

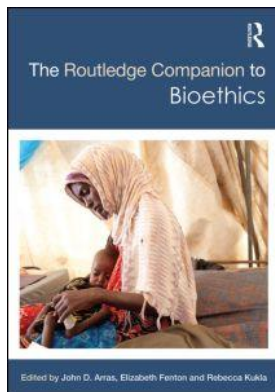
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### **End-of-Life Decisions for Newborns**

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# END-OF-LIFE DECISIONS FOR NEWBORNS

*Marian A. Verkerk and Hilde Lindemann*

In *Neonatal Bioethics: The Moral Challenges of Medical Innovation*, John Lantos argues that neonatology should be viewed not as “one of the pinnacles of modern medical success, but instead as one of the best examples of modern medicine’s moral ambiguity or hubris” (Lantos and Meadow 2008: 4). On the one hand, its successes cannot be denied: Every year in neonatal intensive care units (NICUs) around the world, thousands of newborns are saved who, had they been born 50 years ago, would have died. On the other hand, the cost to these infants in what might be years of suffering, disability, or fragile health can sometimes be so high that it might have been better had they not been saved. Then too, there are moral puzzles that arise in the NICU that have nothing to do with end-of-life decisions. Given the moral ambivalence that characterizes all the decisions that must be made, ethics is an inseparable part of neonatology. In this chapter we focus on end-of-life decisions, examining many of the considerations that matter morally when they must be made, paying special attention to recent developments in The Netherlands. We’ll argue that the best ethical response to mortally ill newborns is to set treatment decisions into the context of palliative care.

## A New Neonatal Ethics?

NICUs are a fairly recent medical innovation and an instance of scientific progress. Respirators, the routine use of surfactants to keep the baby’s lungs working properly, and other relatively new biomedical technologies mark a kind of medical progress: They make it possible to save the lives of babies born as prematurely as 24 weeks’ gestation, although with a considerable risk of damage to the lungs and brain. Such innovations do not necessarily give rise to new ethical complications, nor do they routinely give rise to dramatic, life-or-death moral dilemmas, but they do require an approach to ethics that can capture all the considerations that are salient in a given set of morally puzzling circumstances.

On our view, approaches that apply moral principles deduced from idealized moral theories to hard cases are not up to the task, as they leave us with guidance that is either too vague to be useful or so precisely specific that we would constantly have to wonder about legitimate exceptions. So we favor a neonatal ethics that draws on the best moral knowledge we can find in the actual world—where “best” means critically reflective, politically skeptical, and aimed at ways of life that are good for everyone concerned

(Walker 1998; Verkerk and Lindemann 2008). Because we conceive of morality as something the members of a moral community do together, we endorse an ethics that proceeds by means of conversations in which all those with a stake in the outcome try to reach a consensus about what should be done, from whose point of view it should be done, and who is responsible for doing it. The process of decision-making takes time and must be negotiated by all those involved. We will show how end-of-life decisions for newborns should be the result of exactly this collaborative morality: The medical team and the parents all deliberate to make the morally best response to an often very difficult situation focusing on the suffering of a newborn.

### The Central Moral Question

The focus of this article is on the morality of end-of-life decisions for neonates. These include decisions about letting a newborn die or sometimes even deliberately killing them; they encompass deciding whether to withdraw or withhold treatment where the foreseen or intended outcome is the infant's death. Palliative sedation and other interventions to relieve suffering are also part of the palliative care process. Any decision about stopping or sustaining a neonate's life should be considered an end-of-life decision.

Health care professionals evaluate various kinds of decisions differently. Between one-third and two-thirds consider withdrawing treatment to be morally more serious than withholding treatment (Wilkinson 2013). Others act on what Wilkinson and Savulescu have dubbed the Equivalence Principle, which states that "other things being equal, it is permissible to withdraw a medical treatment that a patient is receiving, if it would have been permissible to withhold that same medical treatment and vice versa" (Wilkinson and Savulescu 2014: 128; see also Sulmasy and Sugarman 1994). While many bioethicists dismiss the moral distinction between withholding and withdrawing treatment as not ethically justified, one way the professionals' feelings can be explained is as a cognitive bias based in the perception that acts carry greater moral weight than omissions (Kordes de Vaal 1996; Baron and Ritov 2004). In any case, as long as there is a gap between ethical analysis and professional practice, there is something here that is worthy of investigation (Wilkinson and Savulescu 2014). It is worth asking whether professionals' feelings about this should be taken more seriously, as an indication that something morally more complex might be going on than bioethicists typically recognize.

