

Deferring decision-making in the face of uncertainty

Dominic JC Wilkinson^{1,2, 3},

Affiliations:1. Oxford Uehiro Centre for Practical Ethics, Faculty of Philosophy, University of Oxford, UK. 2. John Radcliffe Hospital, Oxford, UK 3. Murdoch Children's Research Institute, Melbourne, Australia.

Correspondence: Prof Dominic Wilkinson, Oxford Uehiro Centre for Practical Ethics, Suite 8, Littlegate House, St Ebbes St, Oxford, OX1 1PT, UK. Tel: +44 1865 286888, Fax: +44 1865 286886 Email: dominic.wilkinson@philosophy.ox.ac.uk

Funding: This research was funded in part by the Wellcome Trust [203132/Z/16/Z]. The funders had no role in the preparation of this manuscript or the decision to submit for publication. For the purpose of open access, the author has applied a CC BY public copyright licence to any Author Accepted Manuscript version arising from this submission.

Decisions about providing life-sustaining treatments for extremely premature infants born after preterm labour are complex, contested, and fraught. They are medically uncertain – the outcome of embarking on treatment is difficult to predict. They are ethically challenging, partly because of the liminal nature of the infant's status (no longer fetus, not yet child), and partly because of the overlapping interests of the infant and parents. And of course, they are deeply emotionally difficult for all involved, especially the infant's parents. There is a particular challenge related to the urgency of decisions. Parents often have little or no time to contemplate or consider. That might lead to decisions that are less than fully autonomous and do not reflect their core values and commitments. However, once therapy has started, both parents and professionals find it extremely difficult to make a decision to subsequently withdraw treatment (Wilkinson *et al.* 2019). They find themselves stuck on the intensive care "roller-coaster" (Maroney 1994) with no way to disembark and no end in sight.

This scenario is familiar territory for all those who work in newborn intensive care. Syltern and colleagues' target article aims to provide a practical way of improving decision-making (Syltern *et al.* 2022). Their three-part proposal applies to all infants considered to be in the 'grey zone' (Wilkinson 2016) ie those whose degree of prematurity and other relevant prognostic factors means that it would be permissible to either withhold or to provide life-sustaining treatment at birth. They argue that

Proposal 1 P1: In the absence of time to make a considered decision, life-sustaining treatment should be provided as a default for such extremely preterm infants.

Proposal 2 P2: A planned decision about further intensive care should be made at one week.

Proposal 3 P3: At that point, the default should be to cease life-prolonging measures, unless parents have expressed explicitly a desire for them to continue, or the infant's prognosis has improved such that they are no longer in the grey zone.

The authors refer to this as 'the postponed withholding approach' (PPWH) (Syltern *et al.* 2022).

There is a lot to commend in the PPWH approach. I have previously defended a related idea as a way to overcome the psychological barriers to withdrawing treatment in critical care (Wilkinson *et al.* 2019). At the end of a pre-defined treatment period, the default would be for treatment to be withdrawn, absent an active decision to reinstitute therapy or embark on a further period of treatment. In this commentary, I will first identify some conceptual ambiguities in the PPWH approach and suggest a modification. I will then explore the scope of this proposal.

Postponed withholding or deferred decision-making?

The first element of Syltern *et al.*'s proposal (P1) is to make it a default to provide life-sustaining treatment for extremely preterm infants in the grey zone. It is already the case that if there is no chance to counsel/discuss with parents (for example if a mother presents with an eclamptic seizure and is unconscious) that intensive care is initiated and later reviewed. However, P1 would extend this to the majority of births at extremely low gestations.

