

Decisions to forego ‘medically futile’ life-prolonging medical treatment in newborn babies in the Netherlands: a multidisciplinary study*

* Sofia Moratti, Dept of Legal Theory, University of Groningen, the Netherlands

1 Introduction. What this paper is and for whom it is intended

The present paper was written expressively for the GGSL Conference of 20 May 2009. It illustrates the structure and methods of my doctoral research and discusses my research questions. The results of my research are not presented in this paper, and are to be found, for those who are interested, in my PhD thesis.¹

My doctoral research is multi-disciplinary. It consists of (i) a discussion of the concept of ‘medical futility’ from an ethical viewpoint (ii) a legal study of the process of regulation of ‘medical futility’ in Dutch neonatology in the last thirty years (iii) an empirical investigation on medical practice, which takes mainly a sociological approach and at the same time does not treat medical information as of secondary importance. Since the potential reader of the present paper most likely has a background in law, I avoided the use of medical jargon whenever doing so seemed possible without misrepresenting the content.

After a brief introduction to the concept of ‘medical futility’ and its regulation in Dutch neonatology, this paper presents the most original part of my research, that is, the empirical investigation on medical practice.

2 The concept of ‘medical futility’ and the regulation of non-treatment decisions in Dutch neonatology

Over the last fifty years technical advances have taken place in medicine that have greatly increased the possibilities of life-prolonging intervention. The increased possibilities of acting have brought with them new ethical questions. Not everything that is technically possible is appropriate in a specific case: not everything that *could* be done *should* be done. In the 1980s, a new term was coined to indicate inappropriate interventions: ‘medically futile treatment’.² A debate followed, with contributions from the United States and several western European countries. While the concept of futility in theory applies to all sorts of medical interventions that might be performed without being medically indicated – things such as certain medical screenings and

¹ Samples from the results of my research are reported in Appendix, B and D. However, they are not representative of the general findings of my study.

² Murphy 1988 and Youngner 1988.

cosmetic surgery – in practice the literature on ‘medical futility’ deals only with *life-saving* and *life-sustaining* medical interventions.³ It is with this more limited application of the concept of ‘futility’ that this paper will deal. In the international debate, ‘medical futility’ is taken to be a legal and ethical ground for withholding or withdrawing life-prolonging treatment from a patient whose condition is too poor to justify (further) medical intervention. It is supposed to be a ‘technical-medical’ criterion, based on the doctor’s technical expertise.

The use of ‘medical futility’ in Dutch neonatology is regulated by a 1992 report of the Dutch Association of Paediatrics. In the Report, it is argued that the doctor, who is considered responsible for the decision to *apply* a life-prolonging treatment in the first place, should also be considered responsible for the decision to *limit or stop it* when there are reasons for doing so, i.e. if treating would lead, or has already led, to an unacceptable outcome.⁴ According to the Report, there is no ethical difference between not initiating life-prolonging treatment (‘withholding of treatment’) and stopping life-prolonging treatment (‘withdrawal of treatment’).⁵ The Report sheds light on the notion of ‘medically futile treatment’ by introducing a distinction. Medical treatment is ‘kansloos’ (‘impossible’) if the baby has “no chance of survival” and ‘zinloos’ (‘pointless’) if “the expectations for the baby’s future are so poor that treatment would be pointless”.⁶ The Report turns on its head what had previously been a strong assumption in the debate over non-treatment decisions: it states that because medical treatment constitutes an invasion of physical integrity, it is not its withholding or withdrawal that must be justified, but rather its initiation or continuation.⁷ The basic regulation of non-treatment decisions on grounds of ‘medical futility’ in neonatology laid down in the 1992 Report of the Dutch Association of Pediatrics has, to this date, remained unchanged.

3 Research setting

In my research, I investigated the use of ‘medical futility’ in Neonatal Intensive Care Units (NICUs) in the Netherlands. A NICU is a high-technology medical setting, where most of the life-prolonging treatment available today for extremely sick newborns is administered. I carried out an empirical research in two Dutch NICUs, which I will call ‘NICU A’

³ This narrow meaning is reflected in professional guidelines and consensus statements (see Council of Ethical and Judicial Affairs of the American Medical Association 1999).

⁴ NVK 1992: 29.