The question, "Are we justified in ending this baby's life?" touches on several delicate and difficult issues. First of all, there is the question whether it is ever morally permissible to end any human life. The *sanctity of life* doctrine, usually defended with religious arguments, proclaims that all human life is sacred, no matter what its quality. So from a sanctity-of-life perspective, there can be no serious moral discussion about direct killing of infants. Some defenders of the doctrine find it morally permissible to withhold or withdraw "extraordinary means" of sustaining life—means that cause disproportionate amounts of suffering—but all partisans of this doctrine agree that it is wrong to act with the deliberate intention of ending the patient's life.

The sanctity-of-life view can be contrasted with a *quality of life* view, which does not recognize an absolute right to life or an absolute duty to preserve it, but rather judges whether a life is worth preserving (or having in the first place) in terms of its quality (see, among many others, Arras 1987). From this viewpoint, the end-of-life decision is shaped by at least three different considerations. (1) The medical intervention does not improve the situation; it isn't effective (this is a question about medical futility); (2) it

might be effective, but it would cost the child and perhaps others too much to get to the improvement (this is a question about disproportionality); (3) the ultimate quality of life achieved would be very poor. So what we'll do now is focus on the quality of life, but also on the disproportionality of the intervention.

Consideration 1, about medical futility, can only be answered by physicians. Considerations 2 and 3 contain value judgments and raise three sets of moral issues: *How* we can decide someone's quality of life, *who* is to do the deciding, and *from whose point of view* the decision should be made. Newborns are not in a position to assess their own quality of life, so others will have to do this for them. The judgment could be a comparative one, from the point of view of the parents or the health professionals or both: "This level of quality is not good enough for anyone." More typically, however, the judgment is a non-comparative judgment based on the child's own subjective experience; it is made by taking the child's own point of view. So, for example, the parents might ask, "Is it in our baby's best interest to continue all these treatments if the outcome for her is an intolerable life?" Or the physicians might ask, "Is there any point to subjecting this neonate to painful treatments if his death is inevitable?" In addition, however, acting in the baby's interest may be legitimately constrained by other people's interests, or by considerations of justice. In such cases, the salient question from the parents might be, "Would it be permissible to keep our dying baby on a ventilator and morphine drip until tomorrow, when his grandparents from out of town arrive?" Or even, "We have five other young children at home and live too far away to manage the repeated surgeries you say our baby will need, if she survives at all. Is it fair to the others to devote all our resources to this baby?" In perhaps the saddest cases, the infant is so badly damaged that it may be said to have no interests at all, save the interest all humans have in being treated with respect (see McDougall and Notini 2013).

### The Moral Status of the Newborn

How the treatment decision is made depends in part on the infant's moral status. The quality-of-life position presupposes that the infant has a moral status, but that fact alone does not tell us much. Moral status is sometimes discussed as if it were an all-or-none phenomenon: "Does Baby Doe have moral status?" But for those of us who share the intuition that older children and adults have a different moral status from, say, an infant born at 24 weeks' gestation, it arguably makes more sense to conceive of moral consideration as admitting of degrees, and for the appropriate question to be, "What moral status does Baby Doe have?" (Wilkinson 2011: 26; see also DeGrazia 2008). An important reason for considering the moral status of newborns differently is that their interest in their future wellbeing may be diminished by their reduced awareness of themselves, and of that future (McMahan 2002: 170). On this view, it is not future levels of wellbeing that determine the infant's moral status, but, rather, the other way around: The infant's moral status determines how we should take its future wellbeing into account (Wilkinson 2011: 26).