Syltern and colleagues frame P1 as a “non-decision”. This has some practical value, but is conceptually ambiguous. What they are proposing is that parents *are not asked to make a decision*. As they argue, that avoids the need to urgently make a difficult and complex choice. It would make antenatal counselling substantially simpler (and shorter). But it is also valuable for a different reason: it potentially reduces the impact of one cognitive tendency: Plan Continuation Bias (Jackson 2017). Where individuals have chosen a course of action, they are more likely to continue it than to change course, even if it is no longer attractive or even viable. So by not asking parents to psychologically commit to treatment, that may make it easier for them to subsequently accept the alternative (palliative) path. However, it is not correct that P1 is a “non-decision”. That is because parents could choose palliative care at delivery. (Syltern et al do not explicitly say so, but I assume that in their example, had Helen expressed a clear desire for Mina not to be resuscitated, they would support this). It is also because doctors have decided to provide life-sustaining therapies. That might well be the right thing for them to do. It may be recommended in professional guidelines (if Syltern’s proposal were accepted). But that doesn’t stop it being a “decision”.

Next, Syltern et al claim that P3 is a form of “withholding”. This is rhetorically powerful, but conceptually confused. What they clearly are referring to are decisions to “stop life support”. Mina’s breathing tube would “be actively pulled out” and infusions ceased (Syltern et al. 2022). Such decisions, to discontinue therapies previously started, are very standardly referred to as “withdrawing”. In contrast, decisions not to commence treatments are referred to as “withholding”. Many ethicists, including myself, regard withholding and withdrawing as ethically equivalent (Wilkinson and Savulescu 2012). However, Syltern and co-authors do not appear to accept this (Syltern et al. 2022; Ursin 2018). One obvious reason for avoiding talking about stopping treatment is because many families and health professionals find such decisions psychologically harder than not starting. The authors acknowledge this phenomenon, and refer to it as ‘withdrawal resistance’. But they claim (not completely persuasively) that their proposal is not just a matter of moral psychology, nor is it “moral newspeak”, rather that it is a matter of ethics (Syltern et al. 2022).

In fact, what Syltern and colleagues refer to is both withdrawing *and* withholding, since there are elements of both in P3. Some treatments will be stopped. Others will not be provided. It would be better, and more honest, to refer to “Deferred decision-making”, since that is what is being proposed. The main nexus of decisions for extremely premature infants would be shifted from the rushed difficult setting of the labour ward, to a week later. As noted, there are good reasons to do this. But we do not need to resort to euphemisms or conceptual redefinition in the process.¹

The scope of deferred decision-making

One question of scope might relate to the period of deferral of decisions. Syltern et al do not set out why they choose “one week” for P2. This might be simply a convenient time point for review, giving parents some time to absorb information. Should it be shorter? Four

¹ One euphemism that appears in the target article is “redirection to palliative care”. This is a widely used phrase that is designed to make it more palatable or acceptable to discontinue active survival focused therapies and provide comfort focused care. Sensitively and carefully used, euphemisms can be helpful in communicating with families. However, they sometimes obscure, or confuse, (both other professionals and patients) and risk jeopardising informed decision-making (Collins et al. 2018; Rawlings et al. 2017).

or five days may be sufficient time for parents to make an informed decision. Or longer? Given the complexity of the decision and the uncertainty of outcome, perhaps 10 days or 2 weeks would be preferable. There are factors potentially counting against a longer period. One is the concept of a “window of opportunity” for decisions (Wilkinson 2009; 2011). For a number of critically ill patients, longer periods enable more prognostic information to be gathered, but carry the risk that by the time a decision is reached (to stop) the patient is no longer dependent on intensive forms of treatment. This potentially applies to extremely preterm infants, a proportion of whom may be extubated within 1-2 weeks.² But the opposite danger, not discussed by Syltern and colleagues, is that many (perhaps most) families will choose continued intensive care at one week of age. And in the ensuing weeks and months, as the preterm infant experiences repeated failed extubations, difficult lung disease, recurrent sepsis, necrotising enterocolitis etc, both they and the team of health professionals will find themselves unable to escape from the rollercoaster because of ‘withdrawal resistance’.

One possibility, would be for deferred decisions to continue treatment to be followed as a routine by a further time-limited trial of treatment. That might mean review in one week for any extremely premature infant who remains ventilated/critically ill. This could require an active decision at that point to continue intensive care. Regular review, at weekly intervals, might mean that families have the opportunity to openly discuss their concerns, speak with consultants about their child’s prognosis and decide whether continued treatment remains the right thing for them.

