

Comforting the Parents by Administering Neuromuscular Blockers to the Dying Child: A Conflict Between Ethics and Law?

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ABSTRACT *When the decision has been made to stop treatment of a newborn child with a bad prognosis, the child usually dies in a short time. Sometimes, however, gasping occurs, and although it is usually thought that this is not a sign of suffering, the parents can hardly fail to interpret it as such. Could that be a reason to administer muscle relaxants to the child? It would not harm the child and may greatly benefit the parents. So it seems the humane thing to do.*

Legally, however, the action would count as killing, and the prohibition of killing normally implies a denial of the authority to decide on exceptions, which should be understood as a protection of public trust.

I discuss three ways of arguing why the law, nevertheless, should allow for an exception in this case. The discussion identifies and describes this kind of conflict, and shows how to evaluate proposals for solving it, using a particularly clear exemplary case by way of illustration.

1. The Special and the General Problem

When the decision has been made to stop treatment of a newborn child with a bad prognosis, the child usually dies in a short time. Sometimes, however, gasping occurs, and although it is usually thought that this is not a sign of suffering, the parents can hardly fail to interpret it as such. Could that be a reason to administer muscle relaxants to the child? It would not harm the child and may greatly benefit the parents. So it seems the humane thing to do.

Legally, however, the action would count as killing, and the prohibition of killing normally implies a denial of the authority to decide on exceptions. Because such denials protect public trust, there is a moral reason to respect such laws. Therefore what looks like a conflict between ethics and law is really a conflict between two sets of moral considerations.

The conflict could be solved if a justification were provided for allowing an exception in this special case. I will evaluate some justifications that have been proposed. The discussion is meant to identify and describe this kind of conflict, and to show how to evaluate proposals for solving it, using a particularly clear exemplary case by way of illustration.

2. The Issue in its Neonatal Context

The decision to treat a very prematurely-born child or a child born with severe congenital anomalies or asphyxia is a decision made in uncertainty, and sometimes the

subsequent developments are such that it becomes clear that it is better for the child to allow it to die in peace. In the Netherlands, for example, the decision to withdraw or to withhold treatment from newborn children is being made about 600 times a year.¹ In almost all cases this means turning off the ventilator and removing the endotracheal tube.

Normally palliative medication is then increased in order to prevent suffering, in particular from dyspnoea, restlessness and discomfort.² Possible side-effects of this increase (e.g. hypotension and respiratory depression) are at this point accepted, because they no longer interfere with treatment goals.³ The child is placed in the arms of its parents, and it usually dies within a few minutes.⁴ In a substantial number of cases, however, gasping occurs, and even if the parents have been informed about the phenomenon, its cause and its meaning, it is almost impossible for them to suspend their belief that the child is suffering.⁵ In that case the doctors will often administer muscle relaxants to the child, with the result that gasping stops and the child dies. Neuromuscular blockers are being used in 16% of all cases.⁶

This includes a small and decreasing number of cases in which muscular relaxants had already been used during the period of controlled ventilation and continuation of this use is deemed necessary in order to prevent additional suffering. In these cases some authors recommend allowing time for the effects of those agents to wear off before treatment is stopped.⁷ I cannot consider this issue here; my discussion will only concern the cases in which the aim of the neuromuscular blockade is to stop gasping.

From the discussion about the practice in medical journals we know that the practice is not unknown in the United States and elsewhere, but we hardly know anything about the scope of its occurrence.⁸ In one Belgian NICU the child is only given into the arms of its parents after it has died; before that moment it is waiting in a separate room. But because the doctors do not want to prolong this waiting time, they will also occasionally use muscle relaxants to speed up dying.⁹

Gasping is a normal phenomenon in all dying patients. It is the result of a beginning failure of the respiratory function, and hence by itself not a sign of suffering. One could imagine, however, that the underlying malfunction of the lower brainstem *causes* suffering, in particular an experience of suffocation. In that case gasping would be an indirect indicator of suffering. But at the stage of profound hypoxaemia which is also indicated to exist by the very phenomenon of gasping, it is unlikely that the dying person has any remnants of consciousness. If she has, we should expect her to show other signs of suffering; in the case of a dying child, for example, balled up fists, grimaces and cry movements. Such suffering could normally be alleviated by the use of analgesics or sedatives. The standard view therefore is that gasping by itself is not a proper indication for the use of muscle relaxants. And from the descriptions we have of the practice it seems clear that the actual aim of this use, with the one exception I noted, is not to alleviate any supposed suffering of the dying person, but to relieve or prevent the distress of her relatives; in the case of a newborn, her parents.¹⁰

3. Assessing the Issue from an Ethical and a Legal Perspective

If we consider the practice in terms of the interests of the people directly affected by it, it is hard to object to it. Even in the case of a completely healthy child it will hardly make

any difference to its interests whether it dies, e.g. as the result of an accident, some minutes or even hours earlier or later, and the same is true in the case of almost any dying person who is no longer conscious. We usually even hope that the process will be as short as possible. The child is therefore not being harmed at all by the neuromuscular blockade.¹¹ However, it is very important to the parents, who have already gone through a dramatic and traumatising period of loss, that this last intimate moment is not marred by a perception of suffering. This may make a great deal of difference to the way in which they remember that hour for the rest of their lives. In this perspective hastening the child's death clearly and simply seems the humane thing to do. You don't have to be a consequentialist to agree with that judgment: it would also be subscribed to by people in an Original Position who do not know whether in real life they will end up in the position of either the child or the parents.

