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# TOO EXPENSIVE TO TREAT? NON-TREATMENT DECISIONS AT THE MARGINS OF VIABILITY

Tatiana Flessas\* and Emily Jackson\*

## ABSTRACT

This article seeks to challenge the assumption that it is legitimate to consider the costs of premature babies' future social and educational needs when deciding what treatment, if any, to provide in the NICU. It questions the elision that is made between the claim that a particular treatment is insufficiently cost-effective, and the claim that a person will be a burden on the state in the future. It discusses a series of common misunderstandings about how treatment decisions are taken in the neonatal intensive care unit, and concludes by suggesting that the claim that premature babies are too expensive to treat may depend upon regarding a premature infant as if she were not yet a person, with rights and interests of her own.

## Keywords

NICU, Treatment withdrawal, prematurity, resource allocation

## I INTRODUCTION

Ten years ago, the latest EPICure study appeared to show that 24 weeks' gestation had become a fairly stable marker for viability in babies born prematurely.<sup>1</sup> Survival rates without major disability had improved considerably for babies born at 24 and 25 weeks, while survival rates for babies born at 22 and 23 weeks had scarcely improved at all, and continued to be very low indeed. More recently, there has

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<sup>1</sup> KL Costeloe et al 'EPICure 2: survival and early morbidity of extremely preterm babies in England: changes since 1995' (2008) 93 Archives of Disease in Childhood A33–4.

been evidence of marked improvements in the survival rates of babies born at 23, and even 22 weeks.<sup>2</sup> This new data has provoked discussion around two different questions: the legitimacy of the 24 week abortion time limit and the costs of very premature babies, immediately after birth and, if they survive, during their lifetimes. Although we mention abortion in passing later, our focus in this article is instead on this second issue, namely concern about the ‘affordability’ of babies born at the margins of viability.

A recent article in *The Times*, for example, reporting a ‘boom’ in survival rates for babies born at 23 weeks,<sup>3</sup> emphasised how much these babies cost. The article conflates two costs: the cost of treating these children at the start of their lives and the cost of the care that children who survive with mild, moderate or severe disabilities may require in the future.<sup>4</sup> Eight years ago, the cost to the NHS of care in the neonatal intensive care unit (NICU), coupled with the costs of premature babies’ ongoing medical and educational needs was estimated to be almost one billion pounds.<sup>5</sup> Given rising numbers of extremely premature babies, and the other pressures on health and special educational needs (SEN) services, it is not uncommon for academic and media commentators to question whether some premature babies might be ‘too expensive to treat’.<sup>6</sup>

Media interest in extremely preterm infants, defined as babies born before 28 completed weeks of pregnancy, is understandable.<sup>7</sup> The NICU combines advanced technology and sophisticated medical skill, with the human interest of sometimes miraculous outcomes, and stunned, grateful or grieving parents. Even if we are familiar with images of the NICU from the television, it remains a profoundly alien environment. Impossibly tiny babies are contained within plastic incubators or isolettes, their minuscule bodies hooked up to diagnostic machines; intubated and/or sustained by oxygen delivery devices that can hide their faces; monitored by lines and screens that bleep and display myriad figures and graphs. Sometimes babies are lit to help with jaundice and sometimes they are blindfolded to avoid damage to eyes that are not yet open. This world is hushed and urgent, purposive but also a world of stasis and uncertainty, and one that is intensely ‘other’ to the noise and activity of a normal labour ward. The uncanny appearance of these miniature infants, viewed behind clear plastic, in what looks more like

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<sup>2</sup> MA Rysavy et al, ‘Between-Hospital Variation in Treatment and Outcomes in Extremely Preterm Infants’ (2015) 372 *New England Journal of Medicine* 1801-1811, discussed in P Belluck, ‘Premature Babies May Survive at 22 Weeks if Treated, Study Finds’ *New York Times*, May 6 2015

<sup>3</sup> SK Templeton and R Myers, ‘Boom in survival rates for babies born at 23 weeks’ *The Times*, March 5 2017.

<sup>4</sup> See also J Marcus, ‘The test ahead’ *Boston Globe*, October 9, 2011.

<sup>5</sup> L Mangham, et al ‘The childhood costs of preterm birth in England and Wales: A decision-analytic Markov modelling study’ (2009) 123 *Pediatrics* e312-27; K Devlin, ‘Premature births cost the NHS almost £1 billion a year’ *The Telegraph*, 2 May 2009.

<sup>6</sup> C Camosy, *Too expensive to treat? Finitude, tragedy and the neonatal ICU* (Grand Rapids, Michigan: Eerdmans, 2010). See also RH Blank, ‘Rationing medicine in the neonatal intensive care unit’ pp 155-183 in Al Caplan, RH Blank and JC Merrick (eds) *Compelled Compassion: Government Intervention in the Treatment of Critically Ill Newborns* (New York: Springer, 1992); WM Gilbert, ‘The cost of preterm birth: the low cost versus high value of tocolysis’ (2006) 113 *BJOG: An International Journal of Obstetrics & Gynaecology* 4-9; MH Boyle et al, ‘Economic Evaluation of Neonatal Intensive Care of Very-Low-Birth-Weight Infants’ (1983) 307 *New England Journal of Medicine* 1330-133.

<sup>7</sup> See, for example, J Laurence, ‘Extremely Premature Babies: “we wondered if it was right to let him live”’ *The Independent*, 12 February 2013; J Sinconis, ‘Bankrupted by giving birth: having premature twins cost me everything’ *The Guardian*, 16 January 2018.

a laboratory or a spaceship than a hospital ward, converts them into objects of curiosity and wonder.<sup>8</sup> But while extremely premature babies may not look like other sick children, we intend to argue that this does not justify adopting a different approach to decisions about whether to withhold or withdraw life-prolonging treatment from them.

In addition to concern about the cost of treating extremely premature babies, there are also those who worry that, through facilitating their survival, science might be ‘pushing the limits of nature too far’.<sup>9</sup> This sort of argument is a familiar response to novel medical technologies. It has been made recently in relation to mitochondrial replacement techniques,<sup>10</sup> and it is worth remembering that Bob Edwards and Patrick Steptoe faced opposition to their research into IVF by those who argued that infertility only affected a small number of people, and that the more pressing problem was overpopulation.<sup>11</sup> Just because technological progress can enable babies to survive at 22 or 23 weeks, some would question whether it should always be used. Andrew Jameton, for example, has argued that NICUs should be shut down so that we no longer ‘invest our social resources in such an extravagant and unbalanced way’.<sup>12</sup> More moderately, Neera Bhatia concludes that ‘[t]here is a need for a critical re-evaluation of the intersection between what health outcomes *can* be achieved using advanced medical technology and what outcomes *should* be achieved.’<sup>13</sup>

In this article, we seek to challenge the assumption that it is legitimate to consider the costs of premature babies’ future social and educational needs when deciding what treatment, if any, to provide in the NICU. This is not because we think the NICU ought to be a rationing-free zone, to which limitless funds could, or should be made available. As a threshold matter, we point out that NICU care is often surprisingly cost-effective. More fundamentally, we question the elision that is made between the claim that a particular treatment, such as resuscitation, is insufficiently cost-effective, and the claim that a person will be a burden on the state in the future. Next, we will suggest that the claim that some babies are too young, and hence too costly to treat is based upon a series of fundamental misunderstandings about both gestational age and the reality of decision-making in the NICU. On this, we agree with Manya Hendriks and John Lantos’ recent conclusion that ‘[t]he promulgation and use of policies that rely primarily on gestational age seems to be unscientific, inexplicable, and unjust’.<sup>14</sup>

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<sup>8</sup> G Whittier, ‘The ethics of metaphor and the infant body in pain’ (1999) 18 *Literature and Medicine* 210-235.

<sup>9</sup> A Wishart, *23 Week Babies: The Price of Life*, BBC2, March 9 2011.

<sup>10</sup> F Baylis, ‘Human Nuclear Genome Transfer (So-Called Mitochondrial Replacement): Clearing the Underbrush’ (2017) 31 *Bioethics* 7–19.

<sup>11</sup> MH Johnson, SB Franklin, M Cottingham and N Hopwood, ‘Why the Medical Research Council refused Robert Edwards and Patrick Steptoe support for research on human conception in 1971’ (2010) 25 *Human Reproduction* 2157–2174.