### Quality of Life and Suffering

According to Great Britain's Nuffield Council on Bioethics, "It would not be in the baby's best interests to insist on the imposition or continuance of treatment to prolong

the life of the baby when doing so imposes an *intolerable* burden on him or her” (Nuffield Council on Bioethics 2006: 12). There are at least three ethical difficulties here.

The first is that babies cannot judge for themselves when their suffering is so great as to be intolerable. Although they can have a somatic experience of pain (Fabrizi et al. 2011), they do not conceptualize it as pain, much less as their own pain. Slowly, as babies acquire a self, they also acquire a dimension that may be called “subjectivity”—the special understanding we have of ourselves as subjects of our lives, a sense of agency that arises out of the operation of our identities within the social world (Scully 2008). As they gain subjectivity, they develop a sense of a past and future. Then comes self-awareness: The pain the growing child feels becomes “my pain” (Kluge 2009). Only when the child becomes self-aware can she judge that her pain is intolerable.

This last point is connected with a second ethical worry. Even if pain seems to be measurable, and it seems fairly clear that neonates can experience pain, the idea of babies’ suffering is complicated. According to Eric Cassel, suffering is “the state of severe distress associated with events that threaten the intactness of the person” (Cassell 1982). It is awareness of the disintegration, or the danger of disintegration, of one’s sense of self. According to this definition, infants cannot suffer, as they do not yet have a sense of self.

However, there is a perfectly ordinary sense of the word in which one can suffer pain—just as one can suffer humiliation, cold, fools gladly, or the consequences. Babies, being babies, are severely limited in the range of things they can suffer, but they can certainly suffer from pain, air hunger, restricted mobility, and perhaps also isolation and fear. In this article, we use *suffering* in its more extended sense rather than in Cassell’s restricted sense of the term.

Third, the experiential framework of the developing infant is not static—it extends into the future. The question, therefore, is whether we are to take into account only the neonate’s current suffering, or whether we also have a reason to withhold or withdraw treatment if the infant is not suffering now but later will surely suffer unbearably, as can happen, for example, to babies born with necrotic bowel syndrome. Is it humane to keep such a baby alive until it begins to experience treatment as an intolerable burden? Because newborns lack subjectivity and self-awareness, they can have no conception of their future wellbeing, although their current state might be something they care about. So the decision whether to subject them to future unbearable suffering must be made by those who care for them.

On the line of argument we favor, any human being capable of expressing hunger, alertness, or some other mental state can and should be held in personhood—the special moral status we reserve for entities of our kind—by being treated the way we treat persons as opposed to the way we treat pets, plants, or inanimate objects (Lindemann 2002). But we also think that personhood admits of degrees. We contend that while extremely premature neonates are persons, and therefore cannot, for example, be killed merely for others’ convenience, their hold on life is of such a short duration and so tenuous that they cannot properly be said to be persons in the fullest sense. Indeed, it takes interaction with many other persons over the first two years of life for even healthy children to participate completely in the human practice of personhood; before that, they depend on others to hold them in that status. This is not to imply that some persons are better than others or morally more valuable. Rather, it means that some persons have less at stake in their lives than others do, because they have only just started to live them.

### Whose Interests?

Another question to be considered in end-of-life decision-making is, *whose* interests count? Parents are ordinarily the initiators and major contributors to the long process by which their children attain selfhood, enveloping their children with their own sense of what matters and what does not, what one must do, what is forbidden, what is admirable, and in general, how life is to be lived. The parental selves are the closest thing the newborn has to a self of its own. When parents make decisions about the treatment of babies who are very badly damaged, then, they do not and should not decide on the basis of some impersonal and impartial best-interests standard. They do it out of the relationship that holds this particular baby inside the value structure of these particular parents. This could be the basis for an argument that the parents—at least, if they are decent, engaged, and loving parents—have the greatest authority to decide about the infant’s quality of life. But parents are not the only players here. The physicians and other health care professionals involved in the care of the infant are also moral agents, and their knowledge and experience of end-of-life care generally surpasses that of the parents. If the parents have unrealistic expectations or make morally dubious demands on the staff, their authority to decide what should be done is diminished, and the health care professionals should base their decisions on the interests of the child.