⁵ NVK 1992: 41.

⁶ NVK 1992: 23.

⁷ NVK 1992: 37.

and 'NICU B'. Each NICU is part of a large University Medical Center. I will refer to the two centra as 'UMC A' and 'UMC B'. Since the Dutch world of neo-natal intensive care is quite small, it is necessary in order to guarantee the anonymity of the doctors whose behavior is the subject of study, not to give specific information about the two medical centers. They are similar in size. They are among the largest academic hospitals in the Netherlands. Each employs some 9000 health care professionals. About 30.000 patients are hospitalized yearly in and about 3.000 students study in each UMC.⁸

4 Patient population

For practical reasons, I had to restrict my study to babies admitted to each NICU in connection with severe 'perinatal asphyxia'. 'Perinatal asphyxia' refers to the occurrence of a severe shortage of oxygen to the baby, occurring immediately before, during, or soon after birth and causing organ damage. All babies in my sample are dependent on life-prolonging medical interventions. In most cases, the heart of the baby stopped beating either during birth or later and doctors provided resuscitation (consisting of heart massage and possibly injections of a drug that stimulates heartbeat).⁹ In all cases, the baby's breathing failed. NICU doctors intervened by inserting a tube in the baby's throat and attaching the tube to a breathing machine. Brain damage is common among this group of babies. Doctors try to make predictions for the baby's future by assessing the presence and extent of damage in that part of the brain that controls consciousness, thinking, perception, memory, attention, learning, behaviour and emotions (the so-called 'superior' functions) and movement.¹⁰ Brain damage that is likely to cause major motor impairments is also assessed with special attention.

There are two reasons for the choice of this patient population.

An unpredictable event. Many defects of the fetus can be diagnosed early on in the course of the pregnancy. This gives the parents the chance to choose between accepting a severely defective baby or ending the pregnancy. The parents also have time to get adjusted to the idea that their child will need special care. By contrast, *perinatal asphyxia* cannot be diagnosed before birth. Almost all of the babies of my sample were born from a healthy mother. The pregnancy proceeded without a single complication. The babies were perfectly healthy until a sudden and unpredictable event took place shortly

⁸ Data referring to the years between 2004 and 2008. Source: websites of UMC A and UMC B.

⁹ Adrenaline.

¹⁰ The cerebral cortex.

before, during or soon after birth, shocking the parents who are unprepared.

Difficult predictions for the baby's future. The mid-term and long-term consequences of *perinatal asphyxia* are not easy to predict. Even with the technical possibilities and scientific knowledge of today's medicine, the future of babies who have this condition can be predicted only with approximation. The uncertainties concerning predictions for the baby's future make the decision-making process particularly value-laden.

5 Organization of the study

I investigated the use of 'medical futility' in NICU A and NICU B in *perinatal asphyxia* patients by means of a *study of patient files* and by carrying out *face-to-face interviews* with neonatologists.

5.1 Study of patient files: sample and methods

In 2007 I started a study on medical files. I received a table from the administrations of NICU A and NICU B, listing all the entries in their database referring to babies born alive in 2004 and admitted to the NICU in connection with a diagnosis of 'perinatal asphyxia'. My research was retrospective, in order to investigate the condition of alive babies at six months, one year, and three years from birth.

Each patient's file is made up of different sections. Some parts of the file contain only medical data (such as blood values figures) and are not relevant for an investigation of the decision-making process at the end of life. I focused instead on the reports hand-written by each doctor and nurse during his or her shift, documenting the conditions of the baby, the content of the meetings with the parents and *the decision-making process*. The letter that accompanies the patient's discharge from hospital (addressed to the general practitioner of the baby's family) and the follow-up were also relevant. There were only minor differences between the two NICUs in the structure of patient files.

The table I received from NICU A lists 27 babies. The table I received from NICU B lists 61 babies. The names of the patient and all personal information concerning the family can not be divulged. Therefore, I assigned to each baby a letter and a number. I used the letter A for babies that have been hospitalized in NICU A and B for the babies admitted to NICU B. The cases are numbered from A1 to A27 and from B1 to B61. Only the most severe cases are included in my research (12 cases for NICU A and 13 for NICU B), and can be divided up into different categories.