<sup>12</sup> Quoted in JD Lantos, review of RL Guyer, *Baby at Risk: The Uncertain Legacies of Medical Miracles for Babies, Families, and Society* (2007) 7 *American Journal of Bioethics* 45-46.

<sup>13</sup> Neera Bhatia, *Critically Impaired Infants and End of Life Decision Making: Resource Allocation and Difficult Decisions* (London and New York: Routledge, 2015) 189 (emphasis in original).

<sup>14</sup> MJ Hendriks and JD Lantos, ‘Fragile lives with fragile rights: Justice for babies born at the limit of viability’ (2018) 32 *Bioethics* 205–214.

Finally, and in conclusion, we argue that infants born at the margins of viability appear to be located in a morally-ambiguous zone, in which their gestational age can be invoked in order to allow the granting or withholding of life itself. We suggest that the claim that premature babies are too expensive to treat may depend upon regarding a premature infant as if she were not yet a person, with rights and interests of her own. Unlike Helga Kuhse and Peter Singer's controversial 1985 book which maintained that it could be legitimate to kill 'handicapped' infants precisely because they are infants,<sup>15</sup> many of those who worry about the costs of premature babies' future care do not intend to treat them as less than fully human. But it is unimaginable in any other context that treatment would be withheld from a person because that person might impose costs upon the state in the future. If a premature infant's moral and legal status is instead equivalent to that of a fetus, this sort of argument makes more sense. While a fetus is *in utero*, its life can be terminated because the child, if born, would impose costs and burdens on others. After birth, once a baby has an existence separate from her mother, treatment decisions should be taken in the same way as they are for other children. This, we argue, would rule out withholding treatment on the grounds that the child might prove expensive for society to care for or educate in the future.

## II AN ODD WAY TO RATION TREATMENT

We certainly do not intend to argue that cost-effectiveness analysis has no place in the NICU, and that unlimited resources should be diverted away from other parts of the NHS in order to fund expensive neonatology services. On the contrary, we accept that rationing is inevitable, and the task therefore is to ensure that it is carried out as fairly and transparently as possible.<sup>16</sup> In the NICU, this means that new drugs and technologies should be introduced and funded only if they meet a threshold level of cost-effectiveness.

The most commonly-used mechanism through which the cost-effectiveness of medical interventions is assessed is the Quality Adjusted Life Year (QALY).<sup>17</sup> QALYs measure both the amount of life years generated by a treatment, and their quality, and their purpose is to prioritise treatments that offer the longest periods of healthy and active life at the lowest cost.<sup>18</sup> In the UK, although QALYs are not the only relevant consideration, the National Institute for Health and Care Excellence (NICE) has

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<sup>15</sup> H Kuhse and P Singer, *Should the Baby Live? The Problem of Handicapped Infants* (Oxford: Oxford UP, 1985).

<sup>16</sup> N Daniels and JE Sabin, *Setting Limits Fairly—Can We Learn to Share Medical Resources?* (Oxford: Oxford UP, 2000); A Maynard, 'Ethics and health care "underfunding"' (2001) 27 *Journal of Medical Ethics* 223–7, Bhatia (n 13).

<sup>17</sup> A Williams, 'The value of QALYs' (1985) 94 *Health and Social Service Journal* 3.

<sup>18</sup> G Loomes and L McKenzie, 'The use of QALYs in health care decision making' (1989) 24 *Social Science and Medicine* 299-308.

employed a cost-effectiveness threshold of between £20,000 and £30,000 per QALY.<sup>19</sup> Using QALYs as a benchmark, care in the NICU appears to be cost-effective. Writing seven years ago, John Lantos and William Meadow explained that:

neonatal intensive care units are among the most cost-effective of all intensive care interventions. In fact, they are more cost-effective than coronary artery bypass surgery or renal dialysis. Most analyses estimate that NICU care costs well under \$10,000 per quality-adjusted life year (QALY). Some analyses put the number at closer to \$5000/QALY.<sup>20</sup>

At first sight, this comparatively low cost-per-QALY of treatment in the NICU might look surprising. But, as Hendriks and Lantos have explained, the costs of treatment in the NICU are concentrated in the first weeks of a baby's life.<sup>21</sup> Babies who die in the NICU tend to die soon after birth, whereas many of the babies who survive will have normal, healthy lifespans. Hence, as Hendriks and Lantos explain, 'most expenses in the NICU are directed to babies who will ultimately survive and do well'.<sup>22</sup> On average, the cost-per-QALY is therefore low. In contrast, in adult intensive care units, the majority of resources are spent on adults who die soon afterwards,<sup>23</sup> which inevitably makes the cost-per-QALY much higher.

While rationing in the NICU according to cost-per-QALY cost-effectiveness analysis is normal and unexceptional, when the claim is made that a baby may be too premature, and, as a result, too expensive to treat, this is rationing according to how expensive it might be to care for the person treated *in the future*. This would not normally be a relevant consideration when making rationing decisions.

Of course, because rationing means that that some patients will not receive treatment that would benefit them (otherwise, the decision not to treat would be an instance of clinical judgement, rather than rationing), there are indubitably other patients from whom potentially life-saving treatment is withheld on cost grounds. When NICE decides not to approve a new cancer drug for use in the NHS, because it is insufficiently cost-effective, there may be identifiable patients who will suffer, and perhaps die as a result.<sup>24</sup> But the decision in such cases is that drug X is too expensive, because the cost-per-QALY is too high, not that patient Y, if she survives, is likely to be too expensive to look after in the future.

The implication of rationing according to the costs of the patient's future care is that, in some cases, her non-life, or death, might be cheaper and therefore more cost-effective for the NHS. It is

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<sup>19</sup> A Dillon, 'Carrying NICE over the threshold' (NICE, 2015).

<sup>20</sup> JD Lantos and WL Meadow, 'Costs and End-of-Life Care in the NICU: Lessons for the MICU?' (2011) 39 *The Journal of Law, Medicine & Ethics* 194-200.

<sup>21</sup> Hendriks and Lantos (n 14).

<sup>22</sup> *Ibid*

<sup>23</sup> JD Lantos, M Mokalla and W Meadow, 'Resource allocation in neonatal and medical ICUs: epidemiology and rationing at the extremes of life' (1997) 156 *American Journal of Respiratory and Critical Care Medicine* 185-189.

<sup>24</sup> J Raftery, 'NICE and the challenge of cancer drugs' (2009) 338 *British Medical Journal* (online).

unimaginable that cancer services, or emergency or intensive care services would be rationed on the grounds that the death of expensive-to-treat people is more economically efficient for the NHS than their survival. If a child were to suffer a severe brain injury which would leave her completely dependent on others for the rest of her life, the costs of her future care are likely to be very high indeed, but this would not be treated as a relevant factor when deciding whether to withhold or withdraw life-saving treatment from her. Rather the paramount decision-making criterion in such cases is the individual child's best interests.<sup>25</sup>

In the following section, we will query the use of gestational age as predictor of success, but it is also worth noting that rationing on the grounds of gestational age might be said to be contrary to basic principles of fairness in rationing. At the other end of the human lifespan, it would be unthinkable to withhold life-sustaining treatment from *everyone* over a certain age, on the grounds that they will become costly to care for in the future. Of course, there are those who would say that there is a rational reason for making just such a distinction between the very elderly and the very young.<sup>26</sup> An elderly person has a history and a biography, and may be living a life that she values. In contrast, a premature newborn is unaware of anything other than physical sensations like warmth, touch, and hunger. She does not have a sense of self, and is unable yet to place a value on her own life.<sup>27</sup> We return below to the question of whether this should affect the value that society places upon her life.

### III HOW ARE TREATMENT DECISIONS MADE IN THE NICU?

Once a child is born alive, the law which covers the medical treatment of children applies. Of course, this requires us to be able to tell when a child has been born alive, and, as Achas Burin has pointed out, this is not necessarily straightforward.<sup>28</sup> The 'born alive' test for legal personhood was not developed in order to articulate the necessary conditions of personhood, rather, its purpose was, in the criminal law, to establish whether, at the time of alleged criminal conduct which was said to cause the death of a 'child', the child would have lived but for the defendant's act.<sup>29</sup> In the UK, a child is said to be born alive

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<sup>25</sup> Children Act 1989 section 1(1). See, for example, *Yates and Gard v Great Ormond Street Hospital NHS Foundation Trust* [2017] EWCA Civ 410; *Evans v Alder Hey Trust* [2018] EWCA 984 (Civ).