### The Groningen Protocol

Especially relevant to quality-of-life discussions regarding newborns is the Groningen Protocol, which lays out the conditions for legally tolerated infanticide in The Netherlands. The protocol allows doctors, at parental request, to kill neonates if they are experiencing unbearable suffering. This form of infanticide can be distinguished from the active withdrawal of life-sustaining medical care (an intentional act, often referred to as an omission, that kills), which is a standard part of the care of newborns with severe disability and suffering in the U.K., the U.S., the rest of Europe, and nearly all of the world, and which is sometimes called passive euthanasia.

To explain the practice the protocol governs, it is important to draw distinctions among categories of newborns for whom euthanasia might be ethically justified. Eduard Verhagen and Pieter Sauer, the two pediatricians at the University Medical Center in Groningen most intimately involved in developing and publicizing the protocol, distinguish three groups.

Group 1 consists of newborns with no chance of survival. Typically, they have a fatal disease such as severe lung or kidney hypoplasia (the organ is badly underdeveloped), and can only live for one or two days. They are put on life support immediately after birth while their physicians determine the extent of the damage. Once it is clear that treatment is useless, life support is removed. However, if the baby does not die immediately, the doctors may feel they should intervene directly to end the infant’s life. Because infants belonging to group 1 cannot live very long no matter what, the decision concerns only the time of dying, not whether it is better for the newborn to die. They will die soon in any case. For that reason, no quality-of-life judgments are needed for this group.

Group 2 comprises neonates who “may survive after a period of intensive treatment, but expectations regarding their future condition are very grim” (Verhagen and Sauer 2005b: 959). This category includes infants with severe brain abnormalities or extensive

organ damage caused by lack of oxygen. The dilemma for professionals is whether such an infant is so badly off that death is preferable. If neither withholding nor withdrawing intensive treatment will end the infant's life quickly, many Dutch physicians would feel compelled to intervene directly and kill the infant. In the U.S. this would count as a serious breach of medical ethics, as it also would in the U.K. The Nuffield Council makes it very clear that "the active ending of neonatal life even when that life is 'intolerable' is rejected" (Nuffield Council on Bioethics 2006: 20). But in The Netherlands, there seems to be moral room for this option, perhaps because physicians there feel that, having subjected the neonate to intensive medical treatment, they are responsible for extricating it from its present predicament. The end-of-life decision for a group 2 baby is not merely about *when* death should occur, as it is for babies in group 1, but also about the infant's quality of life: Would this baby be better off dead than forced to endure the only kind of life it can ever have?

While actively ending the life of group 2 babies is not morally countenanced in most countries, from the Dutch point of view the controversy centers on group 3. This group is made up of babies with an extremely poor prognosis "who do not depend on technology for physiologic stability and whose suffering is severe, sustained, and cannot be alleviated" (Verhagen and Sauer 2005a: 736). These infants are not and never were dependent on intensive medical treatment. In fact, with proper care, some of them can survive for many years, even into adulthood. A prime example would be a baby with epidermolysis bullosa, which, at its most severe, covers the entire body with fluid-filled blisters, creating continual scarring that fuses the fingers and toes as well as making it terribly difficult to swallow. Progressive paralysis, permanent inability to communicate in any way, and complete lifelong dependency might be other examples of conditions severe enough to put a baby in this group.

Although the decision for group 3 has given rise to the most controversy, the Groningen Protocol, developed in 2002, is applicable to all three groups. It consists of two sections, one setting out the conditions necessary for euthanasia to be performed in a responsible manner, and the other detailing the kinds of records that should be kept "to clarify the decision and facilitate assessment" (Verhagen and Sauer 2005a: 738). The committee that created this standard borrowed heavily from the "due care" criteria that in The Netherlands serve as moral and legal safeguards for physicians who perform active voluntary euthanasia on adults, but they also relied on previous court decisions in which doctors were acquitted in two cases: One dealt with a newborn who had an extreme form of spina bifida (a neural tube defect in which the fetal spinal column fails to close in the first month of pregnancy, causing nerve damage and permanent disability) and the other a severe trisomy 13 (a disorder in which a baby's extra genetic material interferes with normal development, causing over 80 percent of those who have it to die within the first year). Despite the palliative care these infants received, they endured intense suffering that ended only when doctors gave them lethal drugs. "The courts accepted," wrote Verhagen and Sauer, "that the physicians had to choose between the duty to retain life (and accept the severe suffering) and the duty to limit the suffering (and end the life of the child). They considered the choice to end the life of the infants justified because there was no alternative" (Verhagen and Sauer 2005a: 738). Strictly speaking, of course, there was an alternative—to let the child suffer—but the physicians clearly thought it was morally unacceptable. In both court cases, the decision to end life was made only after the decision to withdraw all other medical treatments had been made.

