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Scientific Contribution

Moral dilemmas in neonatology as experienced by health care practitioners: A qualitative approach

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Abstract. During the last two decades there has been an enormous development in treatment possibilities in the field of neonatology, particularly for (extremely) premature infants. Although there are cross-cultural differences in treatment strategy, an overview of the literature suggests that every country is confronted with moral dilemmas in this area. These concern decisions to initiate or withhold treatment directly at birth and, later on, decisions to withdraw treatment with the possible consequence that the child will die. Given that the neonate cannot express his or her own will, who will decide? And on the basis of what information, values and norms? We explored some of these issues in daily practice by interviewing a small sample of health care practitioners in a Dutch university Neonatal Intensive Care Unit (NICU). It turned out that experiencing moral dilemmas is part of their daily functioning. Nurses underline the suffering of the newborn, whereas physicians stress uncertainty in treatment outcome. To make the best of it, nurses focus on their caring task, whereas physicians hope that future follow-up research will lead to more predictable outcomes. As for their own offspring, part of these professionals would hesitate to bring their own extremely premature newborn to a NICU. For the most oppressing dilemma reported – terminating an already initiated treatment – we propose the concept of 'evidence shift' to clarify the ambiguous position of uncertainty in decision making.

Key words: 'evidence shift', empirical ethics, moral dilemmas, neonatology, nurses, prematurity

Introduction

Neonatology is a young medical discipline and concerns the treatment of newborns with disturbed or threatened vital functions. During the last two decades, treatment has become more and more directed at premature and extremely premature infants, the latter being born before 26 weeks of gestation. Apart from their prematurity and low birth weight, these neonates might be perfectly healthy, although some suffer from congenital abnormalities as well. Due to technological developments the survival rate of premature neonates has increased considerably, but not for those born before 23 weeks (Kollée et al., 1999; Hussain and Rosenkrantz, 2003).

At first sight it becomes already clear that neonatology is a discipline with many decisional problems and moral dilemmas. There is much to be gained in this field: survival and (partial) cure followed by many years to live, up to a whole life. But costs may also be high, not only in terms of health care input and energy of caregivers, but also in terms of poor quality of life of the survivor – sometimes as a side-effect of treatment. This holds all the more so for healthy, but very premature newborns. In earlier days these infants died spontaneously at birth. Now they can be kept alive by mechanical ventilation and other new techniques with the result that also more of these neonates survive being doomed to live a life-long handicapped life – together with their caring families (Lorenz et al., 2001).

Moral dilemmas in neonatology often concern decisions regarding initiating or withholding treatment just after birth, and, in the following days or weeks, with regard to continuing or withdrawing treatment. For many researchers the study of Duff and Campbell (1973) is the starting point in reporting moral questions in the field of neonatology. This was years before the rise in treatment possibilities in case of prematurity. They found that, during 1970–1972, in Yale (New Haven), 14% of deaths in neonates was related to withdrawal of treatment. These authors already discuss the problem of severely impaired survivors, the influence of the parents on decision making and the right of the child to die.

In the following we will give an overview of recent literature on ethical issues in neonatal care and comment on these. Thereafter, we will present our own empirical material on how neonatologists and nurses of one Dutch neonatal intensive care unit (NICU) experience moral dilemma's, followed by a model clarifying one of the problems mentioned: the fact that continuing treatment is much easier than the decision to stop it.

Ethical issues in cross-cultural perspective

Treatment practices in different countries

In different Western countries there is some variation with respect to treatment strategy. On the basis of a rather informal study, Rhoden (1986) distinguished three strategies that seem still applicable. First there is the *statistical prognostic strategy*, particularly found in Sweden, implying that in newborns with, statistically spoken, a very unfavorable diagnosis treatment may be withhold directly at birth. Second, particularly in the US, she found the '*wait until certainty strategy*': near universal initiation of intensive care, implying that all premature or impaired infants are treated rather aggressively until there is virtually certainty of either death or irreversible coma. And third, there is the *individual prognostic strategy*: initiation of intensive care in almost every infant followed by regular re-evaluation of its individual prognosis, with the option of withdrawing treatment in case of medically futility or a very poor prognosis. Here, also in extremely premature infants, treatment may be initiated in order to create the opportunity for a more extended diagnostic procedure. This strategy was characteristic for the United Kingdom (UK), and according to a more recent study, also for The Netherlands (Lorenz et al., 2001).

