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Who makes the decision on life and death?

Thou shalt not kill; yet needst not strive,
Officiously to keep alive.

Arthur Hugh Clough's witty Victorian Ten Commandments for the comfortable sometimes have a very modern ring to them—none more so than the sixth when put in the context of modern medicine. Last week BBC television gave us two looks at spina bifida; the first was an hour-long documentary of great distinction which managed at once to educate, to convey a message of hope, to present the caution of scientists in an understanding light and to provoke on the question of whether severely handicapped babies should be left to die. The second took up the running on this last issue in the programme "Controversy", and Dr John Lorber, who is one of many pediatricians who give parents the chance to withhold treatment in bad cases, was confronted with two doctors and a theologian who believed this option should not be given, and an audience which seemed (at least after editing) to divide roughly equally; it's tantalising that the producers of "Controversy" don't ask for a vote, even after the formal ending.

It was no great surprise that the parents at the debate provided the most emotional and memorable contributions, nor that the lady from the National Secular Society should have said what she did about terminating more lives. Somewhat suprisingly, the theologian Professor Gordon Dunstan, stated the case for preserving life in muted terms: let them die and you reduce the capacity for heroism and the incentive to medical science. For the rest, the debate rested fairly inevitably on the technical data and philosophies of different doctors.

And yet one thing did emerge with remarkable clarity—that it is the doctor, not the parents who makes the decision whether the child lives or dies. If the doctor believes severe cases should be allowed to die relatively peacefully then he will be capable of convincing almost all his clients to follow this course. If, on the other hand, he believes severe cases deserve every attention that medical science can bestow, he will be able to take parents along with him in that direction.

There is nothing new in all this. In the matter of birth control and abortion, sophisticated women have recognised for many years the necessity for pre-selecting the person whom they consult.

The reason that the doctor has so much power in the decision-making process is not simply that he has immense knowledge where his client has none—after all, the decision that the parents have to make is one in which technical knowledge is only one ingredient. Rather, the parents must be only too aware that if the doctor expresses a view one way and they choose to ignore his opinion, they have to live not only with their own decision but with the doctor himself for months if not years. It is presumably for the same reasons that people don't more often pick arguments with teachers, bosses and dentists.

Dr Lorber has broken valuable new ground by publicising a new option for parents so courageously (although the point was made in the programme that doctors do occasionally confront comparable problems in other circumstances). Many have, and will, object to the granting of the option on grounds that there are possibilities that the child could live a happy life, but it is striking how little public uproar there has been on grounds of morality; it must be that the obvious detached sincerity with which many parents have elected not to support their child's life, and the frequent damage to family life—even culminating in suicide—that spina bifida can bring, prevents some of the more conventional sanctity-of-life responses that one would otherwise expect. But how do we ensure that it is truly an option, and for that matter that the option is available to those that need it, regardless of the hospital area in which they happen to live?

However carefully the doctor may present both sides of the case it is inevitable that his clients are strongly influenced by the slightest hint of a preference one way or the other, and the choice which was originally theirs has subtly been surrendered to the doctor. In many cases this may be no bad thing, but this does not necessarily justify continuing a procedure in which some clients may eventually look back in some puzzlement at how they reached a particular decision. Offering a second opinion does not seem a good safety net; few seek it, and although doctors may claim this is because clients can come to their own conclusions, it may equally indicate tentativeness of clients in the face of medical men.

An idea worth consideration is that the medical profession, or even some organisation outside the profession, should provide a new sort of service to doctors and clients in such circumstances. Someone without any involvement in an individual case should be deputed by the doctor to present the options to the client, proffer advice if requested and then convey the decision to the doctor. In this way not only would it be clearer that the decision has been made by those who must ultimately bear the responsibilities, but also there would be assurance that the range of options discussed reflects all medical possibilities. □

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