<sup>26</sup> J Harris, 'Human Beings, Persons and Conjoined Twins: An Ethical Analysis of the Judgment in *Re A*' (2001) 9 Medical Law Review 221–36.

<sup>27</sup> SA Sayeed, 'Futility in the NICU: my life without me' in H Colt, S Quadrelli and F Lester (eds), *The Picture of Health: Medical Ethics and the Movies* (Oxford: Oxford UP, 2011) Part 9, chapter 6.

<sup>28</sup> AK Burin 'Beyond Pragmatism: Defending the "Bright Line" of Birth' (2014) 22 Medical Law Review 494-525.

<sup>29</sup> K Savell, (2006) 'Is the "born alive" rule outdated and indefensible?' (2006) 28 Sydney Law Review 625-664.

if it can breathe through a ventilator,<sup>30</sup> or ‘through its lungs alone’,<sup>31</sup> but not if it derives ‘any of its living or power of living by or through any connection with its mother’.<sup>32</sup>

In practice, if a baby is capable of being resuscitated in the delivery room, she has been born alive and her parents acquire the right to take decisions about her medical treatment,<sup>33</sup> subject to being overruled by the courts if the decision they wish to take is not in their child’s best interests.<sup>34</sup> If a child’s parents refuse to consent to treatment that the doctors believe to be in her best interests, the NHS Trust can apply to the court for a declaration that treatment would be lawful.<sup>35</sup> Or, if the treating team believe that it would not be in a child’s best interests to receive futile or burdensome treatment, but the parents want treatment to continue,<sup>36</sup> or want their child to receive experimental treatment against medical advice,<sup>37</sup> the NHS Trust can apply for a declaration that it would be lawful to withdraw or withhold treatment. As with adults, the courts can declare that treatment, or non-treatment, would be lawful, in a child’s best interests, but they will not force doctors to act contrary to their clinical judgement.<sup>38</sup>

There is now a significant body of cases in which decisions about whether to withhold or withdraw life-prolonging treatment from a gravely ill child have come before the courts,<sup>39</sup> but none of these cases has involved an extremely premature baby in the NICU. In part, this is a question of timing. Decisions in the NICU often have to be taken quickly, and there may be good reasons not to delay decision-making in order that the child’s situation can be subject to expert evaluation and thorough legal argument. But the lack of time for lengthy legal proceedings cannot be the whole story. There are mechanisms which enable *ex parte* court decisions to be made quickly in an emergency, but these do not tend to be employed in relation to life and death decisions in the NICU.<sup>40</sup> Instead, it seems that, aside from the wholly exceptional conjoined twins case in 2001,<sup>41</sup> neither parents nor doctors in the NICU are

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<sup>30</sup> *Per* Sir John Donaldson MR, *C v S* [1988] QB 135, at 151,

<sup>31</sup> *Per* Brooke J, *Rance v Mid-Downs HA* [1991] 1 QB 587 at 621.

<sup>32</sup> *Ibid*

<sup>33</sup> Anyone with parental responsibility for a child can give consent to her medical treatment. Provided that both parents have parental responsibility, each would normally be able to give a valid consent to their child’s treatment without consulting the other. For certain treatments, including non-therapeutic male circumcision and vaccination, if those with parental responsibility cannot agree, the court will make the decision in the child’s best interests: *Re B and G (children) (care proceedings)* [2015] EWFC 3; *F v F (MMR Vaccine)* [2013] EWHC 2683 (Fam).

<sup>34</sup> Children Act 1989 section 1(1).

<sup>35</sup> *The NHS Trust v A (a child)* [2007] EWHC 1696 (Fam).

<sup>36</sup> *Kings College Hospital NHS Foundation Trust v Thomas* [2018] EWHC 127 (Fam).

<sup>37</sup> See, for example, *Yates and Gard v Great Ormond Street Hospital NHS Foundation Trust* [2017] EWCA Civ 410.

<sup>38</sup> *per* Lord Donaldson MR in *Re J (A Minor) (Child in Care: Medical Treatment)* [1991] 2 WLR 140.

<sup>39</sup> See, for example, *An NHS Trust v B* [2006] EWHC 507 (Fam); *Re K (A Minor)* [2006] EWHC 1007 (Fam); *NHS Trust v Baby X* [2012] EWHC 2188 (Fam); *Re A (HR)* [2016] EWCA Civ 759; *Great Ormond Street Hospital v Yates* [2017] EWCA Civ 410; *Kings College Hospital NHS Foundation Trust v Thomas* [2018] EWHC 127 (Fam).

<sup>40</sup> See further A Morris ‘Selective Treatment of Irreversibly Impaired Infants: Decision-Making at the Threshold’ (2009) 17 *Medical Law Review* 347-376.

<sup>41</sup> *Re A (Children) (Conjoined Twins: Medical Treatment)* [2001] Fam 147.



inclined to go to court to resolve questions over the treatment, or non-treatment of babies born very prematurely.<sup>42</sup>

How then are best interests decisions made in the NICU? Interestingly, there would appear to be some internal inconsistency within the Royal College of Paediatrics and Child Health (RCPCH)'s guidance on withholding and withdrawing life-sustaining treatment for children. In its preface, it is clear that 'it describes situations in which individual children should be spared inappropriate invasive procedures—NOT *types* of children to whom *appropriate* procedures should be denied'.<sup>43</sup> The guidance also makes it clear that the RCPCH's ethics and law committee does 'not believe that decisions about who is offered intensive care should be motivated by resource constraints, but should be determined by whether such care was appropriate for that particular child at that time'.<sup>44</sup> According to this guidance, it may be appropriate to withdraw life-sustaining treatment either when 'such treatment would be medically inappropriate and could not achieve its intended purpose of preserving life or restoring health', or when 'treatment would no longer be in the best interests of the child in that its burdens outweigh the benefits'.<sup>45</sup>

But while the RCPH's guidance suggests that decisions to withhold or withdraw life-prolonging treatment must be based upon the individual child's prognosis, with or without treatment, when discussing very premature babies, the guidance appears to suggest that it will sometimes be appropriate to base decisions to withhold treatment upon the newborn baby's gestational age:

Neonates should almost always be resuscitated in the labour ward, unless there is a clear decision to do otherwise made with the consent of parents *and based on appropriate guidelines*.<sup>46</sup>

According to the footnotes, the 'appropriate guidelines' to which this refers are those set out in the Nuffield Council on Bioethics' 2006 report, *Critical care decisions in fetal and neonatal medicine*,<sup>47</sup> and in Andrew Wilkinson et al's 2009 'framework for clinical practice'.<sup>48</sup> Wilkinson et al's framework mirrors the Nuffield Council's proposed scheme for the resuscitation of premature babies, which recommended no resuscitation for babies born earlier than 23 weeks: 'If gestational age is certain and less than 23<sup>+0</sup> (ie 22 weeks), it would be considered in the best interests of the baby, and standard practice, for resuscitation not to be carried out'.<sup>49</sup> This recommendation was based upon the findings

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<sup>42</sup> The reasons for this are worthy of further empirical investigation, but there are comparatively few empirical studies of decision-making in the NICU. For a notable exception, see HE McHaffie, et al, 'Deciding for imperilled newborns: medical authority or parental autonomy?' (2001) 27 *Journal of Medical Ethics* 104-109.

<sup>43</sup> Royal College of Paediatrics and Child Health, *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice* (RCPCH, 2015) (emphases in original).

<sup>44</sup> *Ibid*, para 3.3.3.

<sup>45</sup> *Ibid*, para 2.4.8.

<sup>46</sup> *Ibid*, para 3.1.2 (our emphasis).

<sup>47</sup> Nuffield Council on Bioethics, *Critical care decisions in fetal and neonatal medicine: ethical issues* (NCOB, 2006).

<sup>48</sup> AR Wilkinson et al, 'Management of babies born extremely preterm at less than 26 weeks of gestation: a framework for clinical practice at the time of birth' (2009) 94 *Archives of Disease in Childhood - Fetal and Neonatal Edition* 2-5.