Since Rhoden, many studies compared actual treatment practices in different countries in order to get a better grip on what 'ought to be done' and to infer moral rules. In Europe, the EURONIC-study was carried out in order to make an inventory of neonatal treatment practices in seven European countries: Italy, Spain, Germany, France, Sweden, The Netherlands and the UK. Here, on the basis of 1235 completed questionnaires with a response rate of 89%, Cuttini et al. (2000) reported that most physicians had been involved at least once in setting limits to intensive care of neonates because of incurable conditions. The withdrawal of mechanical ventilation was mentioned as the most difficult decision. Here, the highest frequencies were found in The Netherlands, the UK and Sweden. Furthermore, administering drugs with the aim of ending life was reported only in France and in The Netherlands with some, although still a very low, frequency. It should be noted that the data in this study are self-report anonymous data. These may differ from official registration. Syvertsen and Bratlid (2004), for example, reported that in Norway the decision making process in withdrawing treatment is poorly documented.

Another way to study cross-cultural differences and moral standpoints is to relate physicians' attitudes to their practices. As part of the EURONIC-study Rebagliato et al. (2000) collected data on an attitude scale concerning end-of-life decisions in neonates, ranging from absolute value of survival versus valuing quality of life as well. Physicians wanting to preserve life at any cost were mostly found in Hungary, Estonia, Lithuania and Italy. The quality-of-life pole was taken into account most in the UK, The Netherlands and Sweden.

Despite cross-cultural differences in treatment strategies moral dilemmas are found in every country. Very recently there was a heated debate in the literature between Silverman (2004) and Lorenz (2004). Silverman worries about the possible over-treatment of neonates in the US and he attributes this over-treatment to opportunistic forces aiming at financial profits, stripped of any form of compassion with the neonate and its future (see also Silverman, 1992). Lorenz (2004), however, points to the fact that, particularly in the US, it is the parents who decide about treatment of their neonate and who, indeed, often want to prolong treatment as much as possible. Therefore, he argues, it is very important how physicians actually inform parents.

The decisional role of parents

This brings us to the further issue of: who decides about treatment and on the basis of what information? Because the neonate cannot speak for himself or herself, others have to decide. In some cases, the physician intends to initiate treatment or to continue it against the parents' wish. In other cases it is the parents who desire treatment prolongation against the advice and willingness of the doctors. They may even fight this in court –

as happened in 2004 with regard to baby Charlotte in the UK.

Also with respect to the decisional role of the parents cultural differences have been reported. Garel et al. (2004) interviewed obstetricians and midwives in France and found that parents were not involved in decision making. They consider this a disadvantage. The study of Orfali and Gordon (2004), however, points to the opposite. They interviewed mothers in an American NICU where decision making is based on autonomy and informed consent of the parents and in two French NICU's where medical authority and a paternalistic attitude prevailed. They concluded that in both countries mothers experienced the NICU as negative, whether she was prepared for it or not. The longer the baby's stay in NICU, the more problematic a bad outcome or treatment limitation became. The American model involved unrestricted visiting hours, switchover of doctors, and being exposed to either optimistic or highly uncertain information. This seemed to incur more distress than the French situation where parents received information only in terms of certainty and experienced emotional support. Here, the decisions the doctors made became perceived as the parents' own choices. In contrast, the American parents perceived care as impersonal and felt left alone with their decisions, worries and emotions. It should be noted further that none of the parents, neither in the US nor in France, was eager to take over the terrible end-of-life decision. This study raises questions about the adequacy of the principle of parental autonomy in case of neonatal decisions (see also Reiter-Theil, 2004, p. 27).