In some cases, on the basis of medical evidence and observation of the condition of the baby, doctors come to the conclusion that the baby is facing a gloomy future and remove the breathing tube, with the approval of the parents of the baby. In very few cases, the non-treatment decision does not consist of withdrawal of ventilation but of withholding of life-prolonging surgery.

In other cases, a non-treatment decision is considered or even agreed upon with the parents, but eventually not carried out. Typically, this is connected with two reasons. In some cases, the condition of the baby improves. Therefore, doctors become more optimistic with regard to the baby's future, and opt for a full treatment policy. Still in other cases, the withholding of resuscitation in the event of heart failure is agreed upon and heart failure does not take place.

Finally, in three cases, no discussion of non-treatment decisions is documented in the file.

A sample case from the cases I investigated is reported in Appendix, B.

5.2 Interviews with neonatologists: sample and methods

After having completed the study on patient files, I contacted neonatologists in NICU A and NICU B for face-to-face interviews. The interviews were based on a 10-questions questionnaire and took between 40 minutes and one and a half hours to complete. In order to protect anonymity, the doctors' family names have been replaced with fictional names. Reporting personal data about each neonatologist would result in a breach of confidentiality. I therefore restrict myself to a general description of my sample.

The staff of NICU A consists of 11 doctors. Two recently graduated young doctors (who had just begun their internship in the NICU and therefore had no professional experience yet) were not interviewed. Four of the doctors I interviewed are women. Four of the doctors are aged between 40 and 45; three are older than 45 and two are younger than 40. Four doctors have between 5 and 10 years of professional experience as neonatologists, three doctors have more than 10 years of professional experience, and two have less than five years. All doctors answered my question concerning their religious affiliation. Six of them are Catholics but only one is observant (four define themselves 'not strictly observant' and one was raised in the Catholic persuasion but is currently a non-believer). Two doctors belong to reformed confessions (one is Lutheran but is not observant and one was raised

in a Calvinist community but is currently a member of an Ecumenical congregation). The last doctor is not religious.

The medical personnel of NICU B consists of 11 doctors. However, five of them were not available for my interviews (for illness or other reasons) and one young doctor with very little professional experience was excluded from the present study. All of the doctors I interviewed are men. One doctor is aged between 40 and 45, two are older than 45 and two are younger than 40. One doctor has less than 5 years of professional experience as a neonatologist, two doctors between 5 and 10 years, one between 10 and 15 years and one more than 15 years. Like their colleagues in NICU A, neonatologists in NICU B were very open about their religious affiliation. One of them is a practicing Dutch protestant. The remaining four are not religious (one of them was raised in a non religious family, two were raised in Dutch protestant families and one in a strict Catholic family).

All face-to-face interviews were recorded. Each doctor received a CD with the recording and a word-by-word transcript of his or her interview, and was given the chance to further clarify and explain the content later on. Two doctors made use of this option and sent me an e-mail with clarifications.

The list of questions used is reported in Appendix, C. A sample from one of the interviews is reported in Appendix, D.

6 Research questions and expected findings

Most of my expectations on the findings of my empirical study were based on the results of other studies carried out in the Netherlands and in other European countries and published in the 1990s and 2000s.

6.1 National and European studies published in the 1990s and 2000s

A national study shows that more than half of all infant deaths that took place in 1995, 2001 and 2005 were preceded by a decision to abstain from (further) life-prolonging treatment.¹¹ The same study shows that more than half of infant deaths take place in the NICU. Roughly two-thirds of end-of-life decisions are based on the lack of prospects of survival for the child, one third on a poor prognosis. In nearly all cases, the decision was discussed with the parents; in roughly 30% the

¹¹ Onwuteaka-Philipsen et al. 2007: 122.

decision was made at the explicit request of the parents. In nearly all cases the decision was discussed with other doctors.¹²

A recent comparative study made it possible to compare NICU end-of-life medical practice in The Netherlands with that of other European countries.¹³ The study was carried out in 1996-97 and secured data from doctors working in NICUs in Italy, Spain, France, Germany, the Netherlands, the UK, and Sweden. In the Netherlands and the UK, the percentage of doctors who report having made non-treatment decisions at least once in their career is close to 90%. In Sweden it is close to 80%. France and Germany follow, with percentages around 70%. The lowest percentages are to be found in Spain and Italy. In conclusion, end of life medical practice in neonatology in The Netherlands as far as non-treatment decisions are concerned does not seem to differ significantly from that of other European countries, especially Sweden and the UK.