However, if we look at the decision from the point of view of the law, the picture is very different. To begin with, using muscle relaxants in this way determines the exact moment at which the child dies, and therefore amounts to killing.¹² In all countries the law knows a medical exception to the prohibition of killing: if there is a medical justification for a certain treatment, for example that it alleviates or prevents suffering, a doctor is allowed to proceed, even if he knows or suspects that the patient's death will thereby be hastened, provided only that he satisfies a requirement of proportionality. In such cases the medical action will legally not be considered to be killing, and the death of the patient will be classified as a 'natural' one, even if it would not have occurred at that time but for the doctor's action. This could be called a doctrine of double effect, but it should be noted that, as I have stated it, it differs from the ethical principle usually referred to by that name, because on this doctrine the law in such cases is not interested in the intention of the doctor, but only in the availability of a medical justification.¹³ But if no such justification can be provided, we cannot avoid counting the action as killing.

In that case, present Dutch law is unique in the world by sometimes still allowing the doctor a legal defence.¹⁴ He can appeal to the justifying ground of necessity, interpreted as a conflict of duties. But the only duty which in the present state of the law can possibly weigh on the duty not to kill is the doctor's professional duty to prevent further suffering of the patient. Therefore, according to the Guideline for Prosecutorial Decision-making concerning termination of life without a request (2007), the only allowable aim is to end present unbearable suffering without a prospect of improving. But, as we have seen, gasping by itself isn't supposed to be a sign of suffering, and therefore the defence of necessity will not be available when muscle relaxants are being administered to stop it.¹⁵ If such a case comes to court, at this moment it seems inevitable that even a Dutch court will convict the doctor, even if it will also pay homage to his good intentions and punish him very leniently, if at all.¹⁶

4. The Ethical Credentials of the Law

So we seem to have a conflict between ethics and the law. We could respond to that conflict by saying with Mr Bumble, commenting on the legal view that he was the Head of his wife, that the law is an ass and an idiot.¹⁷ If the law forbids you to do the humane thing, you should not necessarily be very much impressed by its authority.

That response, however, would be too quick, for the law might have moral credentials of its own, by taking into account other legitimate concerns than only those of the baby and its parents. For many people this is even self-evident, for on their view ‘Thou shalt not kill’ is a basic moral datum which is not in need of any further argument. However, as soon as we start making the prohibition more precise, the sense of self-evidence quickly disappears. What is usually said to be forbidden is not all killing, but killing the ‘innocent’, which in this context is an almost technical term. More importantly, killing is not always forbidden: there are cases in which the foreseeable effect of an action is someone’s death, but this is allowed because that effect is not intended. However, that judgment, in its turn, also has to be qualified: a criterion of proportionality requires the intended effect to weigh up, in a way which is rarely spelled out, against the merely foreseeable one. At the end of this series of qualifications it is no longer plausible to hold that the doctrine as a whole is not in need of some kind of argument. This is not the place to discuss the arguments which have been suggested.¹⁸ Rather, what I propose to do is to look at some considerations which are characteristic of the broader moral perspective of the law, which might even to some extent explain or at least confirm our absolutist (or quasi-absolutist) intuitions.

As generally conceived ethics is concerned with answering the question: what should I do on the balance of reasons, prominently including moral ones? The law, however, understood in a broad sense to include authoritative conventions and professional guidelines, is concerned with another moral question: what can we legitimately expect each other to do and not to do? On this second level, which I will call the level of regulation, it is possible that we are not even *empowered* to do what we should do on the balance of reasons, for example because we don’t sufficiently trust each other to make correct judgements of that balance.¹⁹ Regulatory norms may be ‘entrenched’, to use a helpful concept introduced by Frederick Schauer: they may protect some of our interests by forbidding other people to balance those interests against others.²⁰ The question addressed by such norms does not concern the right decision, but rather the authority to make certain decisions at all, and possibly the range of reasons to take into account in making them. These norms may be justified by the *external* effects of such choices, i.e. the effects on people who are not directly affected by them and normally will not be intentionally considered in deciding upon them.

