Dutch doctors & dying

Do doctors’ personal views influence their professional care at the end of life – and should they?

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Chapter 3
Paediatricians’ views on good dying for neonates

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Abstract

Objective To assess Dutch paediatricians’ views on neuromuscular blockers for dying neonates.

Study design Qualitative study involving in-depth interviews with 10 Dutch paediatricians working with severely ill neonates. Data were analysed using appropriate qualitative research techniques.

Result Participants explained their view on neuromuscular blockers for neonates with a protracted dying process. Major themes were the interpretation of gasping, the role of (the suffering of) the parents, the need for judicial review and legislation's impact on the care participants provide for dying neonates.

Conclusion The interviews show no consensus between paediatricians and provide insights into the points of disagreement. Interviews also suggest friction between the convictions of paediatricians and legislation, which seems to have an undesirable impact on Dutch care for dying neonates and their parents. This study raises important questions for paediatricians worldwide to reflect upon, such as: ‘what constitutes ‘dying well’?’ and ‘what role should the parents’ perspective play?’.

Introduction

In the Netherlands, a legal provision exists to allow for deliberately ending the life of a neonate (DELN). (1) This is defined as: the administration of a drug by a physician with the explicit intention to end the life of a severely ill neonate. (2) This legal provision, however, does not function well.
Paediatricians do not report cases of DELN and the desired transparency about the practice of DELN is not realized. (2,3) More insight into the practice of DELN and paediatricians’ views on it may provide explanations for the lack of cases being reported.

The Dutch have a long history of public debate about (legislation on) medical decisions at the end of life in general, and about end-of-life decisions for neonates in particular. (4-7) Due care, transparency and accountability have been keywords in this debate. In 2006, the debate about DELN for severely ill neonates resulted in a legal provision that makes it possible for a physician to perform DELN without being prosecuted in case certain criteria of due care are met. (1)

These criteria of due care entail that the child is suffering unbearably and hopelessly, that the parents are fully informed about diagnosis and prognosis, that the paediatricians and parents together have reached the conclusion that there are no other reasonable ways to relieve the suffering of the child, that the parents have given consent, that an independent physician has been consulted and that the DELN will be performed ‘lege artis’. In addition, the legislation entails that a physician who performs DELN has to report this to an expert committee (with three paediatricians, a lawyer and an ethicist) that was installed to judge cases of DELN by assessing the criteria of due care. The expert committee will inform the public prosecutor, who ultimately decides whether to prosecute (for murder or manslaughter) or not.

This legal provision, however, appears not to function in practice; in seven years just one case of DELN has been reported to the expert committee, while based on earlier research the estimated number of cases was much higher. (8-10) One possible explanation for the lack of reported cases is that it is not clear what actions should be classified as ‘deliberate ending of life’. This seems to apply to the use of neuromuscular blockers (NMBs) to end a protracted dying process. (2,11,12) From earlier research, we know that the NMBs are sometimes used in the Netherlands to hasten the death of a gasping neonate whose dying process takes long. (11,13,14) Although these cases, strictly interpreted, might be classified as DELN, paediatricians have not reported these cases to the expert committee. This might be because paediatricians do not perceive the use of NMBs as DELN. Practice and legislation do not match in this respect. (2,11,12) The aim of this study is to gain more insight in paediatricians’ views on the use of NMBs for dying neonates against the background of the current legal provision for DELN and to find explanations for the mismatch between practice and legislation. This insight can be a step to let legislation and practice be better aligned.
The research question of this study was: what do Dutch paediatricians think about the use of NMBs to end a neonate’s protracted dying process accompanied by persistent gasping? More specifically, we wanted to know: 1) Would paediatricians find the use of an NMB in the dying phase acceptable and for what reasons? 2) Would paediatricians classify the use of an NMB in the dying phase as DELN (and why or why not)? 3) Do paediatricians think the use of NMBs in the dying phase should be subject of judicial review (and why or why not)? 4) What is, in the paediatricians’ view, the influence of the current DELN legislation on the care they provide for dying neonates? To answer these questions we have conducted qualitative interviews with Dutch paediatricians working in the care for severely ill neonates.