<sup>49</sup> *Ibid*

of EPICure 2,<sup>50</sup> which, as we saw earlier, have been supplanted by more recent evidence. While the RCPCCH guidance makes it clear that ‘In acute situations it is usually necessary to give LST [life-sustaining treatment] first and to review the decision to continue when enough information is available, taking into account more experienced clinical opinion, the evolution of the clinical state, or the results of investigations’,<sup>51</sup> it simultaneously cross-refers to guidelines which recommend the blanket non-treatment of babies born earlier than 23 weeks.

The Nuffield Council’s report specifically recommended that ‘should professional bodies choose to produce guidelines for instituting intensive care, these should be reviewed regularly and revised to reflect any changes in outcomes for extremely premature babies.’<sup>52</sup> Given recent improvements in survival rates for babies born at 22 and 23 weeks, these guidelines are, at the very least, in need of some updating. We would, go further, however, and suggest that gestational-age based thresholds for resuscitation are inherently problematic.

Guidelines for the treatment of premature babies based upon gestational age are, as Hendriks and Lantos point out, undoubtedly well-intentioned.<sup>53</sup> Decisions to withhold life-sustaining treatment in the NICU are complex and difficult: ‘The parents are stressed, the prognosis is uncertain, the treatment is expensive and burdensome, and the consequences of being wrong can be tragic’.<sup>54</sup> Gestational-age based guidelines enable decisions to be taken quickly, and may make these life and death decisions less morally burdensome. The question for the clinician is not then: ‘should I save this baby?’, but becomes the less fraught one: ‘what is the gestational age of this baby?’; with the decision to treat, or not, flowing automatically from a neutral finding of fact.

There are, however, three reasons for challenging the use of gestational age thresholds for the provision of life-sustaining medical treatment. First, it is almost impossible to establish gestational age precisely, unless the pregnancy resulted from IVF, when the date of the embryo transfer is known. Otherwise, gestation is estimated through a combination of the date of the woman’s last menstrual period and evidence from the pregnancy-dating ultrasound scan. Because there is a margin of error of a week or two,<sup>55</sup> a child born at an estimated gestational age of 23 weeks might, in fact, be as young as 21, or as old as 25 weeks.<sup>56</sup> Parents may be surprised that a child they had assumed was old enough to be viable is in fact not, or vice-versa. Given this inevitable uncertainty, and the life-and-death implications

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<sup>50</sup> Costeloe et al (n 1).

<sup>51</sup> Royal College of Paediatrics and Child Health (n 43) para 3.1.2.

<sup>52</sup> Nuffield Council on Bioethics (n 47) para 9.17.

<sup>53</sup> Hendriks and Lantos (n 14).

<sup>54</sup> Ibid

<sup>55</sup> JD Lantos, *The Lazarus Case: Life and Death Issues in Neonatal Intensive Care* (Baltimore, Johns Hopkins UP, 2001), 76.

<sup>56</sup> Hendriks and Lantos (n 14).

for children, many neonatologists now argue that doctors should base their decisions on the patient in front of them, and not ‘fetishize’ gestational age as a surrogate for best interests decision-making.<sup>57</sup>

Secondly, aside from the question of how accurately gestation can be dated, the implication of determining that treatment should not be provided to babies born at 22 or 23 weeks’ gestation is that treatment in such cases is futile. This claim is hard to sustain, however, in the light of evidence that at (approximately) 22 weeks’ gestation, and with intensive care, between 5 and 32 per cent of babies will survive.<sup>58</sup> For babies born at 22 and 23 weeks, with interventions, between 20 and 70 per cent will survive.<sup>59</sup> Of course, an individual infant’s prognosis might be better or worse, but it would be impossible to categorise the treatment of all babies born at 22 and 23 weeks’ gestation as futile. Furthermore, there is evidence that extremely preterm and hence low birth weight infants often overcome their early disadvantages. In their comparison between extremely low birthweight infants and normal birthweight infants once they had reached young adulthood, Saigal et al found no significant differences in educational attainment, employment status and living independently.<sup>60</sup> Dupont-Thibodeau et al point out that:

the long-term outcomes of ELGANs [extremely low gestational age neonates] are in many ways superior (or at least equivalent) to those of Down syndrome children. It is rare for an ELGAN to have cognitive impairments in the long term as marked as those that are common for children with Down syndrome.<sup>61</sup>

Yet it is unimaginable that anyone would argue that all babies born with Down’s syndrome should be allowed to die because of the costs of treating them, and meeting their special educational needs in the future.

Keith Barrington has recently pointed out that neonatal outcome studies have had an ‘unfortunate’ tendency to focus upon ‘disability-free survival’. This is unfortunate, according to Barrington because it conflates death and disability, which, he argues are both important, but ‘should be considered separately, not lumped together as if they had equivalent impact, or were treated and valued the same by families.’ In particular, ‘disability’ in the context of long-term outcome studies for premature babies usually means low scores on developmental screening tests, and not the presence of a disabling condition. Barrington notes that that ‘...most extremely preterm babies who survive do so

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<sup>57</sup> K Gallagher et al ‘The attitudes of neonatologists towards extremely preterm infants: a Q methodological study’ (2016) 101 *Archives of Disease in Childhood - Fetal and Neonatal Edition* 31-36.

<sup>58</sup> D Austeng et al, ‘Incidence of and risk factors for neonatal morbidity after active perinatal care: extremely preterm infants study in Sweden (EXPRESS)’ (2010) 99 *Acta Paediatrica* 978-992.

<sup>59</sup> Rysavy et al (n 2).

<sup>60</sup> S Saigal et al, ‘Transition of Extremely Low-Birth-Weight Infants From Adolescence to Young Adulthood: Comparison With Normal Birth-Weight Controls’ (2006) 295 *JAMA* 667-675.

<sup>61</sup> A Dupont-Thibodeau et al, ‘End-of-life decisions for extremely low-gestational-age infants: Why simple rules for complicated decisions should be avoided’ (2014) 38 *Seminars in Perinatology* 31-37.

without serious impairment, even those who really do have serious impairments have a good quality of life, and there is little impact of gestational age at birth on the frequency of impairment.<sup>62</sup>

Two years ago, Annie Janvier and John Lantos published a trenchant critique of basing treatment decisions in the delivery room upon gestational age:<sup>63</sup>

There are three common arguments against the treatment of extremely preterm neonates. First, it is seen as futile. Second, it is seen as too expensive. Third, it is thought that the majority of survivors are disabled. The medical literature does not support any of these arguments. Treatment of neonates born at 22 and 23 weeks is clearly not futile: with interventions 20%-70% of such babies survive. No other treatment with such survival rates or long-term outcomes would be called futile.<sup>64</sup>

This led them to ask the following ethical question, which is worth quoting at length:

Are similar policies applied to other groups of patients? In our view, it makes sense to allocate healthcare resources in a way that maximises good and minimises bad outcomes, but the standards for making allocation decisions should be applied fairly to different groups of patients. Policies that limit treatment for babies born at lower gestations but do not limit treatment for patients with even worse outcomes – for example, patients with advanced cancer... -- are policies that unfairly deny interventions to one group of patients even though that group has outcomes that are demonstrably better than other groups.<sup>65</sup>

Janvier and Lantos acknowledge the expense of long NICU stays, and the higher rates of disabilities among extremely preterm survivors, compared with babies born close to, or at term. However, they point out the relevant comparator should instead be babies born just above the treatment cut-off point. That is, it does not make sense to compare the outcomes for babies born at roughly 23 weeks with those of babies born at term, rather an appropriate comparator would be babies born after approximately 24 or 25 weeks, for whom treatment is not generally controversial.<sup>66</sup>

Thirdly, and perhaps most importantly, the reliance on gestational age as a marker for prognosis fails to capture what may be the most distinctive feature of decision-making for extremely premature babies, namely that immediately after birth, their prognosis is usually both unknown and unknowable.<sup>67</sup>

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<sup>62</sup> See further a recent debate in *Acta Paediatrica*, for example, PA Lönnqvist, 'The potential implications of using disability-free survival and number needed to suffer as outcome measures for neonatal intensive care' (2018) 107 *Acta Paediatrica* 200-202. Barrington's response is available at < <https://neonatalresearch.org/2018/02/02/new-published-letter-a-response-to-the-number-needed-to-suffer/> > accessed 13 August 2018.