The situation in The Netherlands

Also in The Netherlands, neonatology is a young discipline, starting with the first case of mechanical ventilation of a newborn in 1969. At present there are ten neonatal intensive care units, eight of these related to a university hospital. Treatment is carried out by neonatologists: paediatricians with an additional neonatology education of two and a half years. For the 24-h care of one neonate three fulltime specialized nurses are occupied.

As to treatment outcome an early, nationwide prospective study on very-low-birthweight infants hospitalized after birth in 1983, reports that, of the discharged infants, 6% proved to have a major handicap at age two, and 12% lived with a minor handicap (Zeben van-van der Aa et al., 1989). These data were received as rather disappointing. More recently, Van der Heide et al. (1997) studied medical end-of-life decisions in Dutch NICU's by means of anonymous questionnaires and strictly confidential interviews. As motives for end-of-life decisions they found: no chance of survival and/or a very poor prognosis (see also Provoost et al., 2004). In 1% of neonates not dependent on life-sustaining treatment a drug was given explicitly to hasten death. In those dependent on life-sustaining treatment, withdrawal of treatment was an option, yes or no accompanied by potentially life-shortening drugs to alleviate pain or other symptoms, or – very seldom – by drugs with the explicit aim of hastening death. In 79% of the cases parents had been involved in decision making and in 88% colleagues had been consulted. Physicians welcomed formal review by colleagues together with legal and ethical experts, and the authors plea for more effective public control.

In a qualitative study, Mesman (2002) observed the route of several newborns in a Dutch NICU whereby observations in a North-East American NICU served as a contrast. She points to a decisional bias towards intensive treatment, also in The Netherlands, because it postpones more difficult decisions. Moreover, the irreversibility of withholding and withdrawing are difficult to deal with. Several other studies mentioned above included Dutch data, e.g. Lorenz et al. (2001) disclosing an 'individualized prognostic treatment strategy' in The Netherlands, and Cuttini et al. (2000) pointing at the importance of the quality of life criterion in end-of-life decisions in The Netherlands.

In answer to the plea for more effective public control, Verhagen and Sauer (2005) very recently developed the 'Groningen protocol' for decisions to actively end the life of newborns in The Netherlands. The protocol concerns newborns with either no chance of survival, or those, being yes or no dependent on intensive care, with unbearable suffering and/or an extremely poor prognosis and a poor quality of life. These authors consider intensive care treatment not as a goal in itself and state that its aim is not only survival, but also acceptable quality of life. Furthermore, they point to the fact that in The Netherlands euthanasia has been legally accepted since 1985. One big problem in case of a neonate is that the patient cannot verbally express his or her own will. However, the authors consider it possible to assess in a neonate extreme and sustained suffering that cannot be alleviated, together with an extremely poor prognosis. The protocol specifies further requirements, such as parental consent and consultation with an independent physician.

The authors hope that end-of-life decisions become transparent when neonatologists will make use of this strict protocol including the obligatory reporting to the Public Prosecutor. Furthermore, they propose that the Public Prosecutor will be advised by a multidisciplinary committee.

Conclusion

Along with technological developments in neonatology there has been a continuing debate about ethical issues, among these end-of-life decisions. And notwithstanding cross-cultural differences in treatment strategy, moral dilemmas are found in all countries. Although there is already a lot of information and discussion available, studies wherein health care practitioners are directly questioned about their experience of ethical dilemmas are almost absent. Also, the role and experiences of nurses has been under-exposed. In order to further promote ethical discussion in this field we sought for empirical input filling in these gaps.

Empirical input

In the following, we will present research exploring ethical issues as these are lived in daily practice in a NICU. We used a qualitative approach for this delicate task, with direct questions to several categories of health care practitioners about ethical issues and moral dilemmas. For this purpose, we had access to the NICU of a university hospital in an urban environment in The Netherlands. Our aim was to understand the significance of the dilemmas encountered and to develop more insight into the relevant ethical issues behind decisional problems.

