Book review: Death or Disability? The ‘Carmentis machine’ and decision-making for critically ill children

In his book *Death or Disability? The ‘Carmentis machine’ and decision-making for critically ill children* Dominic Wilkinson presents his “threshold framework”, as the first step towards developing more detailed guidelines for treatment decisions for children who may have severe disabilities. His philosophical approach and his basic assumptions are not new. With slight modification they seem broadly in line with those of Michael Tooley, Jeff McMahan, Julian Savulescu, Helga Kuhse and Peter Singer. Moreover his thresholds share similarities with the criteria used in the Groningen Protocol for euthanasia of newborns (p.298). However, given that Wilkinson appears to speak out of practical medical experience rather than abstract thinking and that he has presented much the same line of thought in several other publications, this book requires both serious and critical reading. A discerning approach to this book and its underlying assumptions is even more pressing since Wilkinson benignly states that he offers a framework that is not based on “mere whims” or the opinion of single individuals but on “considered, reasoned judgments of a community caring for sick children and infants” (p.288).

In Part I of his book Wilkinson pairs a story from ancient Rome with one from the future to introduce his imaginary Carmentis machine that gives an accurate prognosis for newborns. He can then use philosophy “to develop important distinctions”, “to reflect on the key values at stake” and on “key arguments” (p.14) and to focus on what he sees as the “central questions” for treatment decisions without having his analysis unnecessarily complicated by uncertainty. Having analysed treatment limitation decisions made by competent patients in terms of a life not worth living, a state that is so undesirable that the patient would rather die, he applies the same quality of life judgment to infants. Examining medical cases and healthcare guidelines he decides that the best interests principle, the mainstay of current guidelines, is imprecise, vague, difficult to apply and unclear about which impairments are sufficiently severe to justify withdrawing treatment. Instead Wilkinson argues that best interests essentially refer to worthwhileness of life and since death for an infant is absence of experience while continued existence in a life not worth living is a negative experience he concludes that in many cases of severe disability, particularly the risk of future severe cognitive impairment, continued life is not in the child’s best interests (p.248).

Concerned that the current best interests principle leaves no role for parental decision-making Wilkinson addresses the interests of family members. Having accepted without question that infants are replaceable and that replacement is significant only regarding the interests of other family members (p.108) he concludes that life-sustaining treatment can sometimes be withdrawn for mild and moderate disability (pp101-102). Where there is “potential conflict or competition” between family interests and the child’s interests (p.125) Wilkinson claims that newborns have a relatively weak interest in continued life, though this grows stronger with age, so this can be outweighed by family interests. He adds that this is “most likely” the case for infants with severe impairment (p.151). Although he briefly notes some possibly positive impacts on the family of the birth of a disabled child, Wilkinson takes considerable time to detail the negative consequences, burdens and therefore the considerable harm to the family and the harm of a continued life of negative experiences for the child. Notably the only situation where the child’s interests are stronger than its parents is where the child’s ‘interests’ favour the withdrawal of treatment (p.151).

Having set out his philosophical argument unclouded by uncertainty Wilkinson says that even if a “Carmentis machine” existed that could eliminate prognostic uncertainty there would still be “moral uncertainty” about how good or bad severe conditions are and what ought to be done, as well as “ethical uncertainty” about which rules or theories to apply. Wilkinson responds to these uncertainties in Part II with his “threshold framework”, a system that retains an important role for ‘best interests’, as Wilkinson interprets them, and a lesser role for parental wishes. At the “upper threshold” where prognosis for the child is sufficiently good treatment must be provided even if against the wishes of the parents. This threshold protects some disabled children with mild cognitive impairment. At the “lower threshold” where prognosis is poor life-sustaining treatment should not be provided even if parents request it (p.271). There is a “grey zone” between the lower and upper thresholds where parental discretion holds more weight principally because of the combination of prognostic and moral uncertainty. The lower threshold fits Wilkinson’s claim that survival is not in the best interests of a child with possible future cognitive impairment – death is preferable to severe intellectual disability – even if the child’s life is deemed to be worth living. According to Wilkinson a “life worth living” is related to well-being which includes the potential to have desires and preferences fulfilled (pp.84-85). An infant who has severe cognitive impairment will simply not be able to rise above the lower threshold and even if the infant would appear to have pleasurable experiences the ‘prognosis’ would never be good enough.

