Euthanasia

MANAGEMENT OF CONFLICTS WITH THE PARENTS OVER ADMINISTRATION OF LIFE-PROLONGING TREATMENT IN DUTCH NICUs

Sofia Moratti*

Abstract: In the Neonatal Intensive Care Unit (NICU) setting, the patient’s parents and the medical team dispute sometimes over the administration of life-prolonging treatment to be provided to the patient. This article focuses on the situation where the parents insist on the treatment, whereas the doctors are of the opinion that the prospects for the future of the baby are too poor to justify (further) artificial prolongation of life. The article provides an informative background on the regulation of the decision-making process in relations with the administration of life-prolonging treatment in Dutch neonatology. It also presents the results of a set of interviews with Dutch neonatologists. These results suggest that the doctors are very inclined to take the parents’ preferences into account.

Keywords: the Netherlands; Medical Futility; Neonatology; Ethnography; Decision-Making; Negotiation.

INTRODUCTION: THE NATURE OF THE PROBLEM

Technical advances in medicine have made it possible to artificially prolong the life of extremely sick and severely suffering babies, dependent on Intensive Care. In some cases, the situation of the baby is transitory: once dismissed from the NICU, the baby can have a healthy life. In other cases, the baby is severely and irreversibly damaged and will live a life characterized by pain, suffering and major permanent functional impairments. The baby may be unable to communicate and dependent on others in daily life. The baby’s condition may be further worsened by lack of hope for the future and dependency on

* J.D., Ph. D.* Department of Legal Theory, Faculty of Law, P.O. Box 9700 AS, University of Groningen, the Netherlands.
continuous and painful medical treatment. For a baby in such conditions, (further) life-prolonging treatment can be withheld or withdrawn, thereby letting the baby die. In the Netherlands, the decision-making process over administration of life-prolonging treatment to severely defective newborn babies is regulated in two reports by the Dutch Society of Pediatrics and the Dutch Medical Association (NVK 1992, KNMG 1997, NVK 2000). These reports provide that the decision-making process over administration of life-prolonging treatment should always include the parents. Several recent studies have shown that this rule is applied in Dutch medical practice. The parents are involved in the decision-making process in over 90% of cases of end-of-life decisions in neonatology (Vrakking et al. 2005, Verhagen et al. 2007, Griffiths, Weyers and Adams 2008), and according to the most recent study, in 100% of cases (Verhagen et al. 2009). Comparative medical (Cuttini et al. 2000) and socio-legal (Griffiths, Weyers and Adams 2008, Anspach 1993, Paillet 2007, Vermeulen 2004) studies have shown that in this respect the Dutch situation is unique. The wishes of the parents regarding treatment do not always coincide with doctors’ professional judgment. The two professional reports by the Dutch medical profession also regulate the management of conflicts between the medical team and the parents.

REGULATION OF THE DECISION-MAKING PROCESS: WHEN THE PARENTS INSIST ON TREATMENT

The regulation of the decision-making process for the administration of life-prolonging treatment in Dutch neonatology has been extensively discussed in the literature (Sauer 1992, Griffiths, Bood and Weyers 1998, Verhagen 2006). For the purpose of this paper, we are concerned with the procedure outlined in the two professional reports mentioned above for managing the parents’ request for life-prolonging treatment that doctors deem ‘futile’.

The reports emphasize the importance of involving the parents in the decision-making process. In case of disagreement, the medical team (and the attending neonatologist in particular) should postpone the decision and hold new meetings with the parents. If the disagreement cannot be solved through communication,
the reports suggest seeking a ‘second opinion’ from a doctor attached to another hospital. The choice should fall on a professional who is accepted by the doctors as well as the parents. The ‘second opinion’ can be requested either by one of the members of the health-care team or by the parents, through the ‘attending neonatologist’. As a general principle of Dutch health law, there is one neonatologist primarily responsible for treatment decisions for a particular baby (Leenen 2007). If there are differences between the ‘second opinion’ and the views of the attending neonatologist, the parents should be offered the option to entrust the baby to the care of the consultant (NVK 1992: 63).

If the consultant advises against (further) treatment but the parents keep insisting on treatment, their wish should, in principle, be followed, unless that is expected to lead to “unacceptable suffering that cannot be relieved” or to a “life not worth living”. In the latter case, the medical team might seek a court order imposing temporary removal of parental custody. If granted, this would allow doctors to stop treatment, by-passing the opposition of the parents (NVK 1992: 66).

In conclusion, the regulations prescribe that parents’ request for treatment must be taken very seriously, and can be overridden only if there are very serious reasons (related to the best interest of the baby) for doing so.

WHAT IS KNOWN ABOUT THE MANAGEMENT OF CONFLICTS WITH THE PARENTS IN DUTCH NEONATAL PRACTICE?