<sup>63</sup> A Janvier and J Lantos, 'Delivery room practices for extremely preterm infants: The harms of the gestational age label.' (2016) 101 *Archives of Disease in Childhood – Fetal and Neonatal Edition* F375-6.

<sup>64</sup> *Ibid*

<sup>65</sup> *Ibid*

<sup>66</sup> JD Lantos and WL Meadow, *Neonatal Bioethics: The Moral Challenges of Medical Innovation* (Baltimore: Johns Hopkins Press, 2006) 122-3.

<sup>67</sup> N Aladangady, K Costeloe, and V Larcher, 'Decision making and modes of death in a tertiary neonatal unit' (2004) 89 *Archives of Disease in Childhood - Fetal and Neonatal Edition* F527-F530; J Kattwinkel et al and American Heart Association, 'Neonatal resuscitation: 2010 American Heart Association guidelines for cardiopulmonary resuscitation and emergency cardiovascular care' (2010) 126 *Pediatrics* e1400-13.

When a baby is born alive at 22 or 23 weeks, it is impossible to tell whether she will thrive in the future, or die soon after birth. As Lantos and Meadow have explained, when resuscitation takes place,

nearly all of these babies are in a situation of radical prognostic uncertainty. Doctors cannot say what the outcome for any particular baby will be. Instead, the range of possibilities covers the spectrum of outcomes, from the very best to the very worst.<sup>68</sup>

Prematurity is, in Lantos and Meadow's words, 'both an acute crisis and a chronic condition.'<sup>69</sup> Decision-making about the treatment of extremely premature babies in the NICU is not a matter of making one treatment decision about one condition (or known complex of conditions). Instead, it can be broken down into two classes or kinds of decisions: first, the decision to resuscitate in the 'acute crisis'; and then, the multitude of decisions to provide or continue care for the 'chronic condition'. Importantly, these decisions often have to be made when doctors are unable to make any predictions about the child's short or long-term prognosis.

Unlike other interventions in acute illnesses, in the NICU there is rarely one moment, or one decision, in which a practice or decision can be equally predictably therapeutically beneficial across a cohort of children. Even when considering children born at the same gestational age, treatment decisions and possible outcomes are profoundly specific. This understanding of particularity is at the heart of decision-making in the NICU.<sup>70</sup> Multiple variables affect a baby's chances of survival, including but not limited to her birthweight, race, gender, whether she was delivered by caesarean section and whether her mother took steroids before delivery.<sup>71</sup> When deciding whether to spend money on the treatment of very premature babies, it is vital to recognize the profound specificity of treatment options and outcomes for children born at the same gestational age.

In many cases, the child's 'radical prognostic uncertainty' predates her birth and forms the backdrop to interventions during high risk pregnancies. There are a number of known risk factors for very preterm delivery including IVF/ICSI,<sup>72</sup> twin or higher order multiple pregnancies,<sup>73</sup> maternal youth or advanced age; maternal race,<sup>74</sup> and conditions like type 1 diabetes and pre-eclampsia.<sup>75</sup> Some women will experience sudden placental abruption or other bleeding or infection that results in premature delivery. While some parents will be shocked by the preterm delivery of an otherwise healthy pregnancy,

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<sup>68</sup> Lantos and Meadow (n 66) 16.

<sup>69</sup> Ibid 15-17.

<sup>70</sup> Ibid

<sup>71</sup> JE Tyson et al and National Institute of Child Health, & Human Development Neonatal Research Network, 'Intensive care for extreme prematurity — Moving beyond gestational age' (2008) 358 *New England Journal of Medicine* 1672–1681.

<sup>72</sup> K Wisborg et al. 'In vitro fertilization and preterm delivery, low birth weight, and admission to the neonatal intensive care unit: a prospective follow-up study' (2010) 94 *Fertility and Sterility* 2102 – 2106.

<sup>73</sup> A Janvier et al, 'The epidemic of multiple gestations and neonatal intensive care unit use: the cost of irresponsibility?' (2011) 159 *Journal of Pediatrics* 409-13.

<sup>74</sup> BE de Jongh et al, 'The differential effects of maternal age, race/ethnicity and insurance on neonatal intensive care unit admission rates' (2012) 12 *BMC Pregnancy Childbirth* 97.

<sup>75</sup> RL Goldenberg et al, 'Epidemiology and causes of preterm birth' (2008) 371 *The Lancet* 75-84.

others will have been counselled in advance about the risks of premature delivery, and their prenatal care will be designed to ensure that the pregnancy is maintained for as long as possible, and that, after birth, the baby will have the best chance of survival.<sup>76</sup> It almost goes without saying that, before delivery, the future costs of a premature infant's life do not dictate the standard of care that a woman receives in pregnancy.

It is, however, evident that policies which use a baby's gestational age in order to determine whether to provide life-sustaining treatment may become a self-fulfilling prophecy.<sup>77</sup> If treatment is not provided to babies born at 22 weeks, survival rates at this estimated gestational age will obviously be very low indeed. Moreover, as Hendriks and Lantos point out, if a woman goes into labour after 22 weeks of pregnancy and is told that her baby will not be resuscitated, this is likely to shape decisions about her obstetric care. If she has been told that her baby is not going to be treated, there may be little point in her taking steroids or undergoing caesarean delivery, without which her baby's survival becomes much less likely.<sup>78</sup>

A much better predictor of long-term survival than gestational age is, in fact, short-term survival. As John Lantos explains, 'the chance that any particular baby will ultimately survive increases enormously with each day that they actually do survive'.<sup>79</sup> Crucially, this is independent of birthweight: 'any baby, regardless of birthweight, who has been in the NICU for three days and is still alive has a nearly 90 per cent chance of survival'.<sup>80</sup> After four days' survival, birthweight is no longer relevant, and a baby born at 600 grams has the same chance of long-term survival as a four day old baby who was born at 1600 grams.<sup>81</sup> 'Response to therapy', or waiting for babies to 'declare themselves',<sup>82</sup> therefore becomes, in itself, a prognostic test, but one that works only if all newborn babies receive life-sustaining treatment.

Waiting for the baby to 'declare herself' as a test for whether or not treatment should continue to be provided has the advantage of simplicity, and it might also be easier for doctors and parents since they are not, on this view, making life and death decisions, but waiting for the baby to elect to live or die. Of course, there are also potential costs to this approach. For the babies who do not survive, they may have been subjected to four days of burdensome treatment, which turns out also to have been futile, and not in their best interests. And while in most cases, these 'declarations' are fairly reliable predictors of long-term survival, in a minority of cases, they are not.

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<sup>76</sup> Royal College of Obstetricians and Gynaecologists, *Perinatal Management of Pregnant Women at the Threshold of Infant Viability—the Obstetric Perspective* (Scientific Impact Paper No. 41) (RCOG, 2014).

<sup>77</sup> M Hendriks and Lantos (n 14).

<sup>78</sup> Ibid.

<sup>79</sup> JD Lantos (n 55) 77.

<sup>80</sup> Ibid

<sup>81</sup> Ibid

<sup>82</sup> Ibid 78.

New software which captures and processes patient data, across multiple measures, in real time may provide more accurate prognoses in the future. Interestingly, Viktor Mayer-Schonberger and Kenneth Cukier point out how a system developed by a Canadian researcher which tracked 16 different data streams, such as heart rate, respiration rate and blood oxygen levels, resulted in the surprising conclusion that ‘very constant vital signs’ among premature babies appeared to correlate with the underlying presence of a serious infection.<sup>83</sup> Stability was not a sign of improvement therefore, but, as Mayer-Schonberger and Cukier put it, ‘the calm before the storm - as if the baby’s body is telling its tiny organs to batten down the hatches for a rough ride ahead’.<sup>84</sup>

What is clear, however, is that given inevitable uncertainty as to prognosis in the NICU, treatment decisions have to be taken incrementally, one-by-one, as more information about the baby’s condition becomes available. Of course, this does not mean that treatment will always be in a child’s best interests. Non-treatment decisions, taken in the best interests of the child, are always likely to be common in the NICU.<sup>85</sup> In one study in a London NICU, 40 per cent of deaths were the result of the withdrawal of life-prolonging treatment, 15 per cent followed a ‘Do Not Resuscitate’ decision, and 3 per cent were the result of withholding life-prolonging treatment; a minority of deaths (42 per cent) were described as ‘natural’.<sup>86</sup> If continued treatment would be futile or burdensome, it may be in the child’s best interests to receive comfort care only, and to be allowed to die peacefully. But this has to be an individual decision, grounded in consideration of the child’s best interests, rather than because she fits into a category which has been pre-labelled as ‘too expensive to treat’. As we have seen, some children born at an early gestational age will thrive, while others will not. To withhold treatment from a group with an uncertain prognosis, on the grounds that some members of that group are likely to be disabled and/or expensive to care for, even though we know some others are not, is to fail to treat each individual child as a person to whom individual duties are owed.