We abstained from interviewing parents in order not to loose the cooperation from the NICU involved. To give them something in return, we communicated the results in two meetings: one for the medical staff, the other for the nurses.

Method

As starting point we used the notion of the '*embedded researcher*' as proposed by Reiter-Theil (2004; Reiter-Theil et al., 2005) in order to get familiar with the setting. We gathered oral and written information about the procedures in the NICU, studied year reports and the medical records of two complicated cases. With the consent of the head of the department we sent staff members a letter explaining the aim of our upcoming visits and of our explorative research. Thereupon, we observed the daily routine in the NICU, attended a doctor's visit round and a staff meeting.

In order to explore moral issues more specifically, we were allowed to interview staff members. In total, we interviewed 13 staff members: five neonatologists (three women and two men), six neonatological nurses including the head nurse (all women), one pastoral worker and one social worker, both women. In addition, we had extended conversations with the head of the department, a male neonatologist. The experience of these persons with working in a NICU varied from 5 up till 20 years. For one nurse this was somewhat more than one year. There was also considerable variation in age (19–63 years).

In the interviews we tried to create an atmosphere of trust and understanding and to stay close to the train of thought of the respondent. We started by asking our respondents about their daily routine. With the aid of a list of topics we made sure that, in the end, these topics were covered by the interview. Topics for physicians concern their tasks, how they arrive at a medical diagnosis and treatment plan, and the role of parents, nurses and physicians in decision making – all these with special attention to moral implications. Topics for the nurses concern their daily care for the newborn, their role in medical decisions and their contacts with the parents. Throughout, we focussed on moral dilemmas in the different tasks and roles of the respondents, and on their reflections on these.

The interviews took place in the hospital in a separate room, were audio taped and lasted between 30 and 60 min. The verbal transcripts were analysed by both authors. For each respondent we made a summary text containing themes relevant for this subject accompanied by relevant quotations. Furthermore, we compared respondents on similarities and differences on corresponding themes and tried to label these themes on a higher level of abstraction (Glaser and Strauss, 1967; Glaser, 1992). We also studied the group of physicians and the group of nurses separately. The respondents consented in anonymous use of the data.

Findings and reflections

Experience of dilemmas

All staff members interviewed – except one – experienced moral dilemmas. These dilemmas were seen as inherent in this particular work and as occurring regularly. Particularly in the first year of their work these might cause sleepless nights.

Nurses coped with these dilemmas in several ways. First, they coped by attributing decisional competence to physicians. As one nurse put it:

> I don't have the knowledge and the power to make the right decisions.

Second, they coped by caring for the newborn as good as possible. And third, they reflected on their dilemmas by comparing these with dilemmas in other medical disciplines and with a situation where modern technology is absent, e.g. a Third World country. They also pointed at societal implications:

> There are ever increasing treatment possibilities. This creates the norm that there is a remedy for every defect. (...) All these new possibilities might become too much of a burden for the child, for parents, for society.

Physicians labelled ethical issues as 'one of the hard aspects of the job', but experienced dilemmas also as a challenge. They coped by seeking as much prognostic predictability as possible and by welcoming follow-up research for better predictability of treatment outcome in the future. Furthermore, the head of the department considered it necessary to sometimes tell the physicians to reflect on problematic decisions outside working hours and to discuss these – anonymously of course – with intimates, e.g. their partner.

The one physician who reported not to experience moral dilemmas, a female neonatologist, attributed this to being able to talk things out in the medical team and reach consensus.

Decisions in own life

One of our first respondents mentioned spontaneously that, in case she would deliver an extremely premature (24 weeks) child herself, she would hesitate to take this child to a university hospital. Questioned about this, several other respondents answered in the same vein. Nurse:

> In that case I will not go to hospital. I would still deliver at home and would let the child pass away in my arms, being together as long as possible.