Wilkinson seems keen to overrule carers who think that a life of severe impairment, particularly intellectual disability, is still a life worth living. He argues that the profoundly disabled themselves cannot affirm this, that carers are often biased in their assessments and that crucially we cannot take into account the views of the profoundly disabled who are dead and so possibly ‘better off’. Certainly he says that where there is disagreement about whether treatment is in the interests of the child then choice motivated by the interests of the parents may be given more weight. But it could still be overridden if that choice is likely to cause “substantial harm” (p.258). And for Wilkinson families are inevitably harmed by the birth of a severely disabled child moreover, since his argument rests on predicted quality of life in many cases continued life for the infant is more harmful than death (p.217). Furthermore Wilkinson claims that a “keep-alive mistake”, where while waiting for a clearer prognosis life turns out to be not worth living, is more serious than a “let-die mistake”. So he suggests that “we should therefore choose a *higher* threshold in the face of uncertainty for decisions about treatment”, a cut off point above where benefits and burdens balance (p.248).

Specifically Wilkinson appears to be interested in when treatment can be withheld or withdrawn so that infants can be allowed to die. He makes the case both for infants in intensive care and later on at “windows of opportunity” when infants and older children may “no longer be physiologically dependent on intensive care treatments” (p.204) but where the withdrawal of hydration and nutrition, “a sanctioned alternative” to euthanasia, could be appropriate (p.231). Wilkinson does not rule out euthanasia indeed he sees the issues raised for euthanasia as essentially the same as those for treatment limitation (p.34) hence perhaps his few pages on infanticide and exposure in ancient Rome. To be sure Wilkinson’s framework does not lead to the withdrawal of life support from children “with a reasonable chance of a good life” (p.303). However he believes that “the great advantage” of his threshold framework is that it does not commit to saying that there are lives that are not worth living (p.296). He is clear that children with severe impairment do have interests (albeit weak ones), they can be benefited or harmed and their lives may hold some meaning for them. Nevertheless if there is “clear and convincing evidence” that a child will have severe impairment, and this probability is “less stringent than beyond reasonable doubt”, or there is evidence that “continued treatment” (or possibly life?) would harm the child then treatment should not be provided even if parents request it and even if from the child’s perspective life is worthwhile (p.294).

Wilkinson’s account is well-argued but seriously problematic. Despite his claims to develop important distinctions and to reflect on key values and arguments he is uncritical of and over reliant on assumptions that are broadly utilitarian. He does not ask deeper questions. Although he acknowledges that his balance sheet approach to the best interests test is not truly objective (p.77) there is no mention of the patient’s clinical best interest or interest in care that is delivered effectively and with respect. The patient’s interest in not being killed intentionally is belittled. Wilkinson cursorily dismisses any challenge to his view that decisions should be made on quality or worth of life and he misdescribes any counter argument as vitalist thus indicating a lack of appreciation for the Christian, specifically the Catholic perspective (p.27). This is further evident in his misapprehension of Clark’s position (p.220). Wilkinson includes a lengthy discussion of the principle of double effect, he revises it to fit in with the ‘window of opportunity’ and then says that there are “good reasons” to doubt whether we should be bound by it, because, after all he acknowledges that death is intended and this automatically violates the principle (p.217). Importantly Wilkinson does not think his arguments are discriminatory or at least he concludes that “not all discrimination is the same, and not all discrimination is problematic” (p.54). His title says it all: ‘death or disability?’ Instead of disability being another way of living a human life, for Wilkinson it is worse than being dead.