In many parents’ highly medically-managed journey to the NICU, the costs of premature babies only tend to be discussed at the most dramatic point in the process, when the newborn infant is surrounded by high-tech machinery. If there are concerns about the costs of extreme prematurity, this is certainly not the first or the most useful point to intervene. Reducing the number of high-risk pregnancies would represent a more economically efficient intervention, and it would not be attended by the psychological and emotional costs to parents. While the Human Fertilisation and Embryology

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<sup>83</sup> *Big Data: A Revolution that will Transform how we Live, Work and Think* (Boston: Mariner Books, 2014) 61.

<sup>84</sup> *Ibid*

<sup>85</sup> See further Morris (n 40).

<sup>86</sup> R Roy et al, ‘Decision making and modes of death in a tertiary neonatal unit’ (2004) 89 *Archives of Disease in Childhood - Fetal and Neonatal Edition* F527-F530.

Authority has been successful in reducing the multiple pregnancy rate in the UK,<sup>87</sup> women who travel overseas for cheaper IVF treatment, as a result of inadequate NHS funding for fertility services, may return to the UK pregnant with twins, triplets or quads, when the risk of extreme prematurity will be very high.<sup>88</sup> Better funding for fertility treatment in the UK might, in fact, reduce the economic burden of extreme prematurity, but this is not generally the conclusion drawn by commentators worried about the costs of babies born at the margins of viability.

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<sup>87</sup> See further, HFEA, 'Our campaign to reduce multiple births' < <https://www.hfea.gov.uk/about-us/our-campaign-to-reduce-multiple-births/> > accessed 13 August 2018.

<sup>88</sup> A McKelvey et al, 'The impact of cross-border reproductive care or "fertility tourism" on NHS maternity services' (2009) 116 *British Journal of Obstetrics & Gynaecology* 1520–3.



#### IV THE SIGNIFICANCE OF BIRTH

The implication of the claim that non-treatment decisions should be taken for a whole category of children – such as those born at 22 or 23 weeks – rather than on an individual best interests basis is that the ordinary obligations of clinicians and parents do not apply in the normal way within the NICU. One possible explanation for treating extremely premature babies differently from other children might lie in the claim made by some philosophers and ethicists that birth is an arbitrary cut-off point for the acquisition of moral status.<sup>89</sup>

LW Sumner, for example, has argued that ‘Birth is a shallow and arbitrary criterion of moral standing’,<sup>90</sup> on the grounds that newborn infants and fetuses have ‘the same size, shape, internal constitution, species membership, capacities, level of consciousness, and so forth’.<sup>91</sup> Similarly, Helga Kuhse and Peter Singer maintain that while the moment of birth is ‘clear and precise’, it ‘is not really crucial from the point of view of the moral status of the foetus or infant’.<sup>92</sup> And Jeff McMahan has said that ‘it may be difficult to see how birth, which involves only a change in the fetus’s location, could significantly affect the fetus-cum-infant’s moral status, which ought instead to be determined entirely by its intrinsic properties’.<sup>93</sup>

If there is no ‘intrinsic’ difference, and hence no change in moral status, between a fetus of 23 weeks’ gestation, which can, in theory at least, be aborted lawfully under the so-called ‘social ground’ in the UK,<sup>94</sup> and a newborn baby, born after 23 weeks’ gestation, does this mean that it could be legitimate to kill the newborn baby at her mother’s request? This is the controversial conclusion of Alberto Giubilini and Francesca Minerva, who argue in favour of what they call ‘after-birth’ abortion on the grounds that it is impossible to harm a newborn baby:

If a potential person, like a fetus and a newborn, does not become an actual person, like you and us, then there is neither an actual nor a future person who can be harmed, which means that there is no harm at all. So, if you ask one of us if we would have been harmed, had our parents decided to kill us when we were fetuses or newborns, our answer is ‘no’, because they would have harmed someone who does not exist (the

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<sup>89</sup> R Gillon, ‘Is there a “new ethics of abortion”?’ (2001) 26 suppl II *Journal of Medical Ethics* ii5–ii9.

<sup>90</sup> LW Sumner, *Abortion and Moral Theory* (Princeton: Princeton UP 1981) 52.

<sup>91</sup> *Ibid* 53.

<sup>92</sup> Kuhse and Singer (n 15).

<sup>93</sup> J McMahan, *The Ethics of Killing: Problems at the Margin of Life* (Oxford: Oxford UP, 2002), 340.

<sup>94</sup> In practice, although such terminations might be lawful, very few providers offer termination of pregnancy late into the second trimester.

‘us’ whom you are asking the question), which means no one. And if no one is harmed, then no harm occurred.<sup>95</sup>

Michael Tooley, while questioning Giubilini and Minerva’s conclusions, agrees with them that ‘the crucial issue here ... is at what point a developing human acquires the capacity for thought’.<sup>96</sup> And Tooley himself has argued that to have a strong right to life, an entity must be capable of desiring its own continued existence, thus ruling out newborn babies.<sup>97</sup> Derek Parfit, similarly, maintains that ‘to be a person, a being must be self-conscious, aware of its identity and its continued existence over time’.<sup>98</sup>

These sorts of arguments rest upon the idea that the moral status of an organism – a fetus or a newborn baby – depends upon its inherent characteristics, such as its capacity for thought or its ability to value its own existence. If a baby born at 23 weeks has the same inherent characteristics as a fetus at 23 weeks, it has been suggested that its moral status, and hence the duties owed to it, are the same. For four reasons, however, this argument, and its implication for the treatment of premature babies, is problematic.

First, the fetus does not exist as an independent entity, whose characteristics can be measured and compared with those of a newborn baby. A live fetus is necessarily inside a woman’s body, and wholly dependent upon her body to sustain its life. This is not ‘just’ a question of location, or, according to Raanan Gillon, ‘biological geography’,<sup>99</sup> rather it is what the fetus *is*. During pregnancy, a fetus is a part of the woman’s body; after birth, a baby is no longer a part of someone else, but is an individual with a separate existence in the world. Before birth, in Mary Anne Warren’s words, ‘It is impossible to treat fetuses *in utero* as if they were persons without treating women as if they were something less than persons’.<sup>100</sup> As Kate Greasley explains, it is only after birth that a baby has interests that can be protected independently:

The fetus is, in important ways, set apart from the world of common humanity. It is only upon emergence into that common world at birth that other humans can fully *treat* it as a fellow person—can directly see it, touch it, speak to it, assess and respond to its needs or confer benefits upon it, without going through the body of the pregnant woman.<sup>101</sup>

Secondly, it is not true that there are no intrinsic as well as extrinsic changes in a baby when it is born alive. Birth involves significant *intrinsic* changes in the newborn baby. According to Noah Hillman et al, ‘The transition from foetus to neonate is the most complex physiologic adaptation that occurs in

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<sup>95</sup> A Giubilini and F Minerva, ‘After-birth abortion: why should the baby live?’ (2013) 39 *Journal of Medical Ethics* 261-263.

<sup>96</sup> M Tooley, ‘Philosophy, critical thinking and “after-birth abortion: why should the baby live?”’ (2013) 38 *Journal of Medical Ethics* 266-272.

<sup>97</sup> M Tooley, *Abortion and infanticide* (Oxford: Oxford UP, 1983) 41.

<sup>98</sup> D Parfit, *Reasons and Persons* (Oxford: Oxford UP, 1984, reprinted 1987) 202.

<sup>99</sup> Gillon (n 89).

<sup>100</sup> MA Warren, ‘The moral significance of birth’ (1989) 4 *Hypatia* 46-65.

