Non-treatment Decisions on Grounds of “Medical Futility” and “Quality of Life”: Interviews with Fourteen Dutch Neonatologists

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ABSTRACT: This essay opens with background information about the concept of “medical futility” and the regulation of non-treatment decisions in Dutch neonatology. The regulations include a list of criteria for predicting the baby’s future quality of life. The second part presents the findings from interviews with fourteen Dutch neonatologists on the manner in which they apply the criteria in their practice.

The concept of “medical futility” has been the object of debate in the medical literature.1 “Futility” is a criterion for decision-making for withholding and withdrawal of life-prolonging medical treatment in individual cases. Treatment is “medically futile” if its benefit to the patient is insufficient to justify its initiation or continuation. The core of the “futility” debate is the presence of “quality of life” judgments in “futility” assessments in individual cases. Through self-regulation, the Dutch medical profession introduced a number of criteria that, taken together, may be of help to predict a baby’s future “quality of life” and to make a decision for or against further life-prolonging treatment.

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1 S. Moratti, The Development of “Medical Futility”: Towards a Procedural Approach Based on the Role of the Medical Profession, 35 J. MED. ETHICS 369 (2009).
**Reports by the Dutch Pediatrics Association and the Royal Dutch Medical Association**

In the early 1990s, the Dutch Association of Pediatrics\(^2\) and the Dutch Medical Association\(^3\) issued guidelines on end-of-life decisions in neonatology.\(^4\) According to the reports, life-prolonging treatment is “impossible” if the baby has “no chance of survival,” and “futile” if “the expectations for the baby’s future are so poor that treatment would be pointless.”\(^5\) This article is devoted exclusively to the second category of “futile” cases.

The reports regulate the decision-making process, when withholding or withdrawal of life-prolonging treatment on grounds of “medical futility” is considered. The decision-making process should involve the entire medical team, nurses included, and the baby’s parents. Non-treatment decisions should be documented, with adequate explanations, in the patient’s medical file.\(^6\)

According to the reports, the choice for or against life-prolonging treatment should be primarily based upon the condition of the infant at the time the decision is made. However, the infant’s predictable future condition should be taken into account as well, with particular attention to:

- expected extent of *suffering* (in terms of permanent functional impairments, pain, anxiety, prospects for the future and room for hope);
- *life expectancy*;
- expected possibilities of *communication* (both verbal and non-verbal) and interpersonal contact;
- expected possibilities of *self-sufficiency* (ability to sit, walk, and take care of oneself independently);
- expected possibilities of *personal development* (ability to read, write and work);

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\(^2\) Nederlandse Vereniging voor Kinder geneeskunde (NVK) [Dutch Pediatrics Association], Doen of laten? Grenzen van het medisch handelen in de neonatologie [To Act or To Abstain? The Limits of Medical Practice in Neonatology] (Utrecht, 1992) (hereinafter “NVK Report”).

\(^3\) Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst (KNMG) [Royal Dutch Medical Association], Medisch handelen rond het levenseinde bij wilsonbekwame patiënten [Medical Practice in Connection With the End of Life of Non-competent Patients] (Houten/Diegem, Bohn Stafleu Van Loghum, 1997) (hereinafter “KNMG Report”).

\(^4\) English language summaries of the two reports are available in Euthanasia and Law in Europe (J. H. Griffiths, H. Weyers & M. Adams, eds., 2008); and Euthanasia and Law in the Netherlands (J. Griffiths, A. Bood & H. Weyers, eds., Amsterdam Univ. Press, 1998).

\(^5\) NVK Report, *supra* note 2, at 23.

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• extent of dependency on medical care and impact of further treatment on the patient (for example, frequency of hospitalizations).

The reports stress the relevance of “proportionality.” “Medical futility” considerations are especially relevant where there are significant chances that the treatment will cause a harm that is not proportional to the benefit.

