

*Ethics, Conflict and Medical Treatment for Children: From disagreement to dissensus.* By Dominic Wilkinson and Julian Savulescu Pp.192 London. Elsevier. 2018. £34.99 (Paperback). ISBN: 9780702077814

The late Nicholas Tonti-Filippini once lamented that, in general and for the most part, education in bioethics focuses excessively on for-or-against debates, reinforces divergences of view, and encourages a tendency to “*slash and burn* alternative views” (*About Bioethics Vol I* Ballan VIC: Conor Court Pub., 2011, p. 169). There is little serious education in how people holding divergent views can come to mature and principled agreement. And yet, in practice, in the complex, collaborative business of providing healthcare within and to a pluralistic society, this is precisely what is needed.

The present (deceptively slim) volume by Dominic Wilkinson and Julian Savulescu is a welcome contribution to a more constructive form of bioethical reflection. This may come as a surprise. Savulescu is better known for his provocative attacks on the concept of human dignity, the sanctity of life and the right of healthcare professionals to conscientious objection. Much of his writing is archetypal of the kind of “*slash and burn*” bioethics that Tonti-Filippini had in mind. However, in this volume Savulescu finds himself engaging with “an equal”, an interlocutor whom he greatly respects and yet with whom he disagrees. The results are revelatory. “We continued to debate and both of us found where we disagreed; we were both prepared to revise our views if certain facts came to light. For me, this has been the most important lived experience of practical ethics in my life. To be engaging in dialogue and argument with an equal whom you respect and to find your own and their thinking advancing is perhaps the main aim of practical ethics” (p. 164). What emerges from this dialogue is a grown-up book not directed at scoring points or winning debates (between the two contributors, at least) but seeking understanding and a way forward that is both practical and principled.

The case which provides the focus for the discussion is that of the infant Charlie Gard, raising the question whether to allow the healthcare team to withdraw ventilation or whether to allow Charlie’s parents to take him to America for experimental “nucleoside” treatment. Savulescu and Wilkinson discuss the medical facts as far as they are in the public domain, and discuss the public reasoning used by the doctors and the judges in this case. Wilkinson gives a clear account of the relevant professional guidance, which he helped to develop, but Savulescu is acute in unmasking the quality-of-life considerations that are smuggled into seemingly uncontentious judgements of best interest, dignity and futility of treatment. He argues persuasively that the judges in this case understated the degree to which there could be reasonable disagreement about Charlie’s best interests, and hence gave too little weight to the views of the parents.

Abstracting from the question of whether the case was decided correctly in relation to the English law, Savulescu and Wilkinson argue that the ethical test should have been one of harm rather than best interests. If it could not be shown that what the parents proposed would have harmed the child (or harmed others) then the parents’ views should have prevailed. Where Savulescu and Wilkinson differed was on whether the experimental treatment proposed would have done harm. Savulescu thought not. Wilkinson thought that it would have resulted in harm but, ironically, less harm than that caused by the protracted court case. “In retrospect, I wish that Charlie had received the nucleoside therapy back in January 2017. Even if it had not helped at all, that could not have been worse than the long struggle that followed. It would have saved months of heartache for everyone involved” (p. 156).

While it might seem that the decision to give treatment in this kind of case would not harm others, this is to forget that healthcare in general, and the provision of intensive care in particular, is a

scarce resource. Providing care to one is thus limiting, delaying, or preventing care to another. The book quotes with approval the statement by US Vice President Mike Pence: "The heartbreaking story of the 11-month old Charlie Gard in England is a story of single payer [healthcare]" (p. 49). Savulescu and Wilkinson defend the view that allocation concerns did influence the case (pace comments by Justice Francis) and argue that such concerns *should* have influenced the case. Furthermore, they argue persuasively that it is because allocation issues were not addressed overtly that doctors and judges were led to exaggerate the burdens of the treatment to the child (though Wilkinson and Savulescu differ on whether and to what extent Charlie was in fact suffering).