In his classical book *Tun und Unterlassen* Dieter Birnbacher discusses the old question whether, all other things being equal, there is any morally relevant difference between action and omission.²¹ One quality of his discussion is that he explicitly addresses the issue of regulation. Even on that level his general conclusion is that there is no morally relevant difference between action and omission. Whether or not one considers his arguments fully convincing, the interesting point in the present context is that even Birnbacher recognises an exception to his general conclusion. It is more important for us that killing rather than that letting die is being prohibited, because we experience our vulnerability to people’s ill will as more threatening than our dependence on their good will.²² Killing is more often the expression of an aggressive motive, directed against the victim, and not only of indifference to his fate. We tend to resign ourselves more easily to the outcomes of even preventable natural disasters than of intentional human intervention; our emotional responses — sadness rather than resentment — to such events are weaker, and the subversion of our trust is less. For such reasons torture is a much greater evil than a preventable accident or illness which causes the same amount of pain and

suffering. Finally, the opportunity to implement an aggressive intention by letting the victim die is normally fairly rare, but the would-be killer often can take the initiative himself.

For such reasons the prohibition of killing is a particularly clear example of an entrenched norm. As I suggested, this may to some extent explain our (quasi-) absolutist intuitions. In particular it explains why, even in a legal system in which doctors are allowed to kill under certain strict conditions, the conditions normally will only refer to the interests of the patient, not of others.

Considerations similar to these have often been appealed to in justifying the so-called dead donor rule.²³ If organs could be taken from people from the moment on that an irreversible phasing out of the vital functions starts, and if the actual moment of their death could be adapted to the requirements of optimal organ procurement, more *post mortem* organs and of better quality would be available for transplantation. Deep sedation could assure that the dying person is fully unconscious, and in that case she would not herself be harmed by the procedure in any way. The nephrologists themselves, however, are always the first ones to reject any suggestion of that kind, for they are all too aware of suspicions which already exist at present that they are too keen to acquire organs. Even the very concept of brain death is still widely perceived as a doctor's trick to facilitate body-snatching.

The proposal to allow the use of muscle relaxants to prevent gasping is obviously close to the proposal to relax the dead donor rule. But the proposals differ from each other in one important respect: the beneficiaries of the first proposal are the parents of the patient, but of the second they are 'strangers'. The practice of organ donation itself shows that people are much more willing to accommodate the interests of relatives than of strangers. Because of such differences we have to assess each example of entrenchment on its own merits. Even if we accept that the entrenched character of law in some area requires a certain rigidity in order to protect public trust, we should not too quickly be prepared to sacrifice real human interests to that aim.

So on the one hand I agree that on the level of regulation the proper question is not whether a sound distinction can be made between morally justified and unjustified applications of a rule, but rather how likely it is that the distinction will generally be recognised and respected.²⁴ But on the other hand we should not allow this perspective to provide an immunisation of the status quo to all criticism. Considering this, the question we should ask about muscular blockades in the case of gasping should be the following. Is it possible to design a system of legal rules which on the one hand allows us to do the humane thing, as regards the baby and its parents, and on the other minimises the risks of the erosion of public trust?

In discussing this question I will put aside proposals for radical changes in the conceptual foundations of the law, for example by generally abrogating the difference between killing and letting die, changing the definition of death, or restricting the category of human beings with full legal standing to exclude newborns. I will consider three possible answers to my question.

5. Can the Practice be Justified by the Interests of the Patient?

The problem arises because the use of life-shortening medicine, in this case, is motivated by the interests of the parents. It would therefore be easier to solve if the treatment could

be shown to be in the possible interest of the child after all. It has been argued that, even if gasping by itself isn't a sign of suffering, and even if it is highly probable that the underlying respiratory pattern doesn't cause any suffering because the patient is already comatose, we cannot be fully sure about that. Hence we should allow doctors to err on the side of safety. To the obvious reply that we can always sedate the patient, it has been replied that we cannot be sure that sedatives are fully effective either.²⁵

If this argument succeeds, that might in the Dutch context enable the doctor to make a justifying appeal to necessity after all. His action could, however, still not be justified by an appeal to the medical exception, for the suffering of the child would only be reduced by accelerating his death, not by diminishing the severity of his supposed distress.²⁶ In other jurisdictions it would therefore still be illegal.

I must confess to a certain initial dislike of this argument because of its apparent disingenuity: as I already observed it seems clear that the actual aim doctors have in mind in administering muscle relaxants is not to prevent any possible suffering of the patient but rather the predictable distress of the relatives; in the case of newborns, the parents. But, as we have seen, according to a prominent although not fully undisputed view, the law isn't interested in the intentions of doctors, but only in the availability of a justification of their actions. So we should inquire whether the justification succeeds, whatever the actual aims and hopes of the doctors involved.

If there would really be cause for the suspicion that the beginning failure of the respiratory function causes suffering to patients who do not give any signs of suffering, that would be a reason for sedating all dying patients, and if we cannot trust the effectiveness of sedation, that would be a reason to hasten the death of all dying patients by using euthanatics such as muscle relaxants. We should also distrust many if not all kinds of anaesthesia. I consider this a *reductio ad absurdum* of the argument. Our practices are generally built on the assumption that, unless all voluntary movement of muscles is paralyzed as in the locked-in syndrome, suffering will always manifest itself by outward signs.