Physician:

> I would prefer to give birth in a non-university hospital so that I won't be faced with difficult decisions.

These answers imply that even professionals working in and used to a high tech environment may privately not be inclined to make use of it.

Core dilemmas

It was the nurses who most explicitly pointed to the direct suffering that treatment devices often impose on the child and who sometimes resented the parents' or doctor's wish to prolong treatment. For these nurses, there is often an imbalance between two important ethical principles: doing well and avoiding harm (Beauchamp and Childress, 2001).

Where nurses point to short-term harm, physicians are concerned about possible damage in the future:

> The greatest dilemma has to do with the handicaps we induce with our treatment. (medically caused damage)

So, clear disadvantages of doing well (treatment) are the immediate suffering of the newborn and the possible damage in the future. As a personal note, we would like to add that the risk of future damage should weigh heavy, particularly in those prematures that were healthy from the outset.

Nurses as well as physicians responded in the affirmative to the following question: "You try to make the child better, but how morally acceptable is this 'better' in the light of possible failures and induced harm?"

> Nurse: "This is the core question."
> Physician: "Yes, one has to weigh one against another every single day."

For physicians another core-dilemma emerged:

> The most pregnant dilemma concerns the termination of an already started treatment with uncertain outcome. (end-of-life decision)

Uncertainty

Uncertainty, in particular unpredictability of the outcome in the child, is seen as a complicating factor in end-of-life decisions, and, to a lesser extent, in the problem of medical damage. As two physicians put it:

> The problem is that in most cases it is impossible to predict how the child will develop later on.

> The moment you start treatment you have no idea what the outcome will be.

And a nurse states:

> You never know. Sometimes we think this child will not make it, but then it survives. But it happens also the other way around.

Long-term follow up is advocated in order to reduce this uncertainty. Physician:

> What I hope for the future is that we will be able to pick out those infants for whom treatment is doomed to fail and try an alternative route.

For these neonatologists, the final criterion to continue treatment is: Will this child have a livable life, i.e. a quality of life criterion. This is in agreement with how Dutch neonatologists appear in the cross-cultural studies mentioned above (e.g. Cuttini et al., 2000; Rebagliato et al., 2000; Lorenz et al., 2001). In order to define quality of life, physicians spontaneously mention the following aspects:

> A child with mild handicaps can have a good life. A child that hardly makes any developmental progress and that will be dependent on others all along .... (unfinished).

> Will the child be able to communicate in the future, will it stay dependent on the care of others for the rest of his life, will it remain spastic, will it be wheelchair-bound? And, apart from that, are the parents capable and willing to take care of the child, now and in the future?

Decisional asymmetry

What strikes in the accounts of several physicians is the statement that particularly withdrawing of an already initiated treatment ('stopping') is problematic:

> Stopping treatment is much more difficult than continuing it.

Although, at face value, this statement makes good sense, we want to further reflect on it, taking into account the route that led to this observation.

At the outset, the decision to withhold treatment in an extremely premature infant implies almost certainly its death. Already for this reason alone, initiating treatment is tempting (see also Mesman, 2002). Moreover, starting treatment creates the opportunity to gain time for more extensive, individualized diagnostic assessment (see also Rhoden, 1986) and is often seen as a trial. Both reasons play a role in The Netherlands, where treatment is started in neonates from 25 weeks on, sometimes earlier.

This rather liberal approach, however, has its drawbacks. First, there is the issue of attachment. Starting treatment implies giving the parents hope. And during the ups and downs in the period of treatment their attachment to the child will only grow. The eventual loss of the child after several days or weeks will strike them more than it would have done in the beginning (see also Orfali and Gordon, 2004). Singh et al. (2004) make the same observation in reporting that, although morally withholding and withdrawing are considered equivalent, in practice the withdrawing decision is harder to take.