Methods

Participants and data collection
We held in-depth interviews with 10 paediatricians working in the care for severely ill neonates. Nine are neonatologists, working on a neonatal intensive care unit (NICU), one is a paediatric neurologist working in a large children's hospital. Because we assumed that practices might vary depending on the affiliation of the hospital and its policies on end-of-life matters, we wanted to interview a neonatologist from every Dutch NICU. We managed to do so, apart from one NICU; unfortunately, it was not possible to arrange an interview in time with a neonatologist from this NICU. We also interviewed a paediatric neurologist, because neurologists are often involved, as well, in the decision-making process for severely impaired infants.

The interviews were part of a larger study; an evaluation of the legal provision for ‘late termination of pregnancy and deliberately ending the life of a neonate’. As a result, the paediatricians in this study were asked about the practice of and the legal provision for DELN, a subject with a broader scope than what is discussed in this article. With regard to the subject of this article the following topics were covered during the interviews: interpretation of gasping, possible suffering of the child who gasps, role of the (suffering of the) parents, the acceptability of NMBs (and the conditions for that), the use of NMBs in relation to the DELN legislation, participants’ view on the DELN legislation and its impact on practice. The interviews were held in the paediatricians’ own offices and each lasted approximately one hour. All participants consented to the interview being recorded with an audio recording device and transcribed verbatim. Many open-ended questions were used in order for participants to tell us about their experiences and
perceptions in their own words. Two researchers conducted the interviews (KC and IB). The first interview was conducted together and was reflected upon to refine the topic list. During the period the interviews were held both researchers met several times to talk about the interviews to stay attuned. Both the researchers are trained in medical ethics, KC also has a medical background.

**Analysis of the data**
The interviews were systematically analysed with techniques for qualitative data analysis by KC. Several measures were taken to increase the validity of the analysis. (15) KC read the interviews several times and every fragment was given a code (open coding). After this initial round of coding, IB read all the interviews, as well, and looked into the codes to make sure that no important themes were missed. Further analysis was done by KC. The focus was on the fragments that had to do with the topic of this article; the use of NMBs in the dying phase and its relation to the DELN legislation. These fragments were further analysed during several phases of coding (axial and selective coding); codes were refined, sub codes and overarching codes were assigned and relationships between codes were explored. (16) Interviews were also analysed as a whole, to look for patterns and inconsistencies in reasoning. Part of the analysis and the methods used were discussed in an intervision group of PhD students, all doing qualitative research.

**Results**

*Paediatricians on the acceptability of NMBs in the dying phase*
In the interviews we encountered proponents, as well as opponents of the use of NMBs to end a protracted dying process accompanied by persistent gasping. (See figure 3.1 for the variety of opinions encountered in the interviews). Proponents gave different reasons why they would find the use of NMBs acceptable. The two main reasons that were mentioned were relieving the suffering of the child and the parents. Proponents of the use of NMBs did not agree on the question whether a dying child could suffer from the gasping. Some said that it is not possible for the child to suffer because of the comatose state it would be in.

‘The child will not suffer from gasping because it will be comatose owing to the high level of carbon dioxide.’ (R9)
'Gasping is a very basic function that remains for a long time, but at that point the child will be brain dead and cannot suffer.' (R6)

Others said that the suffering of the child could not be dismissed off hand, and that therefore it is assumed to be present.

'We do not know if the child suffers from gasping, that is why we interpret it as such.' (R10)

All the interview participants who believed the child might be suffering from gasping would find the use of NMBs acceptable if the suffering could not be relieved in other ways (with a higher dose of analgesics and/or sedation).

For the participants who did not think the child could suffer from gasping, but would find the use of NMBs acceptable, it was the suffering of the parents that made it acceptable. These participants said that a protracted dying process accompanied by persistent gasping could be too burdensome for some parents. Therefore, these participants would find the use of NMBs acceptable in case the parents would indicate that they could no longer cope with the situation and would ask the doctor to put an end to the dying process.

All opponents of the use of NMBs believed that the child could not suffer from gasping. For them, the suffering of the parents did not make the use of an NMB to end the dying process an acceptable option.