As one other report from the same comparative European study shows, the crucial difference between The Netherlands and other countries relies in the *attitude* of doctors rather than in *medical practice*. Doctors expressed their opinion with regard to a number of arguments against the permissibility of non-treatment decisions in neonates. The 'sanctity of life' principle seems to have an important influence on Italian and Spanish doctors¹⁴ while it plays a minor role in all other countries, especially the Netherlands. There are sharp differences between various countries with regard to the importance that should be attached to the child's predictable future physical and mental impairments in the decision-making process over administration of life-prolonging treatment. German doctors appear to be by far the most conservative, followed by the Italians. The Dutch are instead on the other side of the spectrum: a mere 1% of Dutch doctors held that mental disability should not in itself be a reason for a non-treatment policy. These figures show that there is a significant gap between the attitude of Dutch doctors and that of their European colleagues concerning the admissibility of 'quality of life' evaluations in the decision-making process. The attitude of Dutch doctors appears to be different than that of most European colleagues also with regard to the so-called 'slippery slope' argument, as the Dutch are by far the least sensitive to it (9%).¹⁵ Taken together, the data from the study show that

¹² Vrakking et al. 2005: 1330.

¹³ Cuttini et al. 2000.

¹⁴ On the influence of the 'Sanctity of life' principle on Italian medical practice and the perception of 'quality of life' evaluations as a form of discrimination, see Moratti 2008a.

¹⁵ However, other data suggest that the Dutch are not indiscriminately in favour of a permissive policy on end of life decisions. Together with the Swedish, the Dutch

Dutch doctors (and, to a lesser extent, Swedish and UK doctors) tend to emphasize future 'quality of life' as a particularly important factor in the decision making process, by contrast with Spanish, French, German, and especially Italian doctors.¹⁶

In conclusion, empirical research shows no indication of substantial differences in medical practice between the Netherlands and northern European countries. However, the Netherlands is certainly at the 'quality of life' end of the spectrum as far as the attitude of doctors toward withholding and withdrawing life-prolonging treatment for severely defective newborns is concerned.

Tables summarizing the overall findings of the studies described in the present paragraph are reported in Appendix, A.

6.2 Research questions

For practical reasons, in the present paper I restrict myself to presenting my *main* research questions. In my work, I focused on: (1) definition and assessment of 'medical futility' and 'poor prospects' for the future of a baby in individual cases, (2) decision-making process leading to decisions to administer or not to administer life-prolonging treatment, (3) characteristics and duration of the dying process, (4) use of palliative drugs.

6.2.1 Definition and assessment of 'medical futility' and 'poor prospects for the future of the baby'

Based on the data from available empirical studies, I expected to find that brain damage and 'quality of life' would be the crucial factors in 'futility' assessments.

6.2.2 Decision-making process leading to decisions to administer or not to administer life-prolonging treatment

My study of the decision-making process leading to decisions to administer or not to administer life-prolonging treatment, focused in particular on the role of the parents and on the importance of potential ventilator-independence.

Role of the parents

appear to be the most inclined to think that the fact that a handicapped child is a potential burden for his family should *not* influence the decision-making process (35% against the 16% of UK doctors).

¹⁶ Rebagliato et al. 2000.

Based on the findings from the empirical studies available, I expected to find full involvement of the parents in the decision-making process on administration of life-prolonging treatment to their baby. Also, I expected doctors to tell me that the parents *should* always be involved.

Role of the parents' 'draagkracht'

A baby's prospects for the future depend not only on its physical condition. The baby's chances of being adequately taken care of are also relevant. The Dutch use the word *draagkracht* (literally meaning 'bearing power' or 'carrying capacity') to refer to the ability of the parents to accept and take care of a baby with extremely severe handicaps. My interest in the role of the parents' *draagkracht* in the decision-making process did not stem from findings from available studies on medical practice, but rather from the role of the concept in the debate on end-of-life decisions in neonatology in the Netherlands.¹⁷ I did not have any expectation on findings here.