One may counter-argue that parents may feel more legitimated to consent with stopping when indeed treatment has taken place, because, at least, they have 'tried everything'. However, this argument can also be countered by stating that 'to try everything' is determined and provoked by medical possibilities that may, in theory, be endless.

A second drawback of a liberal start concerns decisional complexity later on. Starting treatment in the light of rather unfavorable signs implies a route with an uncertain outcome. The options are: the child may survive with or without handicaps, the child may still die, or the child may stay alive, but turns out to be incapable of surviving without enduring intensive care. Particularly this latter alternative causes much decisional strain, but also survival with severe handicaps may not be considered an acceptable outcome.

We see this decisional complexity reflected in the interview texts. With regard to the initiation of treatment a typical response of physicians is:

> In the end we cannot give the child the cold shoulder and abstain from intervening: the survival chance is too big.

As to continuing treatment, the same type of response is made:

> There was no evidence to conclude that the prognosis was so bad as to make further treatment medically futile.

In other words: as long as there is no full evidence to justify the withholding of treatment, treatment will be initiated. And as long as there is no full evidence to justify the withdrawing of treatment, treatment will be continued. We call this: decisions based on negative evidence.

In contrast, however, withdrawing should ideally be justified with positive evidence: treatment should be stopped only if there are persuasive arguments in favor of stopping. Without persuasive evidence, stopping is unthinkable:

> The complications were not so bad as to urge us to withdraw treatment.

What we see here is an asymmetry in the use of evidence. If both evidential strategies – positive versus negative evidence – would be complementary, there would still be no decisional vacuum: the absence of negative evidence would imply the presence of positive evidence, and vice versa. However, the grey area of 'uncertainty' is the complicating factor.

'Evidence shift'

In order to visualize this state of affairs we propose the model of a decisional balance wherein 'uncertainty' (the 'chance factor') has been taken into account explicitly. Figure 1 shows that, in the beginning, the physician's line of thinking is 'initiate treatment unless...' (I). Here, all evidence in favor of treatment, together with the uncertainty of the outcome, constitutes a justification of the decision to initiate treatment (the scale turns into the direction of the arrow). What actually constitutes evidence in favor of treatment is dependent on cultural and personal values and attitudes. Further in time (II), the physician may continue this line of reasoning, even if in the meantime the evidence in favor of stopping has increased, whereas the evidence in favor of continuing has decreased. This latter evidence, together with the factor of uncertainty still constitutes enough justification for continuing treatment.

But imagine that, as time passes, evidence in favor of stopping increases further, and evidence in favor of continuing diminishes even more (III). The factor of 'uncertainty' may also decrease, but will always play a role. As long as this factor is summed up with the evidence in favor of continuing treatment, the balance will perhaps never change. Probably, only if uncertainty is summed up with the evidence in favor of stopping, the scale can turn to the decision to stop (see inverted direction of arrow).

We call this phenomenon of the changing evidential position of uncertainty '*evidence shift*'. It may clarify the physician's statement cited above that it is '*more problematic to stop treatment than to continue it*.' For parents and other persons involved this turnover in evidential justification is difficult to grasp, and all the more so if it is not made explicit. The doctor's proposal to stop