Proponents of the use of NMBs at the request of the parents argued that the suffering of the parents could be taken into account because the child no longer has any interest in what happens to him as he is in an irreversible coma.

'Almost all parents will accept gasping if they are well prepared in advance. But sometimes it takes so long, twelve hours or so, and then parents become exhausted. Then I wonder what is the use of continuing this for another couple of hours. Why should we make these parents wait until that gasping finally stops, while we know for sure that the child is in an irreversible process and will die within a day? I know it is problematic in a legal sense to take the suffering of the parents into account, but for the child it does not matter anymore. And otherwise parents are left with a very bitter taste about something that is supposed to be a humane and dignified goodbye to their child.' (R9)
‘The suffering of the parents should definitely count in such a situation. Not in decisions to withdraw treatment, then it is all about the child’s interests, but when that child is not there anymore actually, it should be about the parents.’ (R6)

For opponents of the use of NMBs on the other hand, it was precisely their conviction that a child does not suffer from gasping that was the reason not to use NMBs.

‘Yes, there are parents who ask me to put an end to the dying process because of the gasping, but unless the patient suffers I am not going to do something about it.’ (R5)

They favoured a more natural course towards death and did not want to ‘cover up’ a dying process artificially for the sake of the parents.

‘I tell parents it is up to the child to choose the moment it dies. (...) Because we tried to hide death, we are not used to it anymore and we are scared of it. We should not cover it up, it is a normal part of life.’ (R5)

‘Gasping is just a natural part of the dying process. If you explain that to parents and prepare them very well in advance I do not see any reason to use NMBs. I am more a proponent of good counselling for parents, including help from psychologists, spiritual counsellors and social workers. And I see all parents six weeks after their child’s death, I have never heard any complaints.’ (R4)

**Ending the dying process: DELN or not?**

All the interview participants made a clear distinction between ending the life of a child who is already dying and ending the life of a child who would otherwise not be dying. The first situation, so participants explained, applies to the situation already described above; the child in a protracted but undeniable and irreversible dying process accompanied by persistent gasping that receives an NMB to end the process. The second situation then would apply to a child who is not depending on life support (except for maybe artificially given fluids and nutrients) and is not dying, but whose life is terminated deliberately with a lethal drug for reasons of severe suffering that could not be relieved otherwise and/or a very poor prognosis. Although all the interviewed paediatricians regarded the use of NMBs in the dying process (which some would call ‘help with dying’) as a separate issue, distinct from termination
of life of a stable child, participants thought differently about the question whether to regard the use of NMBs as deliberately ending life (DELN).

Most of the interview participants did not regard the use of NMBs as DELN; they would restrict the use of the term DELN for the situation of the child who would not be dying if it would not be given a lethal drug.

‘The DELN legislation was designed for the active ending of life, which in my view refers to a severely damaged but stable baby whose death will be arranged; ‘tomorrow morning 9 o’clock’. That is a totally different situation than a gasping baby in a dying process whose parents cannot cope with the situation any longer. That is not about ending life, it is about facilitating good dying, good dying in the eyes of the parents.’ (R3)

Other participants did regard the use of NMBs as DELN.

‘Yes, I would call this termination of life too, because it is still your action that determines the time of death.’ (R5)

Judicial review
In the interviews it became clear that it is not the case that all participants who think positively about the use of NMBs to end the dying process would be against judicial review of this type of action in the context of current DELN legislation. The interviews showed that there is a range of opinions about this matter, as can be seen in figure 3.1. For example, some of the proponents of the use of NMBs argued that these cases meet the criteria of due care for DELN, because the suffering of the child could not be relieved otherwise. While other proponents suggest that some clause should be added to the current legislation to allow for the suffering of the parents to have a role in these particular cases (cases where the child is in an irreversible dying process and lacks consciousness).