According to the Groningen Protocol, direct physician killing of a neonate is legally justifiable only under these conditions: (1) The diagnosis and prognosis must be certain; (2) hopeless and unbearable suffering must be present; (3) the diagnosis, prognosis, and unbearable suffering must be confirmed by at least one independent doctor; (4) the parents must give informed consent; (5) the procedure must be performed in accordance with the accepted medical standard. The diagnosis, decision to end the baby's life, consultation, and implementation must be fully documented; after the death, similar documentation must include the coroner's findings, how the death was reported to the prosecutor's office, how the parents are being counseled and supported, the case review, postmortem examination, and genetic counseling.

### Problems with the Groningen Protocol

The publication of the protocol in the English-language press in 2005 created a small uproar. The criticisms—which were not so much of the protocol itself as of its complicity in countenancing non-voluntary euthanasia in a highly vulnerable patient population—can be divided roughly into two sets of claims: That infanticide is wrong, and that end-of-life decisions should never be based on judgments of another person's quality of life. It was claimed, for example, that the protocol allows parents to commit infanticide as a way of escaping the responsibility to give their child burdensome care (Chervenak et al. 2006). Quality-of-life concerns included the accusation that the protocol permits doctors to make judgments of what kind of life is acceptable, and that it targets mainly neonates with spina bifida, even though such children often have quite a decent quality of life (Chervenak et al. 2006; Curlin 2005). In addition, the criteria for determining quality of life were criticized as incoherent because they included “unbearable suffering,” even though newborns cannot suffer (Chervenak et al. 2006; Jotkowitz and Glick 2006). Other charges were that the protocol fails to distinguish with clinical precision between neonates who will surely die and those who could continue to live (Chervenak et al. 2006), and that it leaves “doctors alone determining the morality of their actions” (Jotkowitz and Glick 2006: 157).

Here we focus on the quality-of-life criticisms. The protocol requires that “hopeless and unbearable suffering” be present, but hopelessness worries some critics of the protocol because it seems far too subjective for ending the life of another human being. Jack's reason for losing hope might be Jill's reason to press on; what seems hopeless to him may encourage her not to give up. We believe that the brunt of this criticism can be deflected by considering the Dutch word from which the English one was translated. That word is *uitzichtloos*, which literally means “outlook-less,” or, in better English, “without prospect.” While not all are hopeful who have reason to hope, and some continue to hope against all reason, agreement can be reached concerning a baby's prospects for improvement. It is true that the determination that there is no prospect is a judgment, not a self-evident fact, but it is a judgment that will have been based on clinical data and medical expertise, and it will have been confirmed by a second, independent opinion.

The harder quality-of-life judgment to establish is that of *unbearable suffering*. How can Jack know what Jill cannot bear unless she tells him, and if she is a newborn baby, how can she tell him? And then, what is it she cannot bear? Pain? Total lifelong dependency? Lack of any capacity for communication? Progressive paralysis resulting in total immobility? She might find in retrospect that she can, after all, bear what in prospect



seemed so unbearable. And while some have collapsed under the slightest burden, others have borne a very great deal indeed. In the face of all these considerations, surely some argue that none of us has the right to judge another's quality of life.

But quality-of-life judgments for others cannot be evaded—we make them all the time. The routine use of life-sustaining technologies requires that comparative judgments be made as to whether the quality of life the technologies sustain is good enough to be continued. It is one of the harsh realities of twenty-first-century medicine that these judgments must be made. There is something disingenuous about pretending that we do not already make them, not only for competent adults but also for newborn babies.