Importance of potential ventilator-independence and boundaries between 'natural' and 'non-natural' death

Severely asphyxiated infants are as a rule ventilator-dependent at least in the first few hours of their lives. In that situation, the non-treatment decision on a baby with a very poor prognosis will in practice involve withdrawal of ventilation: death is caused by lack of oxygen. As time passes, the baby becomes increasingly likely to be able to breathe without respiratory assistance.¹⁸ In a nutshell, withdrawal of ventilation opens three possible scenarios:

- (i) *Ventilation-dependence*: the baby cannot provide any oxygen intake to itself without respiratory assistance and will die within minutes.
- (ii) *Low ventilation-dependence*: the baby is able to provide at least some oxygen intake to itself without respiratory assistance. Dying could take hours or even days and could involve gasping.
- (iii) *Ventilation-independence*: the baby can provide a sufficient oxygen intake to itself without respiratory assistance and is not in a 'dying process'. Such a baby is intensive care independent.

In most (though not in all) severe *perinatal asphyxia* infants, with time there is a gradual transition from situation (i) to (ii) to (iii).

¹⁷ I first heard mention of the concept of 'draagkracht' at a workshop on end-of-life decisions in infants and children in the Netherlands.

¹⁸ This happens because the baby's brainstem (that controls breathing and other involuntary movements such as reflexes) begins to function, regardless how damaged the rest of the baby's brain might be. This is the same mechanism behind the transition from coma to Permanent Vegetative State in adults.

There is a debate among Dutch neonatologists concerning the use of certain drugs, namely muscle relaxants, in the context of withdrawal of ventilation on grounds of medical futility in situations (ii) and (iii). Muscle relaxants cause paralysis and bring about death by impeding breathing. Some maintain that if muscle relaxants are administered in the context of withdrawal of life-prolonging treatment, the behavior of the doctor amounts to 'deliberate ending of life' and as such is a breach of the Criminal Law, and should be reported to the Prosecutorial Authorities because the baby does not die for 'natural causes'.¹⁹ Others argue instead that the baby dies a 'natural' death and the behavior of the doctor does not amount to a breach of the Criminal Law but rather to 'normal medical practice'. This difference in characterization is potentially critical for the legality of what the doctor does and for the sort of control his behavior receives.

In a workshop I took part in, a Dutch neonatologist reported that she and her colleagues as a rule feel under pressure to evaluate the extent of the baby's damage *before* the baby begins to breathe autonomously. On the basis of what I learned in the workshop, I expected to find that potential ventilator independence does have a role in the decision-making process.

6.2.3 Characteristics and duration of the dying process

In certain cases, the baby's dying process is long. The baby makes movements that adults interpret as signs of discomfort, turns very pale or blue in the face, or continuously gasps for air. In the present state of medical science, it is in fact not altogether clear whether a severely brain-damaged baby experiences the dying process at all. We do not know whether the baby 'suffers' in the sense that we use this word in ordinary language. The gasping may be just a reflex reflecting the fact that the brainstem is still functioning, while the brain cortex presiding over feelings and sensations is destroyed. However, we do not know this with certainty and the baby's discomfort, especially the gasping, is very unpleasant for an adult to see, especially for a parent.

In my research, I investigated the characteristics and duration of the dying process in medical practice (in patient files) and the perception of the dying process by neonatologists (through interviews). I expected to

¹⁹ In the last few years there have been regulative developments in the Netherlands concerning 'deliberate ending of life' of newborn babies. The behavior does amount to a criminal offence. However, if the doctor follows a number of requirements of careful practice in the decision-making process leading to the decisions deliberately to end the baby's life and reports the death of the child to a special Committee which in turn advises the Prosecutorial Authorities on whether the requirements of careful practice have been followed, the Prosecutorial Authorities might order stay of prosecution.

find that apparent suffering is considered always unacceptable. I expected doctors to tell me that in some cases the dying process is 'too long' and that (together with the conditions of the baby) the parents' perception of the duration of the dying process is an important factor to determine whether its duration is acceptable.