<sup>101</sup> K Greasley, *Arguments about Abortion: Personhood, Morality, and Law* (Oxford: Oxford UP, 2017) 198.

human experience'.<sup>102</sup> Here Achas Burin sets out just some of the physiological changes that take place when a baby is born prematurely:

all the neonate's organ systems are involved in birth. With hormonal support, the lungs inflate, circulation is redirected, and the digestive system becomes active. There are also profound changes in hormonal function, metabolism, and temperature regulation. The lungs are emptied of foetal fluid and lubricants secreted to facilitate expansion so breathing can begin. ... The volume of blood pumped from the heart nearly doubles. There are also major structural changes to the circulatory system. Before birth, oxygen is supplied by the placenta, so blood flows from the right to left atrium of the heart without passing the lungs. Following birth, the ducts that enabled this to happen close permanently.<sup>103</sup>

The 'extrinsic' difference of location also has a fundamental impact upon the developing brain, and it is only through interaction with the outside world that consciousness becomes possible.<sup>104</sup> For the newborn baby, birth represents 'a quantum leap forward' in establishing social bonds,<sup>105</sup> and becoming, as Mary Ann Warren puts it, 'a social being':

The infant at birth enters the human social world, where, if it lives, it becomes involved in social relationships with others, of kinds that can only be dimly foreshadowed before birth. It begins to be known and cared for, not just as a potential member of the family or community, but as a socially present and responsive individual.<sup>106</sup>

Thirdly, the claim that personhood is acquired only sometime after birth raises practical difficulties. If a person comes into being during childhood, rather than at birth, when does this significant change take place – at one month, six months, one year or two years of age? Any age-based norm would necessarily be arbitrary, and in tension with a factual criterion for personhood, grounded in the capacity for rational thought. As Jeff McMahan explains:

There is no discernable event in human development that is momentous enough for us to point to it and say, '*Now* that individual is worthy of respect', it simply does not happen that a child goes to bed one night as a being below the threshold only to wake the next morning sufficiently altered to be worthy of respect.<sup>107</sup>

A factual test for personhood acquired during childhood would have to vary for different children, depending upon their cognitive abilities. Not only would this be impossibly vague as a guide to how an individual child should be treated, but also it might mean that there are human beings who never become persons. If non-personhood could be a status that endures throughout someone's life, how should these human non-persons be treated, and what obligations would they be owed? For those who

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<sup>102</sup> NH Hillman, SG Kallapur, and AH Jobe, 'Physiology of Transition from Intrauterine to Extrauterine Life' (2012) 39 *Clinics in Perinatology* 769-783.

<sup>103</sup> AK Burin (n 27).

<sup>104</sup> K Greasley, *Arguments about Abortion: Personhood, Morality, and Law* (Oxford: Oxford UP, 2017) 198.

<sup>105</sup> L Lomansky, 'Being a person—does it matter?' in J Feinberg (ed) *The Problem of Abortion* (Belmont, California: Wadsworth Publishing Company) 161-172, 172.

<sup>106</sup> Warren (n 100).

<sup>107</sup> McMahan (n 93) 261-2 (emphasis in original).

hold to the ‘intrinsic properties’ view of personhood, birth’s legal significance may be a legal fiction, but it is, as Mary Anne Warren suggests, ‘a fiction that we would have difficulty doing without’.<sup>108</sup>

Fourthly, while debates about the moral status of fetuses and newborns are likely to continue, the legal position could not be clearer. Legal personhood is acquired when a child is born alive, and has an existence separate from her mother.<sup>109</sup> When a woman makes a decision to terminate an unwanted pregnancy, the fetus is not yet a separate legal person with rights of its own. Once a child is born, however, unless or until she is formally adopted, the choice not to be a parent has ceased to exist; the child is now a separate legal person to whom clinicians owe a duty of care, and whose parents have acquired duties of support and responsibility for her. Since the law considers a new legal person to exist once a child is born alive, and has an existence separate from her mother, premature babies undoubtedly qualify. And as a legal person, a premature baby acquires the rights to which other legal persons are entitled.

The evidence given in the 1981 trial of Dr Leonard Arthur for the murder of a child with Down’s syndrome (in whose notes he had written ‘Parents do not wish the baby to survive. Nursing care only’, before prescribing an opiate painkiller), suggested that, 37 years ago, there were some doctors who believed that it was legitimate to treat the parental and clinical obligation to care for a child with special needs as effectively optional.<sup>110</sup> The then President of the Royal College of Physicians, Professor Douglas Black, had told the court: ‘I say that it is ethical, in the case of a child suffering from Down’s, and with a parental wish that it should not survive, to terminate life providing other considerations are taken into account such as the status and ability of the parents to cope in a way that the child could otherwise have had a happy life’. Dr Arthur was acquitted, following ‘the virtual collapse of the prosecution evidence’,<sup>111</sup> and Farquharson J’s controversial direction to the jury,<sup>112</sup> but even in 1981, this case is best regarded as an anomaly.<sup>113</sup> In a case decided the same year, the Court of Appeal firmly rejected the parents’ view that life-saving treatment should not be provided to a baby with Down’s syndrome,<sup>114</sup> on the grounds that life with Down’s syndrome was not ‘demonstrably going to be so

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<sup>108</sup> Warren (n 99).

<sup>109</sup> *Attorney General's Reference (No.3 of 1994)* [1998] AC 245; *C v S* [1987] 1 All ER 1230.

<sup>110</sup> *R v Arthur* (1981) 12 BMLR 1

<sup>111</sup> D Brahams, ‘Putting Arthur's case in perspective’ (1986) *Criminal Law Review* 387-389.

<sup>112</sup> Farquharson J downgraded the charge to attempted murder, and after warning the jury ‘all must be alive to the danger of giving too much power to anyone, in the medical or other professions, to exert influence over the life and health of the public at large’, he went on to say, ‘I imagine you will think long and hard before concluding that doctors of the eminence we have heard here have evolved standards that amount to committing a crime’.

<sup>113</sup> H Benyon, ‘Arthur’s case: a further comment’ (1986) *Criminal Law Review* 760-1.

<sup>114</sup> *Re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421

awful that in effect the child must be condemned to die'.<sup>115</sup> In 2018, it is axiomatic that parental reluctance to care for a disabled baby is not grounds for withholding treatment from a child.<sup>116</sup>

It is, of course, true that in some other cultures, infanticide was practised regularly and with impunity,<sup>117</sup> but this does not establish some essential truth about the value of early human life. Insofar as infanticide continues to be treated as a lesser criminal offence,<sup>118</sup> it could be argued that this is more plausibly grounded in an understanding of post-partum psychosis and its implications for the *mens rea* of murder, rather than because the killing of newborn babies is sanctioned by society. In legal terms at least, it is clear that once a child is born, she becomes a person to whom duties of care are owed, and her best interests, judged on an individual case-by-case basis, are the paramount consideration when making decisions about her medical treatment.

## V CONCLUSION

Evidence of a reduction in the age of viability has also been invoked in order to question the abortion time limit of 24 weeks (for abortions carried out on the grounds that the mother's health would be more at risk from carrying the pregnancy to term than it would be from termination).<sup>119</sup> In the UK, until 1990, the Infant Life Preservation Act 1929 had indirectly created a viability-linked time limit for abortion, which in 1990 was assumed to be 24 weeks. Since 1990, a 24 week time limit has appeared on the face of the statute, but given evidence that some babies can survive at 22 or 23 weeks, some commentators have questioned its sustainability.<sup>120</sup>

The question of abortion time limits is outside the scope of this article, but it is worth pointing out that it sits uneasily with concern about the costs of extremely premature babies. If survival at 23 weeks is judged too expensive, it is, to say the least, peculiar to suggest that a woman might be prevented from terminating a pregnancy at 23 weeks because, if born at that age a baby could survive, but in practice would not do so, since the costs of saving it would be too great. Indeed, if economic rationality were to be the driver of all decisions about fetal survival, it could be argued that instead of reducing the time limit, fewer obstacles should be placed in the way of women seeking abortions because a

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<sup>115</sup> Ibid *per* Lord Templeman at 1424.

<sup>116</sup> JJ Paris, 'Standards, Norms, and Guidelines for Permissible Withdrawal of Life Support From Seriously Compromised Newborns' (2011) 11 *American Journal of Bioethics* 33-34.