### After the Upheaval

While the Dutch euthanasia law was passed in 2001, exempting from prosecution doctors who followed the “due care” criteria for administering euthanasia to competent adults, the government was reluctant to extend the same exemption in cases of non-voluntary euthanasia. However, because of the international attention the Groningen Protocol attracted in 2005, the government decided to keep the direct killing of newborns illegal but to set up a review committee similar to the ones that already reviewed cases of voluntary adult euthanasia. It was expected that several cases would be reported annually. To date, however, it appears that only one case has been brought to the review committee's attention (Buiting et al. 2010).

While there may be a number of explanations for this, the most plausible is that the introduction in 2006 of ultrasound at 20 weeks' gestation has probably resulted in higher detection rates of congenital abnormalities, which seems to have led to more such fetuses being aborted. The fact that the number of abortions per 1000 live births is still rising in The Netherlands supports this assumption (Buiting et al. 2010). We note in passing that the decision to abort for these reasons is no more exempt from quality-of-life judgments than are end-of-life decisions for neonates.

### The Role of Culture

It could be argued that active physician intervention to end the lives of profoundly damaged neonates is ethically permissible, if at all, only in a culture whose institutions and practices are morally sound. It matters, for example, that Dutch people enjoy a fairly robust social safety net, including universal access to health care. Possibly as a result of this, they are much more inclined to trust their health care system, and their own doctors, than are people in, say, the U.S. Moreover, since there is good reason to suspect that physicians everywhere occasionally feel compelled to end an infant's dreadful suffering even if they must do so surreptitiously, the Dutch attempt at transparency and accountability here might strike skeptics as admirable. In these and other ways, the ethical permissibility of direct physician killing of severely damaged neonates can be relativized to specific cultures (Lindemann and Verkerk 2008; for another view, see Swinton and Lantos 2010). Not every society, then, should permit physicians directly to hasten the death of its most severely afflicted infants. Even within a particular society, there may be a number of different hospital cultures, not all of them, perhaps, morally suited to this extreme measure for ending the worst neonatal suffering.

### Palliative Care for Neonates

As a result of the Groningen Protocol there has been an increased awareness in The Netherlands of the importance of palliative care for neonates. According to the World Health Organization:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

(World Health Organization 2001)

Yet while palliative and hospice care are well recognized options for adult patients (even if, in practice, patients do not always receive this care when it would do the most good), health care professionals have been slow to adopt palliative measures for the pediatric population (Romesberg 2007). As with adults, its use for children and neonates encompasses the care of families.

In June 2013, the Royal Dutch Medical Association (RDMA) issued a position paper on end-of-life decisions for newborns. In this paper they stress the idea that end-of-life decisions for neonates should be made within the context of palliative care, a form of caregiving that is a process that unfolds over time. The decision to end the baby's life should therefore not be considered in isolation, but as one that takes its shape and meaning from the ongoing process of giving care when an infant is desperately ill.

Most end-of-life decisions start with decisions about withholding or withdrawing treatment, but it is important that parents realize what will happen after that. Sometimes the dying process will take time—often more time than the family imagined. Sometimes the baby experiences discomfort or pain. When that happens, palliative sedation or muscle relaxants can be an option. Interestingly, the RDMA suggests that when the dying process is a lengthy one, muscle relaxants may be given to hasten death, not so much to end the baby's discomfort as to ease the distress of the parents who are witnessing it. Here the ethos of palliative care is particularly visible, as the ambit of care extends beyond the neonatal patient to the suffering family.

Palliative care requires great skill, sensitivity, and compassion, imposing obligations regarding both decision-making and caregiving on the professional staff. Obligations in decision-making include communicating clearly with parents and other health team members and engaging in fully shared decision-making with parents. Obligations in caregiving include providing options, preparing parents, being with, advocating, creating peace and normalcy, and providing comfort (Epstein 2010: 582–5).