6.2.4 Expected findings: use of palliative drugs

In the context of withdrawal of life-sustaining treatment on grounds of futility, it is appropriate medical practice to administer morphine (or morphine-like drugs) and midazolam (this drug serves also for control and prevention of convulsions). If administered in large doses, each of these drugs is thought to have a life-shortening effect. The extent to which these drugs actually speed up death is unclear. A Dutch anesthesiologist experienced in end of life decisions in adult patients maintains that morphine does not speed up the death of those patients at all;²⁰ his opinion is now backed up by evidence from recent medical research.²¹

I investigated two aspects of the use of palliative drugs: (i) the dose actually used in medical practice and the dose that doctors would deem appropriate to use in a hypothetical case and (ii) doctors' perception of the widely accepted idea that such drugs might shorten life and the influence of this on medical practice.

Based on findings from studies published in the 1990s and 2000s, I expected to find out that most neonatologists do think that palliative drugs shorten life and accept the shortening of life as a 'side-effect' of palliative care primarily aimed to relieve discomfort.²² I expected this to be reflected in medical practice, for example in how the choice to administer palliative medications is presented to the parents. Furthermore, I aimed to investigate whether the dose of palliative medications is similar in similar situations.

7 Further information on the research

Further information on the doctoral research and its findings can be obtained from the author (s.moratti@rug.nl).

In the Appendix, the reader may find tables summarizing information from empirical studies carried out in the 1990s and 2000s and described in Para 6.1, and small samples from the research findings. The samples are meant to clarify my research methodology and do not represent the overall pattern of findings from patient files and interview.

²⁰ Admiraal and Griffiths 2001.

²¹ See Provoost et al. 2005 and the sources they refer to.

²² This aspect of the findings from empirical studies available is not presented in Para 6.1; please refer to the tables in Appendix, A.

Sofia Moratti
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Draft – do not quote

This paper includes the list of references for my PhD thesis, to give readers who are interested the chance to take a deeper dive into my research topic.

Appendix

A. Tables summarizing results of studies carried out in the 1990s and 2000s and referred to in Para 6.1²³

National studies

Table 1. Causes of death for babies under 1 year in 1995, 2001 and 2005 (percentages)			
	1995	2001	2005
No end-of-life decision	38	33	41
Abstention and -			
- no drug* administered	26	26	27
- intensification of pain relief	23	29	20
- drug* administered with explicit intention to hasten death	8	8	8
No abstention and -			
- intensification of pain relief	4	3	3
- drug* administered with explicit intention to hasten death	1	1	1
total	100 (N=1041)**	100 (N=1088)**	100 (N = 834)**
* 'Drug' includes analgesics. ** Estimates. Sample totals 299, 233 and 122, respectively, based on deaths August-November.			
Source: <i>Onwuteaka-Philipsen et al. 2007: 122.</i>			

Table 2. Characteristics of end of life decisions, 1995 and 2001 (percentages)		
	1995 (n=184)	2001 (n=154)
Place of death		
- NICU	50	56
- Hospital	45	37
- Out of hospital	5	7
Diagnosis		
- Congenital abnormality	22	20
- Other	78	80
Reason for end of life decision		
- No chance of survival	76	72
- Poor prognosis	18	23
- Other	6	5
Drugs used		
- Morphine	46	52
- Only sedatives	2	2
- Neuromuscular relaxant	9	4
Estimated shortening of life		
- Less than 1 month	82	85

²³ Terminological note: 'abstention' is a synonym of 'non-treatment decision'.

- More than 1 month	13	12
- Not known	4	3
Discussion		
- With parents ²⁴	91	97
- Decision made at the explicit request of the parents	28	29
Discussion with others ²⁵		
- Colleague (doctor)	91	97
- Nurses (or other caregivers)	40	28
- No discussion	7	3
<i>Source: Vrakking et al. 2005: 1330. Data for 2005 are not available.</i>		

Comparative European studies

Table 3. Proportions of neonatologists who report having made specific end of life decisions (percentages)							
	Italy	Spain	France	Germany	NL	UK	Sweden
Withholding*	36	86	73	75	93	91	80
Withdrawal**	23	38	76	69	93	89	88
Pain relief	26	67	92	74	92	78	82
Deliberate ending of life	..***	..***	86	..***	45	..***	..***
* Withholding of intensive care. ** Withdrawal of artificial ventilation. *** The percentage of doctors who reported having deliberately ended a baby's life was negligible.							
<i>Source: Cuttini et al. 2000: 2115.</i>							

