

Death or Disability?: The ‘Carmentis Machine’ and Decision-Making for Critically Ill Children, by Dominic Wilkinson. Oxford, UK: Oxford University Press, 2013. Pp. viii+311. H/b £42.00.

This book reflects a remarkable blend of philosophical sophistication and clinical expertise. Wilkinson is a practicing neonatal intensive care physician who holds a DPhil from Oxford in the ethics of neuroimaging and decision-making for critically ill newborns. Very few individuals have this dual expertise, and Wilkinson’s book will be mandatory reading for philosophers and clinical ethicists who are writing on or working with critically ill children and their parents.

The book aims to develop a moral framework for determining when it is permissible for parents and doctors to withhold or withdraw life-sustaining treatment from newborns. (Wilkinson flags but sets aside the related but distinct issue of active euthanasia.) Wilkinson develops his framework in two stages. In the first stage, he uses the conceit of the “Carmentis Machine” to assume away “prognostic uncertainty.” He writes: “it is only possible to develop an approach to decision-making in the face of uncertainty if we know how to make decisions in the face of *certain* prognosis” (47). Carmentis was the Roman goddess of childbirth, and she (allegedly) could predict the fates of newborns. Wilkinson thus imagines that a modern-day Carmentis Machine gives us a very clear picture of a newborn’s future physical and, especially, cognitive impairments. Unfortunately, the Carmentis Machine cannot tell us about “the degree of pain or suffering associated with that impairment” (74). Nor can the machine help with the normative evaluation of these predicted health states; that is left up to us mere mortals. Thus the first stage of Wilkinson’s inquiry examines questions that are left open

by prognostic information supplied by the Carmentis Machine. The second stage then “returns to the messy real world” (16) where treatment-limitation decisions must take place upon a background of even more extensive prognostic uncertainty.

To begin his analysis of decision-making under prognostic certainty, Wilkinson engages with the view that treatment-limitation choices should be based exclusively upon the best interests of the child. Three questions are raised by this standard. First, how do we determine what is in the child’s best interests? Second, are there no other interests or reasons that bear on these treatment decisions? For example, should the family’s interests be given any weight? Finally, if the family’s interests are indeed relevant, how should we adjudicate between these interests and the child’s interests when they conflict? These three questions are the subjects of Chapters 2, 3, and 4, respectively.

When a medical decision must be made without the input of the patient, there is broad agreement among bioethicists that it is most desirable to determine what the patient’s own preferences would be if it were possible to consult her. However, if circumstances close off this *substituted judgment* approach, the failsafe is to ask which course of action is in the patient’s best interest. It is obviously not possible to ask critically ill newborns what their preferences are, and while some might think it makes sense to ask what their preferences would be if they were able to assess their own situation, Wilkinson holds that it is more plausible to defer to their best interests. After reviewing existing guidelines that invoke the notion of best interests, Wilkinson teases out two conceptions. The first centers around the idea it is in one’s best interest to avoid

an *intolerable life*. Existing guidelines cash this out in various ways. Some hold that an intolerable life is one that is more than the child is “able or willing to endure”; others say it is one that a third-party would not himself endure; still others say it’s a life that a third-party is “not able or willing for the child to endure” (64-65). According to Wilkinson, all of these conceptions are intolerably vague and are compounded by what he calls the *tolerability paradox*, which states “that beyond a certain point more severe degrees of cognitive impairment may make life more tolerable rather than less tolerable” (67). If severe and profound cognitive impairment decreases the chances that one will experience suffering and distress, then a “tolerability” conception of best interests might not see diminished cognitive impairment as contrary to one’s interests. Wilkinson plausibly suggests that these are serious problems for a tolerability-based understanding of best interests.

The second conception of best interests is the “balance sheet” conception. On this approach, a decision is in one’s interests so long as it contributes to a life whose benefits outweigh its burdens. Later in the book Wilkinson draws a useful distinction between *burdens of treatment*, such as the side-effects of chemotherapy, and *burdens of life*, such as those associated with osteogenesis imperfecta (or “brittle bone disease”) (209). In principle, each kind of burden can make the burdens of continued life outweigh the benefits. But for Wilkinson, the balance sheet conception of best interests holds false promise, as it is simply too difficult to know which burdens of treatment or life will in fact materialize or how severe they will be when they do. Again, the Carmentis Machine doesn’t give us that information, and we certainly don’t have ready access to it in our

world. From here Wilkinson quite quickly concludes “that there is no truly objective way of determining the balance” (77).