No mention is made in the reports of the costs of the treatment in financial terms. The reports do not provide an ethical and legal basis for excluding patients from access to medical care due to their potential monetary cost to society. The term used in the reports is “personal development” and not “productivity.” The focus is on the individual’s ability to evolve and express his personality, not on his potential for being an economic asset to society.

While there have been various reports after 1992 dealing with various aspects of regulation of end-of-life decisions, the basic criteria laid down in the two reports have remained unchanged.

What Is Known About Dutch Medical Practice?

Medical research in the 1990s and 2000s investigated end-of-life decisions in Dutch neonatology. This included withholding and withdrawal of treatment on grounds of “medical futility.” Some studies in the Netherlands and other countries focused on doctors’ justifications for non-treatment decisions and on the application of “futility” in medical practice.

The Dutch studies show that the decision-making procedure designed in the two professional reports has been fully realized in medical practice. A 2005 study based on review of death certificates shows that the parents are involved in the decision-making process in about 80% of cases of end-of-life

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7 KNMG Report, supra note 3, at 77, and supra note 6.
decisions in neonatology. The most recent study reports that the parents are involved in 100% of cases. This study was based on a very large sample, because the researchers reviewed all the medical files of all newborns who had died before the age of two months during one twelve month period in all Dutch NICUs and interviewed the attending neonatologist for each infant. The percentages of involvement of the medical team are reported by the same two studies to be 88% and 100%, respectively.

Another recent study based on reviews of patient files and interviews of neonatologists of all newborns who had died before the age of two months in two Dutch NICUs analyzed the reasons for non-treatment decisions on grounds of “medical futility.” In the cases investigated in the study, the neonatologists applied the criteria laid down in the two professional reports. In particular, the criterion of communication was mentioned more frequently than others.

**The Concept of “Futility” in Dutch Neonatology**

Medical research on the decision-making process at the end of life usually results in concise, condensed reports of mostly quantitative data. My empirical research largely takes a more sociological and qualitative approach. I report extensively doctors’ answers to my questions and their descriptions of the decision-making process, quoting their exact words when these shed light on a particularly interesting issue. This makes my work easily accessible to non-specialists.

**Methods**

In 2008, I conducted face-to-face interviews with fourteen 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.

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13 Id. Infants were admitted to one of the Dutch NICUs between October 2005 and September 2006.
14 A.A.E. Verhagen et al., *Physician Medical Decision-making at the End of Life in Newborns: Insight into Implementation at Two Dutch Centers*, 120 Pediatrics e20 (2007). Infants were admitted to one of the two Dutch NICUs included in the study between January and July 2005. Id.
speakers. This explains and excuses many of the peculiar expressions used. The present article is based on doctors’ responses to the following question: “In general terms, what considerations would be important to you in deciding whether a treatment is ‘medically futile’ in neonatology?”

**Research Sample**

The organization of tertiary care in the Netherlands is regulated at the national level. Only ten 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 associated with university medical centers, and each NICU has about twenty beds. The medical staff consists of little more than ten people per NICU. My interviews were carried out at two NICUs. Not all neonatologists on 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 the doctors were over 45 years of age and have over ten years of professional experience as neonatologists, including 2.5 years of residency, which is required to earn a subspecialization in neonatology. A third of the doctors are between 40 and 45 years of age and most of them have between five and ten years of professional experience. The remaining doctors are under 40 years of age and most of them have less than five 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 conducted were excluded from the study. Almost all doctors in my sample received a religious upbringing. One-third of them were not adherents to any organized religion. The remaining doctors were affiliated with one or another Christian church, but about half of them were not practicing their faith.

**Neonatologists’ Responses**

Table 1 below presents the criteria identified by the doctors.

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15 Some of the neonatologists were on sick leave at the time the interviews were conducted. A few did not accept the invitation to take part in the interviews.