Table 4. Neonatologists' endorsement of arguments against abstention (percentages).*							
	Italy	Spain	France	Germany	NL	UK	Sweden
Life is sacred ¹	33	16	5	3	1	3	8
Physical disability is not a reason for abstention ²	47	43	26	62	8	16	36
Mental disability is not a reason for abstention ³	23	14	4	18	1	9	8
'Slippery slope' argument ⁴	29	61	34	48	9	16	18
Burden for the family is not a reason for abstention ⁵	33	26	25	29	34	16	35
Respect for the law ⁶	35	18	5	34	25	13	3
Treating allows acquisition of clinical experience ⁷	29	19	13	1	3	6	2

²⁴ 'Discussion with parents' is used here in the sense of 'inclusion of the parents in the decision-making process', not in the sense of 'disagreement between doctors and parents'.

²⁵ See previous note.

* Proportions of doctors responding “agree” or “strongly agree” with each statement. 1 “Because human life is sacred, everything possible should be done to ensure a neonate’s survival, however severe the prognosis.” 2 “Some life is always better than no life (even with severe physical disability).” 3 “Some life is always better than no life (even with severe mental disability).” 4 “Limiting IC leads down the ‘slippery slope’.” 5 “The burden that a disabled child represents to the family is not relevant in decision-making. 6 “If the law does not allow treatment limitation, there is no room for end of life decisions.” 7 “Every neonate should be given maximum IC irrespective of outcome, so that the clinical experience acquired can benefit future patients.” Source: Rebagliato et al. 2000: 2454-2455.
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B. Sample case from the Research on patient files (case A8)

Suffocation in uterus -- The mother is admitted to hospital in connection with breaking of the water (which appears to be stained with the baby’s stool). There doctors find out that the heart of the baby is beating abnormally slowly. They immediately perform an emergency cesarean section. Upon birth,²⁶ the baby’s condition is similar to coma. She does not react to any stimulation. Her body and face are blue, her heart is still and she does not breathe. Doctors immediately attach the baby to a breathing tube and provide resuscitation. The baby’s heart does not start beating until 15 minutes after birth. This is a very long resuscitation time, especially for a baby whose conditions were already very poor at birth. A few hours after birth, the baby is transferred to NICU A. She is still attached to the breathing tube.

Admission to the NICU and poor prognosis -- On admission, NICU doctors classify the baby’s condition as Sarnat III. Brain imaging shows that there has been extensive bleeding in the brain.²⁷ Bed-side brain function monitoring shows that the functioning of the baby’s brain is seriously defective.²⁸ On day 0, the doctors meet the parents and explain that there are signs of severe brain damage. They say that the life of the baby is still in danger and that there is a substantial chance of severe handicaps in case of survival. On that night, bed-side brain function monitoring shows persistent convulsions.²⁹ Doctors administer Drug 1. However, within one and a half hours the baby experiences persistent convulsions again. Drug 1 is administered again. After this episode, the doctor on shift on that night writes: “poor prognosis!”

The decision-making process -- In the morning of day 1, bed-side brain function monitoring shows that the part of the brain that controls superior functions has ceased to work. An EEG confirms these findings.³⁰ The doctor on shift writes: “stop treatment because that is futile, with the exception of palliative care”. The doctor meets the parents. If kept alive, the baby is destined to live a **merely vegetative life**, the doctor says. He suggests that treatment should be withdrawn. He adds that there is “no guarantee that the baby will die quickly” after treatment is withdrawn; the dying process “might even last days”³¹ because “the baby will probably be able to breathe by herself after withdrawal of artificial ventilation”.³² Some newborns are in a borderline condition between ventilator-dependence and ventilator-independence and might be able to breathe, albeit with great difficulty, without artificial ventilation. After

²⁶ The baby was born at 38 weeks and five days and weighted 3000 grams. Her Apgar score was 0/0/0 at 1/5/10 minutes from birth.

²⁷ An echography of the brain shows multiple subcortical anomalies.

²⁸ Low voltage CFM.

²⁹ Status epilepticus.