Unfortunately, most doctors and nurses working in NICUs are not required to learn how to give palliative care and have severely limited access to caregivers who are specially trained in such care (Nuffield Council on Bioethics 2006). This needs to change. Good empirical research on the effect of palliative sedation, muscle relaxants, and other palliative measures on neonates is also badly needed, as is a neonatal ethics that specifically includes an important role for families. If NICUs are to divest themselves of the moral ambiguity that currently characterizes them, they must do a better job of not merely saving babies' lives, but also abiding with, comforting, and caring for the suffering ones who cannot or should not be saved.

## Related Topics

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- Chapter 36, "From the Persistent Vegetative State to the Minimally Conscious State: Ethical Implications of Disorders of Consciousness," Joseph J. Fins  
 Chapter 37, "Disability and Assisted Death," Leslie P. Francis and Anita Silvers

## Bibliography

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- Arras, J.D. (1987) "Quality of Life in Neonatal Ethics: Beyond Denial and Evasion," in W. Weil and M. Benjamin (eds.) *Ethical Issues at the Outset of Life*, Boston, MA: Blackwell Scientific Publications, pp. 151–86.
- Baron, J. and Ritov, I. (2004) "Omission Bias, Individual Differences and Normality," *Organic Behavior in Humans Dec Proc* 94: 74–85.
- Belliemi, C. (2005) "Pain Definitions Revised: Newborns Not Only Feel Pain, They Also Suffer," *Ethics and Medicine: An International Journal of Bioethics* 21 (1): 5–9.
- Belliemi, C., Bagnoli, F. and Buonocore, G. (2003) "Alone No More: Pain in Premature Children," *Ethics and Medicine: An International Journal of Bioethics* 19 (1): 5–10.
- Buiting, H.M., Karelse, M.A.C., Brouwers, H.A.A., Onwuteaka-Philipsen, B.D., van der Heide, A. and van Delden, J.J.M. (2010) "Dutch Experience of Monitoring Active Ending of Life for Newborns," *Journal of Medical Ethics* 36 (4): 234–7.
- Cassell, E. (1982) "The Nature of Suffering and the Goals of Medicine," *New England Journal of Medicine* 306: 639–45.
- Chervenak, F.A., McCullough, L.B. and Arabin, B. (2006) "Why the Groningen Protocol Should Be Rejected," *Hastings Center Report* 36 (5): 30–3.
- Curlin, F.A. (2005) "Letter to the Editor," *New England Journal of Medicine* 352: 2354.
- DeGrazia, D. (2008) "Moral Status as a Matter of Degree," *Southern Journal of Philosophy* 46 (2): 181–98.
- Epstein, E.G. (2010) "Moral Obligations of Nurses and Physicians in Neonatal End-of-Life Care," *Nursing Ethics: An International Journal for Health Care Professionals* 17 (5): 577–89.
- Fabrizi, L., Slater, R., Worley, A., Meek, J., Boyd, S., Olhede, S. et al. (2011) "Shift in Sensory Processing that Enables the Developing Human Brain to Discriminate Touch from Pain," *Current Biology* 21: 1552–8.
- Janvier, A., Bauer, K.L. and Lantos, J.D. (2007) "Are Newborns Morally Different from Older Children?" *Theoretical Medicine and Bioethics: Philosophy of Medical Research and Practice* 28 (5): 413–25.
- Jotkowitz, A.B. and Glick, S. (2006) "The Groningen Protocol: Another Perspective," *Journal of Medical Ethics* 32: 157–8.
- King, N.M.P. (1992) "Transparency in Neonatal Intensive Care," *Hastings Center Report* 22 (2): 18–25.
- Kipnis, K. (2007) "Harm and Uncertainty in Newborn Intensive Care," *Theoretical Medicine and Bioethics: Philosophy of Medical Research and Practice* 28 (5): 393–412.
- Kluge, E.W. (2009) "Quality-of-Life Considerations in Substitute Decision-Making for Severely Disabled Neonates: The Problem of Developing Awareness," *Theoretical Medicine and Bioethics: Philosophy of Medical Research and Practice* 30 (5): 351–66.
- Kordes-de Vaal, J.H. (1996) "Intention and the Omission Bias: Omissions Perceived as Nondecisions," *Acta Psychologica (Amst)* 93: 161–72.
- Lagercrantz, H. (2007) "The Emergence of the Mind: A Borderline of Human Viability?" *Acta Paediatrica* 96: 327–8.
- Lantos, J. and Meadow, W. (2008) *Neonatal Bioethics: The Moral Challenges of Medical Innovation*, Baltimore, MD: Johns Hopkins University Press.
- Lindemann, H. (2002) "What Child Is This?" *Hastings Center Report* 32 (6): 29–38.
- Lindemann, H. and Verkerk, M.A. (2008) "Ending the Life of a Newborn: The Groningen Protocol," *Hastings Center Report* 38 (1): 42–51.
- McDougall, R.J. and Notini, L. (2014) "Overriding Parents' Medical Decisions for Their Children: A Systematic Review of Normative Literature," *Journal of Medical Ethics* 40: 448–52.
- McMahan, J. (2002) *The Ethics of Killing: Problems at the Margins of Life*, New York: Oxford University Press.
- Nuffield Council on Bioethics (2006) "Critical Care Decisions in Fetal and Neonatal Medicine," November. Available at: <http://nuffieldbioethics.org/project/neonatal-medicine/> (accessed August 22, 2014).
- RDMA (2013) "KNMG-standpunt Medische beslissingen rond het levenseinde bij pasgeborenen met zeer ernstige afwijkingen, Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst."
- Romesberg, T.L. (2007) "Building a Case for Neonatal Palliative Care," *Neonatal Network: The Journal of Neonatal Nursing* 26 (2): 111–15.