16 A neonatologist’s education consists of a medical school degree, post-graduate training in pediatrics (i.e., a residency), and further training in neonatology (i.e., a fellowship).
Table 1
Neonatologists’ Criteria for Assessing “Medical Futility”

<table>
<thead>
<tr>
<th>Answer*</th>
<th>A</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
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<tr>
<td>Communication (n=8)</td>
<td>x</td>
<td>x</td>
<td>x</td>
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<td>x</td>
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<td>Mental Condition (n=7)</td>
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<td>x</td>
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<td>Motor Condition (n=6)</td>
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<td>x</td>
<td>x</td>
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<td>x</td>
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<td>Dependency on Medical Care (n=5)</td>
<td>x</td>
<td>x</td>
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<td>Self-sufficiency (n=4)</td>
<td>x</td>
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<td>x</td>
<td>x</td>
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<tr>
<td>Pain (n=4)</td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
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<td>Suffering (n=3)</td>
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<tr>
<td>Multi-sensory Impairments (n=2)**</td>
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<td>x</td>
<td>x</td>
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</table>

* For protection of anonymity, each neonatologist was assigned a letter. Doctors B and M are not included in the list because their responses were too generic. “No treatment that can either cure or improve the patient’s condition” and “no chances to improve the outcome” were their respective definitions of “medically futile treatment.”

** Deafness and blindness.

As Table 1 shows, life-prolonging treatment is regarded by doctors as “medically futile” if the prospects for its future include major mental and motor disabilities, particularly if no capacity for communication is to be expected. Dependence on medical care, self-sufficiency and pain are also regarded as having a high relevance, together with suffering and multiple sensory impairments. All of the doctors, with only one exception, mentioned more than one criterion. These results, in particular the primacy of communication over all other criteria, support the findings of existing medical research.17

Some of the doctors further illustrated their answers. Two arguments recur frequently in the doctors’ replies: assessments of “medical futility” and definitions of “quality of life” are always, to some extent, subjective; medical treatment constitutes an invasion of physical integrity, and should not be performed unless it significantly benefits the patient.

Doctor A stresses that there is ample room for flexibility in making “futility” assessments, and says: “I talk about ‘inhumane quality of life’ but if you ask me what it is – it is difficult to give a definition. Usually I focus on severe mental retardation, dependency on the care of others, inability to communicate.”

17 Verhagen et al., supra note 14.
Doctor E illustrates his idea of “a life worth living”:

[M]aybe the baby will survive but the baby will not have a life which I think – because it is really personal I think – I think it’s strange to say the word – worth living. When the baby can’t communicate or has a lot of pain or the baby is just lying there and there is no mobility [...] or there is a life of continuous hospitalization. I think it is really important that you can enjoy life and when you know that that’s not going to happen, I think treatment [...] is futile.

Doctor L talks about “a meaningless life”: “The child will eventually [...] not be able to enjoy life, will not be able to communicate with parents or with other siblings, and will suffer – er – a lot of pain, that’s in general the considerations I use when I think about ‘futility.’”

With much hesitation, doctor O says:

‘Quality of life’ – I think ‘quality of life’ is – it’s – it’s – it’s a word that you use, also because it has a certain meaning, which is – er – er – which is understood. I know what ‘quality of life’ is. [...] I would probably define it as – er – I would go to the WHO definition of ‘quality of life,’ but that doesn’t help much. It’s – it’s a situation physical and mental and environmental of a patient, child, newborn – the – er – I think it’s a balance for the individual of pleasurable factors and damaging factors that are influencing the life of a person and it is – the level of influence of these factors is determined mainly by the person himself, but can sometimes be determined and defined by others if it is of such huge magnitude that nobody would disagree.

Doctor H argues that intensive care treatment should be administered only to children who have “reasonable prospects for the future.” He explains that in his view treatment is “futile” if the patient is not likely to “live a good life.” In order to “live a good life,” one does not need to be “independent all the time,” he says. “Living a good life” is perfectly compatible with being confined to a wheelchair, for example: “It does not need to be perfect. I have seen lots of people who have handicapped children and are very happy with their children.”