<sup>117</sup> See, further, Kuhse and Singer (n 15).

<sup>118</sup> Infanticide Act 1938 section 1(1).

<sup>119</sup> See, for example, N Wolf, 'Face to face with a horrible truth' *Sunday Times*, 11 April 2004; David Steel, 'We need to rethink my abortion law' *The Guardian*, 6 July 2004.

<sup>120</sup> J Wyatt, 'Medical paternalism and the fetus' (2001) 27 *Journal of Medical Ethics* suppl 2 ii15-ii20.

termination will almost always cost less than the delivery of a child, and infinitely less than the costs of her upbringing.

Our point in this article is not to intervene in debates over abortion time limits, however. Nor is it to argue that life-prolonging treatment should never be withheld or withdrawn in the NICU. Rather, we are making the more modest and at first sight uncontroversial claim that non-treatment decisions in the NICU should be taken in the same way as they are for other children receiving life-prolonging treatment, on the basis of what treatment, if any, is in the child's best interests. In these individual 'life and death' decisions, what is relevant is the benefits and burdens of treatment for the child herself. What is not relevant is speculation about the costs of the child's special needs in the future.

But while we maintain that the costs of a child's future care are not relevant when deciding whether he or she should be allowed to live, there are some special features of the NICU that should be taken into account when thinking about how treatment decisions are made for extremely premature babies. Parents who are traumatised and in shock after a very premature birth may find themselves suddenly and unexpectedly faced with difficult medical decisions, often in conditions of radical uncertainty, when the child's prognosis is simply unknowable.<sup>121</sup> In such circumstances, parents need help, support and compassion.<sup>122</sup> As Annie Janvier and John Lantos explain:

Parents are grieving the loss of their hope for a healthy pregnancy, delivery, and term newborn. The sickness of their child is preceded immediately by pregnancy and the major impact that a high-risk delivery entails. ... Furthermore, most of the babies in the NICU depend on life sustaining interventions, making bonding more complex. This bonding may be complicated by the fact that many parents do not know how much time they will have with their child, whether minutes, days, weeks, or years.<sup>123</sup>

The medical literature has evaluated the negative effects of the NICU on parent-child bonding, concluding that the risks to attachment are significant, but that they can be mitigated through practices like encouraging skin-on-skin contact.<sup>124</sup> The early work on parent-child bonding came from NICU nurses rather than doctors,<sup>125</sup> and nurses play a key role in decision-making in the NICU. The relationships between parents, doctors and children are managed and navigated by the 'primaries' or specific nurses assigned to each child upon admission. Increasingly, among the many experts working in

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<sup>121</sup> EM Weiss and DA Munson, 'Action and Uncertainty in Neonatal Intensive Care' (2016) 16 *American Journal of Bioethics* 31-33.

<sup>122</sup> A Janvier et al, 'Stronger and More Vulnerable: A Balanced View of the Impacts of the NICU Experience on Parents' (2016) *Pediatrics* e20160655; SL Hall et al, 'Recommendations for enhancing psychosocial support of NICU parents through staff education and support' (2015) 35 *Journal of Perinatology* S29-S36.

<sup>123</sup> A Janvier and J Lantos, 'Ethics and etiquette in neonatal intensive care' (2014) 168 *JAMA pediatrics* 857-858.

<sup>124</sup> CL Cox and M Bialoskurski, 'Neonatal intensive care: communication and attachment' (2001) 10 *British Journal of Nursing* 668-676; C Franklin, 'The neonatal nurse's role in parental attachment in the NICU' (2006) 29 *Critical Care Nursing Quarterly* 81-85; L Fegran, S Helseth and MS Fagermoen, 'A comparison of mothers' and fathers' experiences of the attachment process in a neonatal intensive care unit' (2008) 17 *Journal of Clinical Nursing* 810-816; R Flacking et al and SCENE group, 'Closeness and separation in neonatal intensive care' (2008) 101 *Acta Paediatrica* 1032-1037.

<sup>125</sup> HE McHaffie et al, 'Deciding on treatment limitation for neonates: the parents' perspective' (2001) 160 *European Journal of Pediatrics* 339-344.

the NICU are parent liaison officers and organizations and charities like Bliss and Fragile Beginnings, which help to support bonding between the premature newborn and her parents, and which help healthcare professionals to translate the medicalised language of the NICU into family-orientated discourses of new parenthood.<sup>126</sup>

What emerges is a growing understanding that despite the unfamiliar technology, parents experience the NICU as more than a high-tech, medicalised space. A rich seam of NICU memoirs demonstrate the family construction that happens among the blue light and the ‘space age’ machines, in which parents become intensely emotionally invested in their children.<sup>127</sup> There is evidence that a model of shared decision-making is particularly helpful for parents, who want to be involved, but are grateful to be able to share decision-making responsibility with clinicians.<sup>128</sup> It is clear that parents in the NICU not only value empathetic and compassionate communication from staff, but also appreciate being involved in minor parental choices and decisions about the daily care of their child.<sup>129</sup>

Indeed, there is growing evidence of the benefits of what is described as family-integrated care in the NICU, for both parents and babies.<sup>130</sup> In family-integrated care, as Chris Gale explains,

Parents are resident in the neonatal intensive care unit for extended periods, learn to provide all care (except intravenous fluid and medications), record observations in medical charts, and participate in ward rounds, with their involvement underpinned by peer support and education.<sup>131</sup>

In a multi-centre, cluster randomised controlled trial of family-integrated care, O’Brien et al found that it ‘improved infant weight gain, decreased parent stress and anxiety, and increased high-frequency exclusive breastmilk feeding at discharge’.<sup>132</sup> If, as we suggest, the claim that extremely premature babies are too expensive to treat relies upon the construction of the NICU as a space in which children are not

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<sup>126</sup> See, for example, the Bliss Baby Charter < <https://www.bliss.org.uk/health-professionals/bliss-baby-charter/resources-and-contacts/bliss-baby-charter-faqs> > accessed 13 August 2018.

<sup>127</sup> TL Parker, ‘I didn’t even raise my hand: A mother’s retrospective journey through end-of-life decision-making at the “threshold of viability”’ (2005-6) 35 *Stetson Law Review* 207; V Forman, *This lovely life* (Boston: Houghton Mifflin Harcourt, 2009); D Fei, *Girl in Glass: How my “distressed baby” defied the odds, shamed a CEO, and taught me the essence of love, heartbreak, and miracles*. (New York: Bloomsbury, 2015); BBC Radio 5, ‘Your stories: What is it like to give birth prematurely?’ <<http://www.bbc.co.uk/programmes/articles/49VIB9NXZG3B1vmh4GR7zw3/your-stories-what-is-it-like-to-give-birth-prematurely>> accessed 13 August 2018.

<sup>128</sup> L Caeymaex et al, ‘Living with a crucial decision: a qualitative study of parental narratives three years after the loss of their newborn in the NICU’ (2011) 6 *PloS one* e28633; T Daboval and S Shidler, ‘Ethical framework for shared decision making in the neonatal intensive care unit: communicative ethics’ (2014) 19 *Paediatrics & Child Health* 302-304; V Xafis et al, ‘Balancing obligations: should written information about life-sustaining treatment be neutral?’ (2015) 41 *Journal of Medical Ethics* 234-239.

<sup>129</sup> H Wigert, M Dellenmark Blom, and K Bry, ‘Parents’ experiences of communication with neonatal intensive-care unit staff: an interview study’ (2014) 14 *BMC paediatrics* 304.

<sup>130</sup> M Bracht et al, ‘Implementing family-integrated care in the NICU: a parent education and support program’ (2013) 13 *Advances in Neonatal Care* 115-126; ME Galarza-Winton et al, ‘Implementing family-integrated care in the NICU: educating nurses’ (2013) 13 *Advances in Neonatal Care* 335-340.

<sup>131</sup> C Gale, ‘Family Integrated Care for very preterm infants: evidence for a practice that seems self-evident?’ (2018) 2 *The Lancet Child & Adolescent Health* 230-231.

<sup>132</sup> K O’Brien et al, ‘Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial’ (2018) 2 *The Lancet Child & Adolescent Health* 245-254.

really children, and, as a result, parents are not really parents, it is not only inaccurate and unhelpful, but also profoundly at odds with best practice in the NICU.