Couldn't it be argued that even if the argument cannot succeed in the case of dying adults, it could succeed in the case of dying newborns? For it is still somewhat more difficult to recognise the outward signs of suffering in newborns; remember that only recently it was thought that newborns could not experience any pain at all. Moreover, we are still also less sure about the effects of the use of analgesics and sedatives in newborns.²⁷ But even if such an argument could still have some plausibility at present, which I doubt, it depends too much on our present ignorance to be very promising. Research on measuring pain in newborns and on the effects of sedation is ongoing, so the argument could still fail any day. If, on the other hand, we are tempted to doubt whether empirical findings can ever conclusively show which mental phenomena correspond to them, we should remind ourselves of the general assumption on which our practices are built. Even if we restrict our doubts to newborns we should still be consistent and be prepared to use muscle relaxants in addition to sedatives or analgesics in the palliative care of all dying children.

Even if these objections to the proposal could be put aside, a final decisive objection remains: the general argument supporting it is internally inconsistent. A Dutch or Belgian doctor is only permitted to use muscle relaxants in order to end a patient's life when he has first made sure by the use of sedatives that the patient is fully unconscious. Otherwise the patient might be aware to some extent of suffocating. But in that case

doubts about the effectiveness of sedation cannot be a good reason for using muscle relaxants: they will suppress *signs* of suffering but not necessarily prevent it, 'leaving the patient to endure the agony of suffocation in silence and isolation'.²⁸ It could be replied that it would only be for a very short time that the child would be suffering in this way before it dies. But a gasping child normally has also only a very limited remaining life-span. And time is not the only relevant dimension for measuring suffering.

6. Help-in-Dying

If this proposal fails, how could we justify making an exception to the entrenched prohibition on killing in the case of a gasping dying child? I will present two other proposals as they have been brought forward in the context of the Dutch debate. But I want to stress that neither of these proposals is logically dependent on the Dutch legal context, though we may at present realistically not expect them to have any chance of being adopted elsewhere.

Twenty years ago the first national survey of end-of-life decisions in the Netherlands found that in about a thousand cases a year doctors had ended the life of patients without their explicit consent.²⁹ The Rummelink Committee, which had to advise the government on policies in response to the findings, considering that almost all these cases concerned dying patients, proposed to create a special legal category of help-in-dying. After the failure of vital functions has become irreversible, doctors would then be allowed to hasten the end of the patient's life. In doing so they would only fix the exact time of an event which could occur at any moment anyway.

According to the Rummelink Committee's proposal help-in-dying would be considered normal medical practice. Hence there would be no requirement of reporting it to any legal authorities. The proposal was not well received by the Dutch parliament, and we haven't heard of it since. But John Griffiths has suggested that a similar approach can be discovered in the judgments of the review committees which the Dutch euthanasia law (2002) has instituted in order to assess in each case of euthanasia or physician-assisted suicide whether the requirements of due care stipulated by the law have been satisfied. One of those requirements is that the patient should be in a state of unbearable suffering with no prospect of improvement. In some cases the 'unbearable suffering' is mainly considered to consist of loss of dignity, and Griffiths suspects that the real beneficiaries of the euthanasia in such cases are the relatives. Administering muscle relaxants to dying patients, including dying babies, in the case of gasping, could also be considered a case of such 'help-in-dying'. Hence, Griffiths suggests we reconsider the proposal of the Rummelink Committee.³⁰

By adopting it the use of muscle relaxants would be allowed in order to stop gasping, not only in the case of newborns but of all patients. It would also be allowed in order to shorten a prolonged dying process that is considered too burdensome for the family.

How should we evaluate this suggestion? Whether or not the pattern Griffiths perceived in the judgements of the review committees can actually be found there, concerns about the family are probably more important in doctors' deliberations about euthanasia requests than they acknowledge in their reports to the committees. This fits into a trend: it is by now fairly common for doctors to recognise a special duty of care to the relatives of their patients.³¹ This is particularly true of paediatricians.

However, it is by itself a revealing fact that doctors tend not to be very open about such concerns. From the beginning, the euthanasia review committees have been reluctant to recognise a patient's wish to avoid being a burden on his family as a major element of the 'unbearable suffering' which is a condition for granting a request for euthanasia. This reluctance should be seen as reflecting regulatory concerns. For the wish of the patient could be a sign of possible explicit or implicit pressure of the family on the patient, and it is one of the major tasks of the system of consultancy and review to check for this possibility. Not because such pressure actually occurs to the extent that many people, including foreign observers, assume it does: in almost 30 years of an increasingly transparent practice of euthanasia, including consultation and review, pressure of this kind has been observed only occasionally.³² But the system should nevertheless remain focused on preserving public trust, given the fact that such assumptions are fairly widespread. Probably for such reasons even the Rummelink Committee, in proposing the special category of help-in-dying, thought of the help as being exclusively provided to the patient.