‘I am not against review. It seems like a good idea to me to have one central point where these cases can be reported and judged to see whether it is done carefully and ‘lege artis’, so it becomes clearer what everybody is doing. However, that means that the criteria should change for these particular cases. Moreover, it is my opinion that in case the expert committee gives a positive judgment, this kind of cases should be kept away from public prosecution. In contrast to the ‘real’ DELN, the active ending of the life of a stable baby; that is such an extraordinary situation, I do not mind that public prosecution looks into those cases.’ (R2)
Other proponents of the use of NMBs were of the opinion that these cases should not be reported to the expert committee at all; they do not perceive them as DELN in the first place.

‘This is not about ending life, but about facilitating good dying in the eyes of the parents. You should not make that subject of judicial review. That makes it a very heavy and complicated decision for a physician to make, due to the fears he then might have for his own position. That is not desirable in an acute situation of a dying baby and its parents who are in need. A physician should be able to do what he thinks is needed to make this a good, meaningful and humane experience.’ (R3)

The current legislation’s influence on care
Interview participants told us that they see an influence of the current legal provision concerning DELN and its interpretation by the expert committee on the care they provide for dying neonates. Some proponents of the use of NMBs, including some who believe the child might be suffering from the gasping, told us that the fear of legal consequences was the reason they refrained from the use of NMBs.

‘I am not against NMBs, it could be a sound solution to stop persistent gasping. But I think I do agree, actually, with those who say NMBs cause an unnatural death and should be seen as the active ending of life. As long as we do not know for sure that we will not get legal trouble with it, we will not use them. So we tell the parents legislation forbids us to make an end to the gasping.’ (R10)

Other proponents reported that they still use NMBs, but less frequently; only when they believe it to be absolutely necessary to prevent severe suffering for the child or its parents. They do not report this as DELN, in the first place because they do not perceive it as DELN, and secondly because they fear legal consequences if it would be judged as such.

‘The expert committee has a rather strict reputation. I think that makes paediatricians reluctant to use NMBs and when they do use them they will not report it.’ (R2)

All proponents of the use of NMBs to end the dying process indicated that they would use them more often if that were permitted. Some participants conclude that the current legislation and the expert committee’s
interpretation of it have made the care they provide less optimal than they would want.

‘A good death, I think that is very important, but I do not fancy 2 years of legal trouble. So yes, I think this influences practice, if you know you could be judged strictly, you will be inclined to ‘play it safe’, but sometimes that will be disadvantageous to the child and its parents.’ (R3)

Besides the alleged negative effects of the legislation, participants also acknowledge that the legislation has led to more awareness of the fact that the use of life-shortening drugs in the dying process will lead to an unnatural death and can therefore be problematic in a legal sense. Participants saw it as a positive thing that, in general, a child is given more time to die in a natural way now, owing to this increased awareness and thus decreased use of drugs that could hasten death, because they believed this to be beneficial to the parents’ grieving process. They were also positive about the fact that the current legislation has urged them to involve the parents more and to prepare them well for what they can expect when their child dies.

‘25 years ago when I did my training, the boss would go home after the decision was made to withdraw treatment and the fellow would pull the tube out and gave the child a huge dose of morphine to be sure it died quickly. With this discussion on DELN, the awareness increased that this, of course, would not be a natural death and thus would be problematic in a legal sense. It is good that we are far away from that type of practice now. (...) Being born takes some time, so does dying.’ (R10)

‘I see in practice that, as the expert committee made clear that they would judge negatively about the use of NMBs, we have taken this into account and only use NMBs when absolutely necessary to prevent trauma for the parents. I have to admit, most of the time patience, explanation and palliative sedation will do very well. (...) The child is given more time to die now, and I think that is fine. To make it a process the parents can even enjoy, holding their child that is finally without all the wires and tubes.’ (R7)

Furthermore, several participants expressed the view that the exact medication at the very end of life was subordinate to the earlier decision to withdraw further treatment. That is the reason some would find it disappointing that the Dutch debate about end-of-life decisions for neonates seems to
Dutch doctors & dying

focus on the use of NMBs to end a protracted dying process, while they believe the debate should be about when to start treatment, and if started, when to stop. Most participants expressed a great need for clear criteria and guidance on this matter and would not mind more debate about, and even (judicial) review of, these treatment decisions. The current focus on the use of NMBs has led to discontent for some participants; they do not

Figure 3.1 Opinions on the use of NMBs for dying neonates encountered in interviews with Dutch paediatricians.
feel acknowledged for the work they do, the difficult decisions they have to make and the good intentions they have.

