and Child Health. *Withholding or withdrawing life-saving treatment in children: a framework for practice*. London: RCPCH, 1997.
- (2) Montgomery J. *Health care law*. Oxford; Oxford University Press, 1997.
- (3) Alderson P. *Children’s consent to surgery*. Buckingham: Open University Press, 1993.
- (4) Alderson P, Montgomery J. *Health care choices: making decisions with children*. London: Institute for Public Policy Research, 1996.