There is much that is good in this book and the outcome of the case would have been better had it been informed to a greater extent by the more thoughtful of the book's reflections. However, while Wilkinson and Savulescu, the clinician and the ethicist, the pluralist and the consequentialist, learn from one another, the dialogue is limited by the absence of any representative of the Hippocratic tradition, or of a Catholic, Evangelical, Jewish or other religious perspective, or of an advocate of natural law or virtue ethics.

Lacking such resources, the book, like the relevant professional guidance that Wilkinson helped to draft, conflates the burdens of treatment itself with the burdens of living with underlying illness. Someone might reasonably forego treatment because of the burdens it involves, the discomfort of intubation or the listlessness caused by sedation. However, to seek to avoid living with an intractable condition, as opposed to living with some side-effect of treatment, is to seek to avoid living at all. This is what seems to be implied by the worrying phrase that recurs throughout the book "a life worth living or worth prolonging" (p. 35). In this regard the authors seem to mischaracterise the "rare apparent agreement" between healthcare professionals and parents about Charlie's quality of life. What his parents in fact said was "we would not *fight* for the quality of life he has now" (p. 35 emphasis added). This is not equivalent to "his quality of life... was not acceptable and *should not* be prolonged" (p. 35 emphasis added), for this latter judgement implies an intention to bring life to an end. The parents, in contrast, only express a judgement on the limits of what they would fight for. A Hippocratic view would pay more attention to the intention present in withdrawing or withholding treatment: a topic of key importance which is lacking in this volume.

Another weakness in the book is the somewhat parochial characterisation of reasonableness and the limits of what can be considered reasonable. It is certainly possible for people to agree that a method of argument is reasonable but differ as to the conclusions they draw using this method, while not every method will be counted as reasonable. Unfortunately, it is notoriously difficult to specify in advance and in general what counts as reasonable and the account given by Savulescu and Wilkinson is clearly inadequate. They state that "a reasonable view... cannot be justified on the basis of reasons that are judged to be unacceptable to wider society" (p. 112). This makes the conventional standards of wider society, and, in context, the very local and contemporary society of modern Britain (as distinct from Italy or America) the arbiter of what reasons are acceptable. On this account Socrates was unreasonable and Jim Crow was reasonable. There can be no challenging conventional standards of what is acceptable or unacceptable on such a view.

In contrast, tests concerning reasoning-processes and reason-sensitiveness provide at least a useful starting point. These tests can be applied to the authors' own conclusions. For example, Savulescu holds that religious values should have no place in treatment decisions because "they are based in faith and are not revisable in the light of any evidence or argument" (p. 114). However, this conclusion is based on an empirical claim that can be shown to be false. Religious people do change their minds in how they apply their religious values and they are influenced by evidence and argument. Indeed, a study at Great Ormond Street published in the *Journal of Medical Ethics*

showed that some decisions which could not be resolved internally were resolved through discussion with someone who had familiarity with and authority within a religious community. A priest or a rabbi could appeal to reasons that made sense to the parents because they made sense within a tradition of thought, even though the same reasons might not have persuaded someone who was unsympathetic with and ignorant of that religion. Faith has a place, as do hope and love, but the application of these dispositions is very often revisable and open to evidence and argument.

Another kind of reason that Savulescu and Wilkinson rule out is what they call “the sanctity of life” or “a strong ‘sanctity of life’ view” (p. 113), by which they seem to mean therapeutic obstinacy and the prioritising of length of life over all other human goods. However, it is misleading to attribute such a view to the traditional Jewish or Christian understanding of end of life ethics. The demolition of this straw man seems to function as a way of dismissing the reasonableness of all those who find some value in life per se, irrespective of its quality. This is unhelpful and runs counter to the scepticism that Savulescu (more than Wilkinson) shows throughout the book in relation to negative judgements on the quality of life of children with cognitive impairments.

The discussion of “sanctity of life” (a term so misunderstood that I think it best avoided) is another example of a weakness in the book caused by the lack of a third interlocutor who is informed about Hippocratic, virtue-based and religious ethics. Nevertheless, the book overall shows a humility and a willingness to listen and learn that is rare and is especially welcome in relation to conflicts between parents and doctors over the treatment of small children. In this respect it is certainly a step in the right direction and shows the possibility of learning through serious dialogue on the basis of mutual respect and a shared commitment to reason and evidence.

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