³⁰ Both CFM and EEG show a flat trace.

³¹ Doctors’ files. Report of the meeting with the parents written by the doctor.

³² Nurses’ files. Report of the same meeting with the parents written by the nurse.

the ventilator is withdrawn, such babies do not live for long, but do not die quickly either. However long the dying process might be, the doctor promises that everything possible will be done to spare suffering to the dying baby: “she will receive drugs and the dose might be increased if necessary to achieve comfort. The parents know about the side-effects of morphine”³³ (morphine might hasten death). The parents are reported to agree with the abstention policy.

The dying process -- The breathing tube is removed at 18.30 of day 1. The baby receives Drug 2³⁴ “because her muscles are very stiff” and morphine³⁵ “in order to prevent discomfort”.³⁶ The baby quickly turns blue. Her heart rate is extremely slow. At first she breaths with difficulty, then she stops breathing and does not move. The heart stops beating at 19.15 while the baby is in the arms of her mother.

C. List of questions asked during interviews with neonatologists

1. Personal data

- University where you received your degree
- Age
- Years of experience as a neonatologist (fellowship included)
- Religious affiliation (including: are you practicing or not)

2. In general terms, what considerations would be important to you in deciding whether a treatment is ‘zinloos’ in neonatology?

3. As a general rule, ‘medisch zinloos’ treatment should not be administered. Are there exceptions to this rule in neonatal medical practice?

4. Before this interview, I have carried out a patient file research. The patient population of my research consisted of ‘perinatal asphyxia’ newborns (Sarnat 2 or 3) hospitalized in the NICU. In some cases, doctors came to the conclusion that the baby’s prospects for the future were poor. Generally speaking, what are ‘poor prospects for the future’?

In particular:

- What is the relevance of brain damage?
- What is the relevance of damage to other organs than the brain?
- What is the relevance of the parents’ “draagkracht”?

5. In the case described: which factors would lead you to consider withdrawal of life-prolonging treatment, which factors would lead you not to consider treatment withdrawal?

6. Think again of the case described. I add another detail to it. The baby is still ventilator-dependent, but is close to achieving respiratory independence. Would this additional factor be relevant for your decision?

- If so, why?
- If not, why?

7. Think again of the case described. The ventilator has been withdrawn. In principle, could one say that a dying process can be ‘too long’?

³³ Doctors’ files.

³⁴ Midazolam 0,2 mg/kg/hour.

³⁵ The dose was 0,04 mg/kg/hour.

³⁶ Doctors’ files.

- *If yes, when is a dying process 'too long' in your view?*

8. After withdrawal of ventilation, would you ever consider administering muscle relaxant?

- *If so, why?*
- *If not, why?*
- *What is the influence of the end of life decisions policy of your institution on your behaviour?*

9. Should a doctor who administered muscle relaxant always report the death as a non-natural one?

10. What would you consider appropriate palliation after ventilation withdrawal?

- *In deciding whether and how much morphine to administer, do you take into account the possibility of a life-shortening effect?*
- *What do you consider to be the maximum dose of morphine for a term baby of normal weight?*
- *In deciding whether and how much midazolam to administer, do you take into account the possibility of a life-shortening effect?*
- *What do you consider to be the maximum dose of midazolam for a term baby of normal weight?*

D. A sample answer from interviews with neonatologists (fragment from a doctors' answer to the last part of Question 4)³⁷

[The draagkracht is] the willingness of the parents to accept a handicap, but also the physical and psychological ability to take care of it, and it is not only the parents but also the whole family, because very often the child with asphyxia is not the only child, but there are brothers and sisters. The life of the family will change, and to keep on a normal life as before and to set down all your expectations from life and to be positive about the life – that is very heavy; and people are very often willing to do so, but are not able. I think you have to discuss that with parents, you have to openly discuss that. I think parents are often willing to do so, but they are not able to see what the future will mean. [...] I think it is physical and psychological ability. There are people who have more strength to deal with problems than other people. That is an ability that one has or does not have. But there is also cultural acceptance of problems. And that can be more emotional. [...] Usually a child will learn to walk and will be able to do things himself. A child with a physical handicap or a mental handicap – you have to do more and you have to be healthy.

³⁷ The doctor's name is a pseudonym.

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