Suppose, contrary to Wilkinson’s claims, that we possessed a workably precise understanding of an infant’s best interests. Still, decisions predicated entirely upon this notion would “leave parents out in the cold” (78), and Wilkinson suggests that parental interests are surely relevant. But exactly *how* do parental interests matter? Wilkinson arrives at his answer rather obliquely, via a discussion of *replacement*. Replacement is the act of letting one individual die so that another individual (who otherwise would not be born) can be brought into existence. Following Parfit and others, Wilkinson distinguishes between *individual-affecting* and *impersonal* reasons. For a newborn who (let us assume) will have a life worth living, there is an individual-affecting reason to prevent its death: averting death is in *that* individual’s interests. But according to R.M Hare, we must also consider the interests of the possible individual who would be created if the current impaired newborn is allowed to die. However, since no such individual currently exists, the reason we have to create him or her is not an individual-affecting reason, but rather an impersonal reason, i.e. the sort of reason one has just in virtue of being able to make the world a better place. “Better” here means something like “contains more goodness than”. Thus, if the possible child would have a better life than the currently impaired newborn, then there would seem to be an impersonal reason to let the newborn die so that the “next child in the queue” can be created. This is the impersonal rationale for replacement.

The impersonal rationale for replacement has nothing to do with parents' interests. For Wilkinson, the interests of parents enter when we see that the impersonal rationale for replacement is very weak, and that *if* there is a compelling rationale, it must make reference to parents' interests in "starting again." Why is the impersonal rationale for replacement so weak? According to Wilkinson, this is because there is always stronger impersonal reason for a childless adult to conceive a non-impaired child than there is for parents to replace their currently impaired one—the former scenario generates greater net well-being than the latter. But since "there is at best only a weak moral reason to bring a child into the world, the reason to replace is slender indeed" (91). Here Wilkinson means to say that the *impersonal* reason to replace is slender, for the entire point of this discussion is to suggest that an impaired child's impact on parents and family can be so negative that it sometimes justifies replacement.

Having argued that both the child's interests and the parents'/family's interests are relevant to treatment-limitation decisions, Wilkinson seeks in Chapter 4 to determine which should be given greater weight. He first recounts real stories of families who are profoundly affected by their role as caregivers for severely impaired newborns. Some of these experiences are positive ("Our family never stopped feeling overwhelmed by Charity's ability to give pure love" (116)), while others are devastatingly negative ("This is what it would feel like if I were to smash her head against the wall...It is too horrible, the ease with which I can truly imagine destroying my child" (118)). Seemingly on this basis, Wilkinson concludes that "it is nevertheless appropriate to take into account the way in which family interests are likely to be affected" by having to care for a severely

impaired child (124). What, then, about the child's interests? Here Wilkinson endorses and draws on Jeff McMahan's "time-relative" account of one's interests in continued life. On that account, the strength of an individual's interest in continued life is largely determined by the degree to which "an individual is psychologically invested in or connected to their future life" (134). Compare here an infant's psychological connection to the 40 year-old it could become with a 30 year-old's connection to the 40 year-old she could become. McMahan's account is intended to capture the intuition that it is a greater tragedy if the 30 year-old dies than if the infant dies, and it does this by claiming that the infant's more diffuse psychological connection to its future self means that the infant has less at stake than the 30 year-old whose connectedness with her future self is well-established.

Just how strong is an infant's interest in continued life compared with an older individual's interest? Consider two scenarios that Wilkinson draws on to help answer this question. In Transplant 2, we can either give a heart to a six-year-old who would then live for 25 years, or to a newborn infant who would then live for 50 years. In Transplant 3, we can either give a heart to a six-year-old who would then live for just one year more, or to a newborn infant who would then live for 50 years. According to Wilkinson, "If we are willing to give the heart to the child in Case 2 but not Case 3, the newborn's interest [in continued existence] appears to be less than half the strength of the six-year-old child, but more than a fiftieth" (143). He concludes that "the strength of a child's or infant's interest depends on the amount of well-being in their future life" (144). But this does not yet follow. Suppose for the sake of argument that the strength of an

infant's interest in continued life really is less than a fiftieth of a six-year-old child's. Still, the *impersonal* reasons associated with 50 more years of life for the infant could very well tip the scales against providing just one year to the six-year-old. If so, our intuition about Case 3 may reflect more than just our view about time-relative interests.

Wilkinson might respond that he has already shown that impersonal reasons are quite weak. But in fact he has not shown that. He has only shown that however strong impersonal reasons are, their force is considerably dulled in the context of deciding *whether* to conceive. But Wilkinson himself acknowledges that in other contexts involving decisions to conceive, impersonal reasons seem extremely weighty. Consider, for example, a woman who has already decided to conceive and now must choose between conceiving a severely impaired child or a child with no impairment. Surely there is a quite weighty reason to conceive the latter child, but this reason cannot be individual-affecting since neither child yet exists. This again suggests that Wilkinson is mistaken to move so quickly from our intuitions about Case 3 to conclusions about the strength of an infant's time-relative interest in continued life. In the end, however, Wilkinson wants only to conclude (1) that parents' interests "may sometimes outweigh the interests of the child," and (2) "that this is more likely to be the case for newborn infants than for older children," since older children have stronger time-relative interests in remaining alive (152).