Recent research (Verhagen et al. 2009) investigated the frequency and characteristics of conflicts about end-of-life decisions in Dutch NICUs. Verhagen et al. reviewed the medical files of all newborns who had died before the age of 2 months during 1 year\(^2\) in all Dutch NICUs and interviewed the attending neonatologist for each baby. They identified 150 deaths (making up 44% of all NICU deaths in that year) that were preceded by a non-treatment decision based on the child’s poor prospects for the future\(^3\). In 14 cases, the parents insisted on continuation of treatment against the opinion of the medical team. Therefore, the decision on administration of further treatment was postponed. In 7 of the 14 cases, additional meetings and a ‘second opinion’

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2. Babies admitted to one of the Dutch NICUs between October 2005 and September 2006.
3. The rest of the deaths were babies who had no chance of survival despite maximal treatment.
from another NICU lead the parents to change their mind. Therefore, treatment was withdrawn with the consent of the parents. In 2 of the 14 cases, the baby’s condition deteriorated, which lead the parents to accept treatment withdrawal. The remaining 5 cases can be classified as situations of ‘persistent disagreement’. The parents refused withdrawal of ventilation because they deemed it contrary to their religious persuasion. Involvement of other family members and religious ministers in the decision-making process did not lead to solving the disagreement. In these five cases, the medical team withheld additional intensive care without withdrawing ventilation, and let the baby die without making a decision that the parents regarded as unacceptable. The doctors tried to find a balance between sparing further suffering to the baby and taking the parents’ preferences into account (Verhagen et al 2009: e115).

In conclusion, the work by Verhagen et al. shows that situations involving disagreements are handled in accordance with the regulations, that cases of persistent disagreement seem a very rare occurrence in Dutch NICUs, and that the doctors attach great weight to the wishes of the parents and are inclined to seek a compromise between their own professional judgment and the parents’ preferences.

INTERVIEWS WITH NEONATOLOGISTS: THEIR ATTITUDES AND EXPERIENCES

The interviews I carried out aimed to investigate medical attitudes, with regard to the proper course of action to take in the situation of disagreement and ‘persistent disagreement’, by which I mean a conflict with the parents that cannot be solved through the strategies for conflict-management ordinarily used in Dutch NICUs.

Methods

In 2008, I carried out face-to-face interviews with 14 neonatologists working in the Netherlands. All of the interviews were tape-recorded. Each doctor received a CD with a recording and a word-by-word transcript of his or her interview. All doctors were given several weeks of time to further explain, clarify or correct their responses; two doctors made use of this option. The interviews were carried out in English although neither the interviewer nor the doctors interviewed were native English speakers. This explains and excuses many of the peculiar expressions used. The present paper is based on doctors’ responses to the following question:
As a general rule, ‘medically futile’ treatment should not be administered. Are there exceptions to this rule in neonatal medical practice?

All doctors who answered my question seemed to have in mind the situation where the parents insist on further treatment.

**Research Sample**

The organization of tertiary care in the Netherlands is regulated at the national level. Only 10 Dutch hospitals are allowed to practice intensive care on newborns. The NICUs are heavily subsidized and the quality of the care they provide is monitored. Most NICUs are attached to university medical centers, and each NICU has 24 beds. The medical staff consists of little more than 10 people per NICU. My interviews were carried out at two NICUs. Not all neonatologists in the staff were interviewed. Most neonatologists were Dutch and all of them had received a substantial amount of their medical training at a Dutch university or university hospital. About one third of the doctors I interviewed were women. Nothing in my results suggested a correlation between the doctors’ gender and his or her answers to the interview. Therefore, for purposes of anonymity, I refer to all doctors as “he”. About a third of doctors were over 45 and had over 10 years of professional experience as neonatologists, including the 2.5-years residency required to earn a specialization in neonatology. A further third of the doctors were between 40 and 45 and most of them had between 5 and 10 years of professional experience. The remaining doctors were under 40 and most of them had less than 5 years of professional experience. Young residents who had just started their post-graduate training in neonatology and had little or no professional experience as neonatal care specialists at the time the interviews were carried out, were excluded from the study. Almost all doctors in my sample had received a religious upbringing. One third of them were not religious. The remaining doctors were affiliated with one or another Christian church, but about half of them were not practicing.

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4. Some of the neonatologists were on sick leave at the time the interviews were carried out. A few did not agree to take part in the interviews.

5. A neonatologist’s education consists of a Medical School degree, a post-graduate training in pediatrics (residency), and a further training in neonatology (fellowship).
Doctors’ Answers

All doctors stressed the importance of providing accurate information to the parents and of maintaining at all times a non-confrontational attitude to them. All doctors said that, through communication, the medical team nearly always reaches an agreement with the parents, and that the cases where this does not happen are extremely rare exceptions. However, as the table shows, their answer differed with regard to the proper course of action to take when the disagreement with the parents is not resolved through communication.