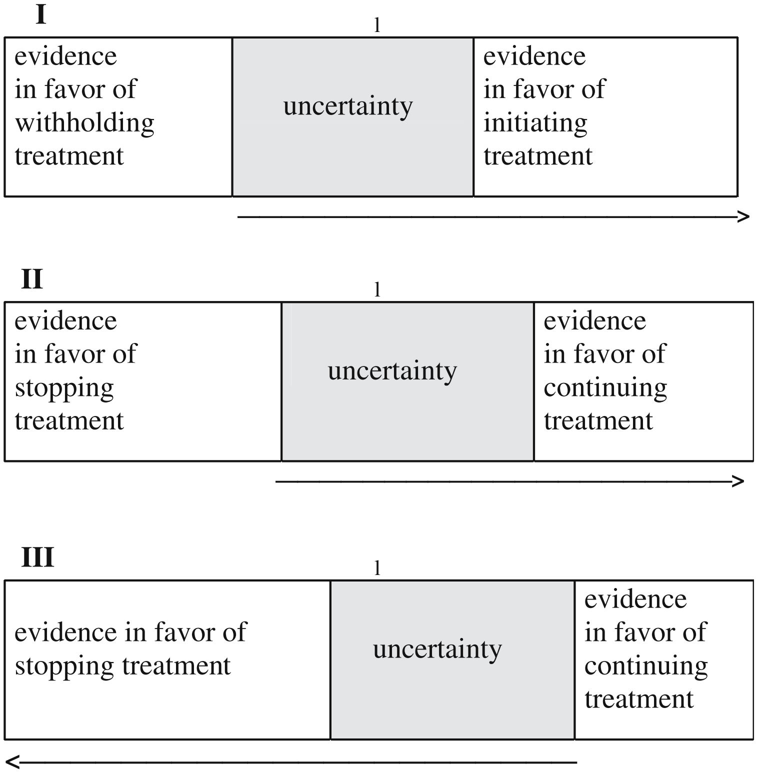

Figure 1. Three step model of decisional balance with 'evidence shift'.

treatment may be experienced as betrayal towards the child: the ‘chance factor’ that pleaded in favor of survival all the time, and that is still present, is used now in favor of stopping and thus against (survival of) the child.

Overall conclusion

Fast developments in the new discipline of neonatology imply that practitioners as well as the public are faced with new moral dilemmas. In different Western countries medical treatment differs along parameters as: financial costs and profits, criteria for initiating versus withholding treatment and for continuing versus withdrawing treatment, quality of life considerations, parental autonomy, empathy and information, and openness in reporting end-of-life decisions in the medical records. Many studies on treatment strategies and outcome have been undertaken, but these do not solve the moral dilemmas in this field.

By using a qualitative method we explored moral dilemmas in various categories of staff members in a NICU in The Netherlands. Themes arose that are underrepresented in the current literature. In particular, these are the problem of medically induced handicaps and the role of uncertainty in decision making. Moreover, the special contribution and viewpoint of nurses came to the fore in that they underline the suffering that treatment often imposes on the child. Furthermore, we were able to present an impression of the no small impact of moral dilemmas on daily functioning of staff members in a NICU. Finally, we introduced the phenomenon of ‘*evidence shift*’ to explain the strongly felt decisional problems in withdrawing an already initiated treatment. In anticipation of these problems a reticent strategy in initiating treatment in severely premature newborns may be considered.

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References

Beauchamp, T.L. and J.F. Childress: 2001, *Principles of Biomedical Ethics*. New York: Oxford University Press.

Cuttini, M., M. Nadai, M. Kaminski, G. Hansen and R. de Leeuw et al.: 2000, ‘End-of-life Decisions in Neonatal Intensive Care: Physicians Self-reported Practices in Seven European Countries’, *The Lancet* 355(9221), 2112–2118.

Duff, R.S. and A.G.M. Campbell: 1973, ‘Moral and Ethical Dilemmas in the Special Care Nursery’, *New England Journal of Medicine* 289, 890–894.

Garel, M., S. Seguret, M. Kaminsky and M. Cuttini: 2004, ‘Ethical Decision-Making for Extremely Preterm Deliveries: Results of a Qualitative Survey Among Obstetricians and Midwives’, *Journal of Maternal Fetal Neonatal Medicine* 15(6), 394–399.

Glaser, B.G. and A.L. Strauss: 1967, *The Discovery of Grounded Theory; Strategies for Qualitative Research*. Chicago: Aldine.

Glaser, B.G.: 1992, *Basics of Grounded Theory Analyses*. Mill Valley, CA: Sociology Press.

van der Heide, A., P.J. van der Maas, G. van der Wal, L.C.M. de Graaf, J.G.C. Kester and L.A.A. Kollée: 1997, ‘Medical End-of-Life Decisions Made for Neonates and Infants in The Netherlands’, *The Lancet* 350(9073), 251–255.