He observes that the most important factor in making predictions for the baby’s future is brain damage, because unlike other conditions it is always “devastating and irreversible.” However, he argues that doctors should always leave room for doubt. In his medical practice he sees children whose quality of life turns out to be better than doctors would ever have expected. Also, some children develop extremely severe mental or physical limitations, although initially their prospects for the future did not seem poor.
Doctor I describes the situation of a baby hospitalized in his ward, born at 26 weeks. At three weeks, the baby still needs very intensive artificial ventilation. There is a large bleed in the baby’s brain. Furthermore, the baby has been operated on and is on heavy medication. The doctor says: “We must not use our high-technology equipment to achieve a situation like that. If we think that we will create that kind of situation and we have a choice between using our technological tools and not doing so, I think we must be wise and refrain from doing so.”

He goes on to explain that doctors’ predictions of the long-term outcome for a baby are based on statistics, which the individual case could defy. Furthermore, predicted “quality of life” is difficult to assess in individual cases, because the idea of “quality of life” is to a large extent subjective: “It is a kind of projection of your own feelings about ‘quality of life’ on a child, I think.”

The parents’ viewpoint should play a role in the decision-making process, “because it’s their child”, the doctor says. He adds that a doctor needs a very strong justification for imposing invasive treatment on a child: “It’s a kind of violence you do to the children, actually. I say to people: if I did what I do on my work in the streets, I would be in prison!”

Doctor N’s opinion is very similar. A treatment is “futile” if it leads to a survival without “self-sufficiency, ability to communicate, awareness of and capacity to react to one’s surroundings, awareness of one’s own existence, of pleasant and unpleasant sensations.” He adds that if the child is “wheelchair-bound, spastic, has severe untreatable epilepsy, is not able to see and hear,” his existence – although not “meaningful” for the baby himself – might still be “meaningful” for the people who take care of the baby. Taking care of a handicapped human being can stimulate desirable characteristics in people, thoughtfulness, loving care, and affection, the doctor argues. However, “that does not concern so much the life of the individual, but more the lives of those who surround him.” “This idea partly touches on my Christian beliefs,” the doctor adds.

Doctor J says that performing “repeated medical procedures” on a patient is not futile if the patient is eventually going to be cured, if the medical interventions are going to bring about an improvement of the patient’s condition; however, in some cases this will not happen.

Doctor G says that treatment is “futile” if the baby’s situation will include “pain, severe mental disabilities, and severe physical disabilities, meaning that one can only lay down and do nothing.” The doctor adds that inability to communicate is another crucial factor, and that suffering “is not only about physical pain.” Impossibility to communicate in the absence of major cognitive impairments can cause profound suffering too, the doctor argues.
Conclusion

As far as one can tell from the doctors interviewed, the analysis of the concepts of “medical futility” and “quality of life” in the two professional reports of the early 1990s is generally shared in the two NICUs. However, there are some differences of nuance. Different doctors assign priority to different factors.

As we have seen, several recent studies suggest that in Dutch NICUs, the decision to abstain from life-prolonging treatment is never made by one doctor alone. It is always a decision of the medical team and the parents. The decision-making process is well-documented in patient files. If interpreted in the light of these data, my interviews indicate that the final decision for or against (further) life-prolonging treatment results from a process of negotiation and integration of different approaches to analyzing “quality of life.” At the same time, all of the responses of the doctors are compatible with the criteria laid down in the two reports that reflect the position of the Dutch medical profession as a whole. Professional standards seem to leave room for different interpretations of the concept of “quality of life” by individual doctors. This can be regarded positively, so long as the boundaries of professional self-regulation are respected and the decision-making process is collective and well-documented.

In the words of doctor N:

There is room for different opinions here [in this NICU]. Room for the person who says: ‘I do not yet want to stop treatment.’ No one will say: ‘you are crazy, you must listen to us!’ [...] There is simply a pleasant openness for everyone’s viewpoint. We listen carefully to one another.
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