The main problem with the proposal, however, is the following. What it amounts to is not to count any killing (at least by a physician) during the dying stage as killing in the legal sense, in the way in which killing by using morphine in an indicated dosage already doesn't count as such. But the concept of the 'dying stage' is highly indeterminate, and if we allow doctors to identify such a stage, we give them a kind of discretion of which the law is properly wary. This would certainly be the case if the law didn't require any check by consultants or review committees, as the Rummelink Committee proposed, but probably also if it did make such requirements. The vagueness of the concept of a dying stage cannot be remedied by merely procedural means. Allowing doctors such discretion would to some extent undermine the present regulation system and the guarantees it provides against intentional and unintentional deviations from the requirements of due care. I therefore doubt whether the proposal by itself satisfies the desideratum of the rigidity of the legal norms in this area to a sufficient extent.

If we want to introduce an exception to the prohibition of killing in order to solve our problem, we have to make it in a more clearly delineated way, on other grounds.

7. Living on Probation

At the beginning of the 1990s two reports appeared about end-of-life decisions concerning newborns, both initiated by professional organisations of doctors, which have largely determined the subsequent legal developments in the Netherlands.³³ Both these reports used a similar argumentative strategy, which, convincing though it is to my mind, unfortunately has not reappeared in later documents.³⁴ When an extremely premature child or a child with multiple pathologies has been born, traditional medical wisdom, as it has been expressed in the maxims '*primum non nocere*' and '*in dubio abstinere*' would provide strong reason for allowing it to die. For example, when children are born after a pregnancy of 24 weeks, the prognosis of survival until discharge from the hospital is 38%, and of severe long-term handicaps of survivors, according to different studies, 12–36%.³⁵ When doctors nevertheless decide to give the baby a chance, they initiate a beginning stage of life which should be considered a life-on-probation. They are only justified in doing so if they can guarantee that, if the prospects for the child to have a life

worth living turn out to be bleak, they can reverse their decision to let the baby live. The baby should never be the victim of that decision. It should therefore always be possible to apply '*in dubio abstinere*' retroactively, as John Griffiths puts it.³⁶

The main objection which has been made to this argument is that, if a decision one has responsibly made turns out to have miserable consequences, one is not responsible for eliminating these consequences by objectionable means.³⁷ That objection, however, overlooks the core of the argument: that in this case the decision *can* only responsibly be made if one can guarantee that miserable consequences will be prevented and that this is relevant for determining whether the means are objectionable. The objection is only cogent if it can point to independent and decisive reasons why doctors cannot give this guarantee of reversal. And in that case the objector should be prepared to conclude that much more restraint should be exercised in starting treatment of highly immature newborns.

If this reasoning is accepted, a consequence (which the two reports did not draw themselves) is that no distinction can be made between the justificatory grounds for withdrawal of treatment and for the active ending of the baby's life. For if such a distinction is being made, it is possible that, even when at the end of the 'probation period' our conclusion is that it would have been better for the child to have been allowed to die at birth, we cannot make good on our guarantee because the child by now is able to survive independently.

If the ventilator has been stopped and the tube been removed, and the baby is dying in the arms of its parents, it is in the dying stage because the medical team has acted on the special responsibility it had of *making sure* that it dies, not only on a judgment of so-called medical futility. But then we can leave it to the professional discretion of the doctors to identify the best mode of implementing that basic decision. Therefore, if the decision to stop treatment has been made on good grounds, there can be no independent objections to the decision to shorten the baby's life by the use of muscle relaxants.

Using them would not only be allowed in the case of gasping. If the exception on the prohibition of killing were justified in this way, that would solve another problem as well. Treatment is being stopped in two kinds of cases.³⁸ In cases of the first kind the child has no chance of surviving. In such cases, even if the child, having been taken off the ventilator, does not die immediately, we could wait for this to happen, providing the necessary palliative care in the meantime. In cases of the second kind, the child has a chance of survival, but the prognosis is deemed to be extremely poor. In deciding this, the relevant criteria, all deriving from the two reports I mentioned include: the burden of future treatment, the child's possibilities for communication in the future, its possibilities for living an independent life, and the degree of its dependency on continuing medical care.³⁹ But if the child after extubation turns out to be able to live independently, the only reason which at present can still justify a Dutch doctor in ending its life actively is actual severe suffering. These cases are extremely rare, if only because almost all children will still depend on artificial nourishment and hydration, but they probably exist. One other unfortunate consequence of this divergence of the criteria is that doctors sometimes feel they cannot prolong the 'probation time' until the moment that the prospects of the child are sufficiently clear: they have to use, while it exists, the window of opportunity for letting the child die. This problem would also be solved by making the two sets of criteria identical to each other.

By doing so the prohibition of killing would be suspended for one particular class of cases: newborn children in a dying stage initiated by the decision to stop an essentially conditional treatment. This class is so clearly delineated that the suspension should not evoke any rational or irrational fears. The exception is much more restricted than the exception universally made and accepted for palliative actions with life-shortening effects, and its delimitation is much clearer. Of course, this conclusion only follows if the criteria used for making the prior decision to stop treatment are themselves justifiable, sufficiently clear, and generally acceptable to the profession and the public.