***Table 1***

*For protection of anonymity, each neonatologist was assigned a letter.

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<tr>
<th>Answer</th>
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<td>Parental insistence on ‘futile’ treatment is an ethical and legal dilemma (n=1)</td>
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<td>The patient should be transferred (n=3)</td>
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<td>Treatment can be continued, but only <em>temporarily</em> (n=6)</td>
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<td>‘Futile’ treatment should never be administered (n=1)</td>
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* For protection of anonymity, each neonatologist was assigned a letter.

*Table 1. Neonatologists’ views of situations of persistent disagreements with the parents, when the parents insist on life-prolonging treatment that doctors deem ‘futile’.  

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LIFE-PROLONGING TREATMENT CAN BE CONTINUED TEMPORARILY, FOR HOURS OR DAYS

Six doctors said that life-prolonging treatment can be continued temporarily if the parents insist on it, in order to get the parents to accept an abstention decision or to give them the chance to see the child before its death. For example, the mother may be under general anesthesia following a particularly complicated delivery. All six doctors very much emphasized that continuation of treatment should be temporary, up to a few days.

In doctor C’s words,

sometimes the parents are not ready to accept discontinuation of treatment. In that case you should wait and maybe administer futile treatment [...] until the parents can accept [that] the best thing to do is stopping treatment.

The same doctor added:

I don’t think that the parents should dictate what you have to do. So if you are not comfortable treating a patient and you think it is futile, I don’t think you should keep treating just because that is what the parents want. You should always look for other solutions.

Doctor G explained that in one case, he and his colleagues kept the baby alive because the mother was unconscious. She had had major surgery. The goal of prolonging the baby’s life was allowing her to see the baby before its death.

Doctor J said he administered ‘futile’ treatment, in order

 to keep the child alive so that the parents can be there for the death. That would be the only reason for me to treat the patient [for] a day or two, not longer.

Doctor L said:

Sometimes one needs time to – er – convince – maybe that’s not a good word – to explain to the parents that treating is really futile.

He, too, was optimistic concerning the possibility of eventually getting the parents to accept the situation:

[I]n my experience of the last few years we are all – always er – able to be – er – to agree on these things with the parents. But there have been situations where because of religious background it is difficult for the
parents because they get – from their religious background they get different advice. Especially with – er – er – people from very strict religious communities, Islamic but also Protestant.

He stressed that treatment should be only temporary. “As a pediatrician”, he said, “one is responsible for the child”; this responsibility includes not administering ‘futile’ treatment.

Doctor M said that ‘futile’ treatment can be maintained “when the infant is at the edge of dying and will die anyway within the next few hours or minutes”, in order to give the parents time to prepare practically and emotionally for the baby’s dying process. Doctors should avoid a confrontational attitude:

I would follow the [wishes of the] parents and treat for some more time until they also see that it’s futile [to keep on treating].

The doctor reported that in his long career, all cases of disagreement with parents were eventually settled through communication, without transferring the child to a different hospital or mobilizing formal legal institutions.

Doctor O said:

I know of certain situations where for a very short period of time a futile treatment is continued in order […] to reach another goal […] mostly related to acceptance by the parents of the situation: helping them bear, helping them in their bereavement […]. I would not object to continuing futile treatment for a very short period of time, if it contributes. [For] hours, maybe one or two days. But not weeks. Never months.

THE PATIENT SHOULD BE TRANSFERRED TO A HEALTH-CARE INSTITUTION WILLING TO PROVIDE THE LIFE-PROLONGING TREATMENT

Three doctors suggested that transferring the patient to a different health-care institution could be the solution to situations of persistent disagreement.

In doctor B’s words:

On the one hand, the parents have the right to decide what is best for their child. However, on the other hand, the neonatologist has the duty to see to it that the patient does not suffer. Intensive Care treatment may cause suffering. Suffering is acceptable if it will lead to improvement or cure the patient’s condition. But if this suffering has to be continued only
because others do not see the suffering, in my opinion, as a professional you have the right to reject further treatment by the team. Somebody else should then take over the treatment.

Doctors D and E recalled one recent case of disagreement that persisted after several multidisciplinary decision-making meetings and a second opinion from another Dutch NICU. A third opinion was obtained, and the third Dutch NICU was willing to treat the baby. However, it was located quite far from the parents’ home and traveling every day would have placed too heavy a burden on the parents. Eventually, doctor D explained,

because that NICU was willing to treat the baby, we were forced to give the treatment over here. [...] I think that, as a doctor, you can’t be forced to do something that you consider not ethical!