Syltern et al focus on extremely premature infants. But the same essential principles could apply to any newborn infant admitted unexpectedly at birth to the intensive care unit. For example, this could apply to term newborn infants with severe hypoxic ischaemic encephalopathy or meconium aspiration syndrome. Or they could apply more broadly to other children or adults admitted urgently severely ill to intensive care. In such circumstances there can be very limited opportunities to make informed decisions about commencement of treatment, so the PPWH approach may be helpful.

One relevant difference is that for many such patients the window of opportunity for withdrawal of treatment is significantly shorter than one week. Another is that many or most of these patients have illnesses (and prognosis) such that in fact limitation of treatment is not an ethical option. So it may be inappropriate to have a default plan to cease intensive care.

Here is an alternative proposal:

In the face of uncertainty, intensive care would be commenced (absent advance decisions) for any critically ill patient where resources are available and it is potentially in their best interests to do so. Routinely, treatment would be reviewed at 48 hours, 1 week, and then weekly for any patients remaining critically ill. Treatment withdrawal should be considered and pursued in the absence of an active decision to continue intensive care for all patients for whom treatment withholding would have been permissible (had current information

² It is possible that those extremely preterm infants who are extubated are, thereby, in a better prognostic group, and thus no longer in the “grey zone”.

about prognosis and treatment response been available at the time of admission) (Wilkinson *et al.* 2019). In fact, this is perhaps not so far from the standard approach in some units, for at least some patients (eg those with hypoxic brain injury). What might be non-standard is the suggestion that it could apply to all emergency critical care patients, and that there is explicit consideration of discontinuation/continuation at each time point.

The foundations of Syltern and colleagues' proposal are strong. It is difficult to make decisions in the face of uncertainty and time pressure. It is often best to embark on treatment and then review. It can be helpful to have clearly defined time points for reviewing decisions and to consider openly whether it is appropriate to withdraw treatment. It is also helpful and important to consider the cognitive and emotional factors that make these decisions even more difficult for parents. It may be helpful to reframe these choices in ways that make it easier for parents to consider their options in a balanced way.

But we also have an ethical duty to be honest with them (and with ourselves) about what we are doing and why.

- Collins, A., S.A. McLachlan and J. Philip. 2018. Communication about palliative care: A phenomenological study exploring patient views and responses to its discussion. *Palliat Med* 32, no 1: 133-42.
- Jackson, S. 2017. Irrationality in decision making: A systems engineering perspective. *Insight* 20, no 4: 74.
- Maroney, D. 1994. Helping parents survive the emotional "roller coaster ride" in the newborn intensive care unit. *J Perinatol* 14, no 2: 131-3.
- Rawlings, D., J.J. Tieman, C. Sanderson, D. Parker and L. Miller-Lewis. 2017. Never say die: Death euphemisms, misunderstandings and their implications for practice. *Int J Palliat Nurs* 23, no 7: 324-30.
- Syltern, J., L. Ursin, B. Solberg and R. Stoen. 2022. Postponed withholding: Balanced decision-making at the margins of viability. *American Journal of Bioethics*.
- Ursin, L. 2018. Withholding and withdrawing life-sustaining treatment: Ethically equivalent? *American Journal of Bioethics*.
- Wilkinson, D. 2009. The window of opportunity: Decision theory and the timing of prognostic tests for newborn infants. *Bioethics* 23, no 9: 503-14.
- Wilkinson, D. 2011. The window of opportunity for treatment withdrawal. *Archives of pediatrics & adolescent medicine* 165, no 3: 211-5.
- Wilkinson, D. 2016. Who should decide for critically ill neonates and how? The grey zone in neonatal treatment decisions. In *When doctors and parents disagree: Ethics, paediatrics & the zone of parental discretion*, eds Mcdougall, R, Delany, C and Gillam, L. Sydney (AU): The Federation Press.
- Wilkinson, D., E. Butcherine and J. Savulescu. 2019. Withdrawal aversion and the equivalence test. *American Journal of Bioethics* 19, no 3: 21-28.
- Wilkinson, D. and J. Savulescu. 2012. A costly separation between withdrawing and withholding treatment in intensive care. *Bioethics* 26, no 1: 32-48.