One could wonder whether the exception is not too restricted. Gasping of course occurs in the case of dying adults as well as in the case of dying babies, and the relatives are prone to interpret it as a sign of suffering in that case as well. But the alternative policy of convincing them that, despite appearances, this is a misinterpretation seems to be more successful in that case. For that reason it seems defensible to restrict the exception we want to introduce in the law to the case of newborns. It remains to be seen whether and how this proposal can find legal recognition, even in the Netherlands.

In no other country can such developments be realistically expected at present, although the arguments supporting them have the same force everywhere. This means that the law will continue to forbid doctors categorically to do the humane thing, as regards the baby and its parents. I have argued that this prohibition has its own moral *rationale*, and this obviously is an important consideration for determining the moral authority of the law in this case, even if its specific provisions are less than optimal. Whether for any doctor who considers disobeying the law this should be a decisive consideration is an issue which merits a separate discussion.

My aim in this article has been to draw attention to this kind of moral conflict between ethics and the law, illustrating it with a particularly clear exemplary case, and to show how to evaluate proposals to solve it. The proper technique of the law for solving such conflicts consists of introducing a restricted exception for the most urgent cases, clearly circumscribing the restrictions, and providing a procedure for safeguarding them. The actual proposals I have discussed for dealing with this exemplary case could have no more than a local meaning in practice. But the problem of how to deal with conflicts of this kind is a quite general one.

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NOTES

- 1 John Griffiths, Heleen Weyers & Maurice Adams, *Euthanasia and Law in Europe* (Oxford & Portland OR: Hart Publishing, 2008), p. 243, summarising data from national surveys from 1995, 2001 and 2005. This amounts to 55–63 % of all deaths under 1 year. According to Verhagen *et al.*, of the 359 babies who died in any NICU before the age of 2 months 87% died after withdrawal of artificial ventilation. A. A. Verhagen, J. H. Dorscheidt *et al.*, ‘Analgesics, sedatives and neuromuscular blockers as part of end-of-life decisions in Dutch NICUs’, *Archives of Disease in Childhood, Fetal and Neonatal Edition* 94 (2009): F434–8.
- 2 In the USA, medication at this time is usually not increased, A. Janvier, W. Meadows *et al.*, ‘Whom are we comforting? An analysis of comfort medications delivered to dying neonates’, *Journal of Pediatrics* 159 (2011): 206–10.
- 3 Verhagen (2009) *et al.* op. cit.
- 4 The mean time is 22,5, the median 5 minutes, A. A. Verhagen, A. Janvier *et al.*, ‘Categorizing neonatal deaths: A cross-cultural study in the United States, Canada, and the Netherlands’, *Journal of Pediatrics* 156 (2010): 33–7. N. Abe, A. Catlin & D. Mihara, ‘End of life in the NICU: A study of ventilator withdrawal’, *MCN, The American Journal of Maternal/Child Nursing* 26 (2001): 141–6, reports for the USA: from 15 minutes to 2 hours.
- 5 I have been sceptical about this claim until I saw a video of a gasping child. Nevertheless, the claim is built on nothing more than anecdotal evidence. Many paediatricians, both in the Netherlands and elsewhere, will maintain that this inevitable parental distress can normally be managed by adequate and timely given information and support. Retrospective interviews with parents should improve our insight.
- 6 A. A. Verhagen, M.A. van der Hoeven *et al.*, ‘Physician medical decision-making at the end of life in newborns: Insight into implementation at 2 Dutch centers’, *Pediatrics* 120 (2007): e20–8.
- 7 For example, R. D. Truog, J. P. Burns *et al.*, ‘Pharmacologic paralysis and withdrawal of mechanical ventilation at the end of life’, *New England Journal of Medicine* 342 (2000): 508–11.
- 8 It did not occur in the two American NICU’s and one Canadian NICU studied by Janvier *et al.* op. cit., nor in the two NICU’s studied by J. P. Burns, C. Mitchell *et al.*, ‘End-of-life care in the pediatric intensive care unit: attitudes and practices of pediatric critical care physicians and nurses’, *Critical Care Medicine* 29 (2001): 658–64. Cf. Note 25 for the UK.
- 9 E. Vermeulen, ‘Uit Nood Geboren: Levensbeëindigend ahdelen in de Belgische en Nederlandse Neonatologie’, in M. Adams, J. Griffiths & G. den Hartogh (eds) *Euthanasie: Nieuwe knelpunten in een voortgezette discussie* (Kampen: J.H. Kok 2003).
- 10 But see §5 for the opposite view.
- 11 At least when the child is properly sedated in the case of possible remnants of consciousness; see §5 below.
- 12 This is also the view of the national Committee of Experts, *Gecombineerd Jaarverslag van de Commissie Late Zwangerschapsafbreking en Levensbeëindiging bij Pasgeborenen over de jaren 2009 en 2010*.
- 13 The relevance of the doctor’s intention is a disputed issue in some jurisdictions, e.g. the UK, though the court in *R. v Woollin* [1999] 1 AC 82, explicitly stated that where an outcome is virtually certain it legally qualifies as being intentional. I cannot discuss this issue here, and my argument does not depend on the position one should take on it.
- 14 This is not statutory law, but the outcome of a historical development consisting of the introduction of a series of professional guidelines from 1990 on (see §7), two court decisions in 1996, and the establishment of a reporting and review procedure, and of a guideline for prosecutorial decision-making, both in 2007. The doctor has to report to the national Committee of Experts, consisting of a lawyer, an ethicist and three physicians, which reviews his action against the requirements of due care and advises the Public Prosecutor who retains the formal authority to decide whether or not to prosecute. For an authoritative overview see Griffiths, Weyers & Adams op. cit., ch. 6, note 1; cf. S. Moratti, ‘End-of-life decisions in Dutch neonatology’, *Medical Law Review* 18 (2010): 471–96.
- 15 The national Committee of Experts op. cit. states that, if there were other signs of suffering, the use of analgesics would be the proper way to deal with those. If the availability of this alternative rules out the use of muscle relaxants, one wonders which cases are left in which this use could be justifiable.
- 16 No case of this type has ever been reported to either the Prosecutor or the Committee of Experts, resp. before and after 2007. The three neonatologists, out of 14 interviewed by Sofia Moratti in 2011, who had used neuromuscular blockers, justified their failure to report by arguments similar to the ones I discuss in §5 (1) and §6 (2). S. Moratti, ‘Ethical and legal acceptability of the use of neuro-muscular blockers (NMBs) in