The same doctor said he chose not to take part in further life-prolonging treatment on that baby, making a sort of conscientious objection:

I refused to intubate [attach a breathing tube] that baby. So I was on call, and the baby was in distress [breathing failure], and I had already discussed with a colleague that was willing to intubate the baby - and he did that.

Also doctor E had strong feelings about that case:

I think we should refer the patient to another center, because I don’t think the teams in this hospital are motivated enough to help this baby. And I think that you can do more damage when you are not motivated to treat the baby than when you are.

**TREATMENT CAN BE CONTINUED**

Doctor F said that if the parents are fully aware of the probable future condition of their baby and insist on prolonging its life, the doctors can consider it:

maybe you [as a doctor] can take them to a rehabilitation centre so that they can see what their child could look like [...] if you can’t persuade them then to stop the treatment, then maybe you should agree with continuation of treatment.

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6. To maintain the full anonymity of the patient and the case, no further details are given about it in this paper.

7. Doctor F adds never having experienced this situation.
Doctor H said:

_They are the parents. I’m just a doctor. […] They have to live with the child. And if they choose, against all medical advice, to see life itself, to be alive as the most important factor, not the quality [of life] but just to be alive, […] I would really stress […] that my concern as a pediatrician is to prevent the child from suffering or pain or – er – future pain or suffering, but […] - I am a doctor and _they_ are the parents!_

Doctor I said that a doctor who has not been involved for a long time in the care of the patient will find it easier to say: […] “although I personally think it is not in the interest of the child [to keep treating], we can do so nevertheless.” But if you have taken care of the child for many weeks, then it might be difficult and different I think. Emotions can also play a role.

**Situations of Persistent Disagreement Are “an Ethical and Legal Problem”**

Doctor A who had a long professional experience recalled that in his entire career he only came across two other cases involving parents insisting on life-sustaining treatment that the medical team considered ‘futile’. In both cases the final choice was for treatment. He said that situations of persistent disagreement between parents and medical team constitute “a big ethical and perhaps legal problem”.

**Futile Treatment Should Never Be Administered**

Doctor N thinks that if a treatment is really ‘futile’, it should never be administered. In the hypothetical case of a baby born at 25 weeks, who suffered bilateral brain hemorrhage, ventricular dilatation, hydrocephalus⁸, who has very sick lungs and needs high pressure ventilation, who has a bowel condition that needs to be operated on, I think we must absolutely not operate. There is a very high chance that such a child – provided it survives – will be extremely handicapped

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⁸ All conditions mentioned by the doctor cause brain damage. ‘Bilateral brain hemorrhage’ refers to a large bleeding in the brain. ‘Ventricular dilatation’ and ‘hydrocephalus’ refer to abnormal accumulation of liquid in the brain.
for the rest of its life [...] wheel-chair bound, spastic with incontrollable movements, will have epilepsy, will be demented and unable to communicate, perhaps deaf or blind or both. I think it is absolutely not good to – it is in fact against nature – to treat the child regardless.

CONCLUSIONS

Existing research has already shown that conflicts between parents and healthcare team are extremely rare and are almost always solved by postponing the decision, holding additional decision-making meetings, requesting second opinions, and improving communication with the parents. In the rare event of “persistent disagreement”, a compromise is generally sought. The interviews presented in this article support these findings. The neonatologists interviewed attach great weight to the parents’ preferences and think the parents should always be involved in the decision-making process. As we have seen, in situations of ‘persistent disagreement’ the medical team could in principle seek a court order, allowing discontinuation of life-prolonging treatment notwithstanding the opposition of the parents. However, the neonatologists seem very determined to avoid polarization of conflict and to seek a compromise between the various interests at stake. On the one hand, the child should not suffer unnecessarily, while on the other hand, the bereavement process of the parents is likely to be easier if they felt listened to and respected.

Some of the doctors interviewed report having experienced situations of “persistent disagreement”. In the cases they recalled, the doctors satisfied the parents’ request for keeping the baby alive, against their own professional judgment. However, most neonatologists say that in such situations, in principle, the final word should rest with the medical team, if reaching a compromise is not possible. There seems therefore to be a discrepancy between doctors’ behavior and the attitude of most of them. The doctors’ answers are consistent with the interpretation of the notion of ‘futility’ in Dutch and international literature (Moratti 2009: 371), but in their practice they seem to be willing to give the last word to the parents who insist on ‘medically futile’ treatment. Further socio-legal qualitative research is needed, focusing exclusively (unlike existing research) on the decision-making process in cases of “persistent disagreement” by analyzing the behavior of the various actors involved and the motivations they give for their choices.
References


implementation at two Dutch centers. *Pediatrics* 120. www.pediatrics.org/cgi/content/full/120/1/e20


**Biographical Sketch**


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