
It is often easy, and generally comfortable, to avoid thinking too rigorously about whether and when life-sustaining treatment should be withdrawn from critically ill children. There are several strategies. One is simply to carry on treating. Another is to make the concepts used in decision-making (for instance ‘best interests’) so vague and blunt that they are incapable of cutting too deeply into the conscience and the peace of mind of the decision-maker. And another is to decide in an unstructured, unexamined way whether or not treatment should be continued, and let that decision determine one’s assessment of prognosis, rather than the other way round.1

Dominic Wilkinson, in this brilliant, important and discomforting book, denies us these sloppy luxuries. He systematically examines the problem through empirical, philosophical and legal lenses. He is sympathetic yet unsentimental. He is both a clinician and a philosopher, and it shows. There are many doctors who have been on an ethics course. That usually just gives them a new vocabulary in which to discuss their dilemmas. Medicine and philosophy rarely cross-fertilize in their heads. But they do in Wilkinson’s. The result is something new and exciting.

At the core of the book is an audacious thought experiment. Suppose, he says, that there is a machine that can unerringly predict a child’s prognosis. It can tell you what the child’s IQ will be; what physical compromise she will have; how she will relate to others, and so on. This he calls the ‘Carmentis machine’, after the Roman goddess of childbirth, who was said to be able to see the future of newborn infants. Perhaps we’re not so far from such a machine. Conventional MRI scans give useful prognostic information: functional imaging does even better — and will do better still, the more we understand what we’re seeing. Clinicians say that they rely heavily on imaging in their treatment decisions. That reliance can only increase. But should it? And if so, how should exact prognostic information be used?

Wilkinson begins, helpfully and unusually, at the beginning. He reviews the bioethical basics in a way which would make this book an excellent primer for students encountering the issues for the first time.2 His writing is always accessible and confident. He avoids the self-indulgent circumlocutions that so often mar academic writing. He does not have to pretend that his subject is weighty by making his sentences ponderous. He knows it is weighty, and so do we.

2) Chapter 1.
Laying the ground for his later argument, he identifies four reasons why it might be legitimate not to provide life-saving or sustaining treatment. The first is that treatment would prolong life, but not for long enough. He might helpfully have explored the question ‘long enough for what?’. The second is that the patient’s quality of life would be poor. A good deal of the book dissects the questions inherent in that proposition. Wilkinson notes the ‘disability paradox’ — the observation that those with significant disabilities often rate their experience of life as high as non-disabled people rate their own lives.

He deals tersely and decisively with the vitalists. Most would agree that treatment can be a harm to an adult. And hence it can, argues Wilkinson, be a harm to a child. Even Dr Everard Koop, the US Surgeon General responsible for the ‘Baby Doe’ rules (introduced in the 1980s to prevent treatment being limited on the basis of judgments about ‘quality of life’), admitted at a court hearing that a child with anencephaly or a non-functioning intestine should receive only palliative care. The third reason is that life-saving or sustaining treatment may be contrary to the wishes of the patient. The notion of substituted judgment may speak for infants, who have no ability to express their own wishes. And fourth: resources. It may be unjust to pour money into the maintenance of a child when that money might better be spent on other things. There is no sustained attempt to deal with resources. This is one of the few major shortcomings of the book. It is the elephant in the room. It is not that Wilkinson has forgotten that it is there. He acknowledges it expressly, right at the end. But it is not allowed to trumpet. That is a shame. Wilkinson is an adept analyst of utilitarian equations. But in every one of those equations ‘resources’ is a major element. The force of his analyses is diminished by failing to deal squarely with it.

Chapter 2 (‘Best interests and the Carmentis Machine’) will be of great interest to lawyers, but it is perhaps the least satisfactory chapter. That is partly a consequence of the blurred boundary between law and ethics. Given the uncertain location of the frontier, there are two satisfactory options for a writer. The easy and cowardly one is to describe and lament the uncertainty. The harder and bolder is to say where the boundary should lie, or at any rate to describe what the relationship between the two territories should be. Wilkinson does neither.

There are also some legal peculiarities and some omissions. Wilkinson regards substituted judgment as the basis for the use of advance directives. This is, to say the least, controversial. Probably the better view is that if the directive applies, no question of interpretation or substituted judgement arises. The decision has been made by the patient.

4) Pp. 299-301.
5) P. 49.