'It should not be about those last five minutes. The focus on that is severely detrimental to all the effort that paediatricians put into those difficult decisions about when to treat and when to stop.' (R1)

Discussion

The results of our study show that paediatricians think differently about the use of NMBs to end a protracted dying process of a child who persistently gasps. They differ in their view on the (lack of) suffering of the child and the role that the suffering of the parents should have. There is also no consensus about how the use of NMBs should relate to the current DELN legislation. These points of disagreement can also be found in literature on this topic. (17-21) Despite their disagreements, however, paediatricians perceive the use of NMBs in the dying phase as clearly distinct from DELN on a stable child. In the first situation the central questions are what ‘dying well’ looks like and how this should be realized. Although this question is answered differently (some believe NMBs can be an answer, while others favour a more natural course towards death), the fact that the doctor has a role to play in the care for the dying child and its parents is not disputed. This contrasts with the situation of the stable child who will not be dying soon, but whose life is ended deliberately because its (future) quality of life is deemed to be very poor.

The DELN legislation was created with the latter cases in mind. (10) However, the expert committee has made clear that the use of NMBs should be reported as DELN, and then, most likely, a negative judgment would be sent to the public prosecutor because the criteria of due care are not met. (2) The effect of the current legislation and this interpretation of it by the expert committee on the care paediatricians provide is that they have become reluctant to use NMBs out of fear for legal consequences. What used to be perceived as normal palliative care by many paediatricians is now drawn into the realm of criminal law. On the one hand, this has increased paediatricians’ awareness that life-shortening drugs can cause an unnatural and hastened death, and thus should be avoided when not necessary. This is probably beneficial for the parents too, because they are allowed more time with their dying child to make it a meaningful experience. (22,23) On the other hand, there are still cases, although rare, where paediatricians
perceive the use of an NMB to be necessary to provide good care for the child or its parents. Some paediatricians set aside their own convictions about what would be best and do not use NMBs, including paediatricians who believe the child might be suffering. Others let their own convictions prevail and do use NMBs, but will not report this to the expert committee. Fear seems to be a poor basis for decision-making, as both situations are not desirable; the first might amount to more suffering than necessary, the second hinders transparent practice.

**Limitations**

This qualitative study was small. Figure 3.1 shows all the opinions encountered in the interviews, but one can conceive of other positions as well that were not represented by the interview participants. The findings of this study cannot be generalized to all Dutch paediatricians working with severely ill neonates. Despite the limitations of this study, however, the conclusion that there is no consensus among paediatricians about the use of NMBs in the dying phase seems very plausible. Furthermore, our interviews have provided more insight into what points of disagreement there are. The interviews also suggest that the current DELN legislation has an effect on the care paediatricians provide to dying neonates and their parents.

**Conclusions**

We conclude that this study signals friction between legislation and the ethical convictions of a part of Dutch paediatricians. This is problematic, especially for legislation, which relies on physicians’ willingness to report. Without the support of those whose practice it is about to regulate, legislation will not serve its purpose. (24) The findings of our study give rise to the question how to let legislation and practice be better aligned. The finding that there is no consensus among paediatricians makes it harder to adjust legislation to fit practice, as practice has a heterogeneous character. More consensus among paediatricians about what would be acceptable ways to deal with a dying neonate and its parents seems needed to bring practice and legislation closer. More debate on this topic might be a step to reach more consensus. We suggest that this debate should be initiated soon. Important ethical questions that need to be reflected upon in this debate are: what comprises ‘dying well’ for a neonate and should the parents’ perspective on that be allowed to have a role? In addition to that, as proponents, as well as opponents of the use of NMBs use the parents’ grieving process, among other reasons, as a justification for their actions, more insight into what is beneficial for parents’ grieving process seems needed.
References


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Katja ten Cate designed the topic list, recruited respondents, conducted interviews, analysed the data and wrote the first draft of this article. Suzanne van de Vathorst was her supervisor; she made a substantial contribution to the conception and design of the article and revised it critically.

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