If that is the best we can say when we *have* a Carmentis Machine, what are we to do when we return to the messy real world? Here is one thing we *shouldn't* do: we shouldn't unreflectively inform parents of the proportion of children like theirs that have

died soon after being born. In Chapter 5, Wilkinson argues that such statistics perpetuate “self-fulfilling prophecies” since they often reflect deaths that occurred as the result of decisions to withdraw treatment (and thus not as the result of the underlying condition). This suggests that what parents need to know is what their child’s prognosis *would be* if appropriate medical care and supportive measures were provided (180). But given how many parents choose to withdraw medical care, there might be insufficient data to determine this “true chance of survival” (181).

Wilkinson is surely correct that it is important to guard against self-fulfilling prophecies. But how do we do that? One solution is to adopt a “treat until certainty” strategy on which treatment is continued until it becomes clearer what lies in store for the child and its family. This strategy, however, carries its own moral risks. For if active euthanasia is not an option, then it is possible that by treating until certainty, one misses a “window of opportunity” within which it is possible to let the child die by withdrawing life-sustaining treatment (204). In that case, if it becomes certain that the severe burdens of the child’s impairment will outweigh the benefits of continued life, or if even mild burdens will outweigh even milder benefits (as in cases of persistent vegetative states), then it may be too late to relieve patients and families of those burdens. Wilkinson responds to this problem by noting that the window of opportunity is often wider than people realize. After all, many severely impaired individuals who live past the “critical” phase of their condition nevertheless require ongoing artificial nutrition. When this is so, “artificial nutrition becomes a life-sustaining intervention” (218). (As Norman Fost noted to me, it is not clear whether Wilkinson would agree that all early life nutrition

is “artificial” insofar as it must be continuously supplied by others.) As Wilkinson notes, artificial nutrition, unlike mechanical ventilation, is associated with few “burdens of treatment,” and so if there is reason to withdraw artificial nutrition, it will be related either to severe burdens of life or to the meagerness of life’s benefits. Of course, it is true that many parents will find the withdrawal of artificial nutrition especially distressing. But medications can resolve any subjective discomfort that the child might experience, and Wilkinson argues persuasively that, other things equal, there is little moral difference between withdrawing extraordinary medical care very early in a child’s life and withdrawing artificial nutrition somewhat later.

Wilkinson’s discussion culminates in a defense of what he calls the *threshold framework*. Suppose there is a “zero” level of well-being at which the benefits of life exactly balance its burdens. Thus, life below that level is not worth living. Above the line, one has a life worth living—worth living, that is, from the perspective of the individual whose life it is. The framework then posits two thresholds. A “lower” threshold is to be drawn such that if a newborn’s well-being is (or is expected to be) at or below that level, life-sustaining treatment *must* be withdrawn. The “upper” threshold is placed such that if a newborn’s well-being is at or above that level, treatment *may not* be withdrawn. In between the thresholds, parents (in consultation with physicians) are to have broad discretion about treatment decisions. Wilkinson claims that “it is the combination of prognostic and moral uncertainty that justify this approach, along with the importance of family interests for (particularly) neonatal decision-making” (273). Wilkinson admits to not knowing where the thresholds should be drawn, and he rightly expects ongoing

disagreement about this. He believes legislation and hospital ethics committees can be parts of procedural solutions that stress adequate deliberation and transparent decision-making, rather than one-size-fits-all line-drawing. Given the ethical fuzziness that seems endemic in this sphere of decision-making, Wilkinson suggests that the strength of the threshold framework lies in its conceptual clarity and its ability to help guide the development and ongoing reevaluation of clinical guidelines.

Wilkinson's threshold framework is a useful way to conceptualize decisions that must be made in the neonatal ICU and beyond. One worry, however, is that the threshold framework is most useful for helping to organize discussions about conflicts of interest between the child and the family. Yet throughout the book, Wilkinson acknowledges that there are other conflicts, especially those between the needs of the child and the scarce resources of society. At one point, Wilkinson concedes that "in a country with very few resources the lower threshold...may even be above the zero point" (301). That is, in some contexts medically indicated treatment might be so expensive that it must be withdrawn *even when* treatment would yield a life worth living. This seems right, but notice that this same issue arises in rich countries as well. (Just how much does this fancy Carmentis Machine cost, anyway?) One suspects that a great deal of moral distress in future NICUs will revolve around the cost of treatments that are medically indicated. Unfortunately, a framework that indexes thresholds to patients' expected well-being cannot capture that more complex picture.

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