- Ross, L.F. (2007) "The Moral Status of the Newborn and Its Implications for Medical Decision Making," *Theoretical Medicine and Bioethics: Philosophy of Medical Research and Practice* 28 (5): 349–55.
- Scully, J.L. (2008) *Disability Bioethics: Moral Bodies, Moral Difference*, Lanham, MD: Rowman and Littlefield.
- Sulmasy, D.P. and Sugarman, J. (1994) "Are Withholding and Withdrawing Therapy Always Morally Equivalent?" *Journal of Medical Ethics* 20: 218–22; discussion 23–4.
- Swinton, C.H. and Lantos, J.D. (2010) "Current Empirical Research in Neonatal Bioethics," *Acta Paediatrica* 99 (12): 1773–81.
- Verhagen, A.A., Dorscheidt, J.H., Engels, B., Hubben, J.H. and Sauer, P.J. (2009) "End-of-Life Decisions in Dutch Neonatal Intensive Care Units," *Archives of Pediatric and Adolescent Medicine* 163: 895–901.
- Verhagen, E. and Sauer, P.J. (2005a) "End-of-Life Decisions in Newborns: An Approach from the Netherlands," *Pediatrics* 116: 736–9.
- Verhagen, E. and Sauer, P.J. (2005b) "The Groningen Protocol: Euthanasia in Severely Ill Newborns," *New England Journal of Medicine* 352: 959–62.
- Verkerk, M.A. and Lindemann, H. (2008) "Epilogue: Naturalized Bioethics in Practice," in H. Lindemann, M.A. Verkerk and M. Walker (eds.) *Naturalized Bioethics: Toward Responsible Knowing and Practice*, New York: Cambridge University Press.
- Walker, M. (1998) *Moral Understandings: A Feminist Study in Ethics*, New York: Routledge.
- Wilkinson, D.J. (2011) "A Life Worth Giving? The Threshold for Permissible Withdrawal of Life Support from Disabled Newborn Infants," *American Journal of Bioethics* 11 (2): 20–32.
- Wilkinson, D.J. (2013) "Which Newborn Infants Are Too Expensive to Treat? Camosy and Rationing in Intensive Care," *Journal of Medical Ethics* 39: 502–6.
- Wilkinson, D.J. and Savulescu, J. (2014) "A Costly Separation Between Withdrawing and Withholding Treatment in Intensive Care," *Bioethics* 28: 127–37.
- World Health Organization (2001) "WHO Definition of Palliative Care." Available at: <http://www.who.int/cancer/palliative/definition/en/> (accessed August 2, 2014).