- connection with abstinence decisions in Dutch NICUs: Interviews with neonatologists', *Journal of Medical Ethics* 37 (2011): 29–33. For an English disciplinary case which resulted in acquittal see Note 25.
- 17 Charles Dickens, *Oliver Twist*.
 - 18 Essential to all of them is the notion of incommensurability, applied either to basic human goods or to the human person, cf. L. W. Sumner, *Assisted Death: A Study in Ethics and Law* (Oxford: Oxford University Press 2011), pp. 78–84, with references; Paul Ramsey, 'Incommensurability and indeterminacy in moral choice', in R. McCormick, S.J. & P. Ramsey (eds) *Doing Evil to Achieve Good* (Chicago IL: Loyola University Press, 1978), pp. 69–144.
 - 19 The relevant rights in such cases, including the right to life, should therefore at least partly be understood as Hohfeldian *immunities*, cf. W. N. Hohfeld & W. W. Cook eds, *Fundamental Legal Conceptions as Applied in Judicial Reasoning and Other Legal Essays* (New Haven CT: Yale University Press, 1919).
 - 20 F. Schauer, *Playing by the Rules: A Philosophical Examination of Rule-Based Decision-making in Law and Life* (Oxford: Clarendon Press, 1991); F. Schauer 'The right to die as a case study in third-order decisionmaking', *Journal of Medicine and Philosophy* 17 (1992): 573–87.
 - 21 D. Birnbacher. *Tun und Unterlassen* (Stuttgart: Philip Reclam Jun., 1995).
 - 22 It seems, however, that this explanation partially appeals to some of the 'hidden parameters' (factors correlated to the distinction between action and omission) which he generally denies to be relevant, in particular intention and opportunity.
 - 23 Stressed by J. Menikoff, 'The importance of being dead: Non-heart-beating organ donation', *Issues in Law & Medicine* 18 (2002): 320; and many other authors. Critics of the dead donor rule argue that allowing some specific deviations from it will not create harms to the dying patients, or only minimal ones, e.g. R. D. Truog & F. G. Miller, 'The dead donor rule and organ transplantation', *New England Journal of Medicine* 359 (2008): 674–5. But even if this is true, the question remains whether this will be understood by the public. For the present state of the complicated debate about the dead donor rule and the whole-brain definition of death see A. Smith Iltis & M. J. Cherry, 'Death revisited: Rethinking death and the dead donor rule', *Journal of Medicine and Philosophy* 35 (2010): 223–41.
 - 24 E. Volokh, 'The mechanisms of the slippery slope', *Harvard Law Review* 116 (2003): 1026–1134.
 - 25 R. M. Perkin & D. B. Resnik, 'The agony of agonal respiration: Is the last gasp necessary?' *Journal of Medical Ethics* 28 (2002): 164–9. The argument has also been used as a ground for acquitting Dr Munro in his General Medical Council Fitness to Practice Hearing of 5–11 July 2007, concerning two cases in 2005, reported (with confused comments) by J. Goodman, 'The case of Dr Munro: Are there lessons to be learnt?', *Medical Law Review* 18 (2010): 564–77.
 - 26 Perkin and Resnik appeal to the principle of double effect, but that appeal, even if relevant, is hardly convincing, amounting as it does to claiming that one only wants to stop breathing, not life, cf. H. Kuhse, 'Response to Ronald M. Perkin and David B. Resnik: The agony of trying to match sanctity of life and patient-centred medical care', *Journal of Medical Ethics* 28 (2002): 270–2. This application reminds one of the argument that, contrary to received opinion, craniotomy can be justified by double effect, because in performing it one doesn't want to end the life of the foetus, but only to reduce the proportions of its head during delivery. If such distinctions are acceptable, one wonders whether the principle has any discriminating force at all, as Jonathan Bennett classically argued: *Morality and Consequences* (Salt Lake City UT: University of Utah Press, 1981), pp. 110–1; cf. Warren Quinn, 'Actions, intentions, and consequences: The doctrine of double effect', in his *Morality and Action* (Cambridge: Cambridge University Press, 1993).
 - 27 B. P. Himelstein, J. M. Hilden *et al.*, 'Pediatric palliative care' *New England Journal of Medicine* 350 (2004): 1752–62.
 - 28 Truog, Burns *et al.* op cit., p. 509.
 - 29 The most recent figure is 300: A. Van der Heide a.o., *Sterfgevallenonderzoek 2010: Euthanasie en andere medische beslissingen rond het levenseinde*. Den Haag: ZonMw 2012. Available at: www.zonmw.nl/nl/publicaties/detail/sterfgevallenonderzoek-2010-euthanasie-en-andere-medische-beslissingen-rond-het-levenseinde/?no_cache=1&cHash=a9b2c46c0065adeeb5b5518b5e71ce1c. Probably a large number of these cases, however, have been misclassified because of the reliance of the classification on the subjective intention of the doctor, see Govert den Hartogh, 'The regulation of euthanasia: How successful is the Dutch system?', in S. J. Youngner & G. K. Kimmsma (eds) *Physician-Assisted Death in Perspective: Assessing the Dutch Experience* (Cambridge: Cambridge University Press, 2012).
 - 30 Griffiths, Weyers & Adams op cit., pp. 71–3, 245.
 - 31 According to the WHO, 'palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness . . .'