Hussain, N. and T.S. Rosenkrantz: 2003, ‘Ethical Considerations in the Management of Infants Born at Extremely Low Gestational Age’, *Seminars in Perinatology* 27(6), 458–470.

Kollée, L.A.A, A. van der Heide, R. de Leeuw, P.J. van der Maas and G. van der Wal: 1999, ‘End-of-life Decisions in Neonates’, *Seminars in Perinatology* 23, 234–241.

Lorenz, J.M., N. Paneth, J.R. Jetton, L. den Ouden and J.E. Tyson: 2001, ‘Comparison of Management Strategies For Extreme Prematurity in New Jersey and The Netherlands: Outcomes and Resource Expenditure’, *Pediatrics* 108, 1269–1274.

Lorenz, J.M.: 2004, ‘Compassion and Perplexity. Commentary’, *Pediatrics* 111(2), 403–404.

Mesman, J.: 2002, *Ervaren Pioniers; Omgaan met twijfel in de Intensive care voor Pasgeborenen*. Amsterdam: Aksant Dissertation University of Maastricht, The Netherlands, ISBN: 90-5260-058-9.

Orfali, K. and E.J. Gordon: 2004, ‘Autonomy Gone Awry: A Cross-Cultural Study of Parents’ Experiences in Neonatal Intensive Care Units’, *Theoretical Medicine and Bioethics* 235(4), 329–365.

Provoost, V., L. Deliens, F. Cools, P.G. Deconinck, J. Ramet, F. Mortier and Y. Vandenplas: 2004, ‘A Classification of End-of-Life Decisions in Neonates and Infants’, *Acta Paediatrics* 93(3), 301–305.

Rebagliato, M., M. Cuttini, L. Broggin, I. Berbik and U. de Vonderweid et al.: 2000, ‘Neonatal End-of-Life Decision Making: Physicians’ Attitudes and Relationship with Self-reported Practices in 10 European Countries’, *Journal of the Amarican Medical Association* 15, 284(19), 2451–2459.

Reiter-Theil, S.: 2004, ‘Does Empirical Research Make Bioethics More Relevant? “The Embedded Researcher” as a Methodological Approach’, *Medicine Health Care and Philosophy* 7(1), 17–29.

Reiter-Theil, S., R. Hentschel and K. Lindner: 2005, 'Lebenserhaltung und Sterbebegleitung in der Neonatologie. Eine empirische Ethik-Studie zu kritischen Therapieentscheidungen', *Zeitschrift für Palliativmedizin* 6, 11–19.

Rhoden, N.K.: 1986, 'Treating Baby Doe: The Ethics of Uncertainty', *Hastings Center Report* 16, 34–42.

Silverman, W.A.: 1992, 'Overtreatment of Neonates? A Personal Retrospective', *Pediatrics* 90, 9761–9763.

Silverman, W.A.: 2004, 'Compassion or Opportunism? Commentary', *Pediatrics* 113(2), 402–403.

Singh, J., J. Lantos and W. Meadow: 2004, 'End-of-Life After Birth: Death and Dying in a Neonatal Intensive Care Unit', *Pediatrics* 114(6), 1620–1626.

Syvertsen, L. and D. Bratlid: 2004, 'Withdrawal of Treatment in Severely Ill Newborn Infants', *Tidsskr Nor Laegeforen* 124(19), 2483–2485.

Verhagen, E. and P.J.J. Sauer: 2005, 'The Groningen Protocol – Euthanasia in Severely Ill Newborns', *New England Journal of Medicine* 352(10), 959–962.

van der Aa Zeben-van, T.M., S.P. Verloove-Vanhorick, R. Brand and J.H. Ruys: 1989, 'Morbidity of Very Low Birth Weight Infants at Corrected Age of Two Years in a Geographically Defined Population', *Lancet* 1, 253–255.