- 32 29% of Dutch doctors who have any experience with euthanasia report ever having had the impression that the request for euthanasia had to some extent been motivated by pressure from relatives. A. van der Heide *et al.*, *Tweede evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding* (Den Haag: ZonMw, 2012), p. 138. Available at: www.rijksoverheid.nl/documenten-en-publicaties/rapporten/2012/12/18/tweede-evaluatie-wet-toetsing-levensbeëindiging-op-verzoek-en-hulp-bij-zelfdoding.html.
- 33 Commissie Aanvaardbaarheid Levensbeëindigend Handelen (CAL), *Zwaar Defecte Pasgeborenen*. Utrecht, KNMG (1990) Nederlandse Vereniging voor Kindergeneeskunde. *Doen of Laten? Grenzen van het medisch handelen in de neonatologie* (Utrecht: NVK, 1992).
- 34 Gezondheidsraad (Author: A. Bood), *Overwegingen bij het beëindigen van het leven van pasgeborenen* (Den Haag: Centrum voor Ethiek en Gezondheid, 2007), p. 25. Griffiths attributes the argument to the ethicist Harry Kuitert; this has been confirmed to me by the then-secretary of the CAL Committee, R. Dillmann.
- 35 Richtlijn Perinataal Beleid bij Extreme Vroeggeboorte (2010). Available at: www.nvog.nl/Sites/Files/0000001346_Richtlijn%20Perinataal%20beleid%20bij%20extreme%20vroeggeboorte.pdf. Following this guideline treatment will now normally start from 24 weeks on. Note that the mortality figure includes the cases in which treatment is being stopped *because of* the prognosis of severe handicaps.
- 36 Griffiths, Weyers & Adams *op. cit.*, p. 222.
- 37 H. Leenen. *Handboek Gezondheidsrecht, deel 1: Rechten van Mensen in de Gezondheidszorg* (Houten/Diegem: Bohn, Stafleu Van Loghum, 4th edn., 2000), p. 317.
- 38 Verhagen (2009) *et al.*, *op. cit.* Elective extubation for quality-of-life reasons occurred in the Dutch (19% of all deaths), the Canadian, and one of the American (both 35%) NICU's studied in Verhagen (2010) *et al. op. cit.* Wall & Partridge found future quality of life to be relevant in 51% of the decisions to withdraw treatment, and the sole reason in 23%: S. N. Wall & J. C. Partridge, 'Death in the intensive care nursery: Physician practice of withdrawing and withholding life support', *Pediatrics* 99 (1997): 64–70.
- 39 These 'quality-of-life' criteria were controversial when the reports introduced them, and still are to some extent, cf. J. H. H. M. Dorscheidt, E. Verhagen *et al.*, 'Parental involvement in end-of-life decisions in neonatology: Legal considerations with regard to Dutch medical practice', *Medical Law International* 11 (2011): 1–22, but by now they have been legally recognised as criteria for withdrawing or withholding treatment. If the objections made to them were valid, their applicability could not be restricted to the active ending of life.