

Challenges in reconciling best interest and parental exercise of autonomy in pediatric life-or-death situations

Eirik M. Hagen\*

Øystein B. Therkelsen\*

Faculty of Medicine

University of Oslo

Reidun Førde

Center for Medical Ethics

Institute of Health and Society

Faculty of Medicine

University of Oslo

Olaf Aasland

Department of Health Economics and Health Management

Institute of Health and Society

Faculty of Medicine

University of Oslo

and

The Research Institute of the Norwegian Medical Association

Annie Janvier

Department of Pediatrics

CHU Sainte-Justine

McGill University

Montréal (QC), Canada

Thor Willy Ruud Hansen<sup>1</sup>

Department of Neonatology

Women and Children's Division

Oslo University Hospital – Rikshospitalet

2

and

Institute for Clinical Medicine

Faculty of Medicine

University of Oslo

Oslo, Norway

\*Both to be considered as first authors with equal contributions

<sup>1</sup>To whom correspondence should be addressed at: Thor Willy Ruud Hansen, MD, PhD,  
Nyfødtavdelingen, Kvinne- og barneklirikken, Oslo Universitetssykehus – Rikshospitalet, N-0027 Oslo,  
Norway Phone: +47-23074573 Fax: +47-23072960 E-mail: t.w.r.hansen@medisin.uio.no

**Abstract****Aim:**

To study attitudes of Norwegian pediatricians regarding ethical dilemmas related to acute, life-saving treatment.

**Methods:**

A questionnaire describing 6 currently incompetent patients who need resuscitation, was administered electronically to all members of the Norwegian Pediatric Association (NPA) (n = 676). Recipients were asked questions about ethical challenges regarding decision-making in acute life-or-death situations. Herein we focused on the four pediatric patients: a 24 week premature, a term infant, a 2 month old, and a 7 year old. The prognosis for the children was described in identical terms as far as survival and likelihood of sequelae.

**Results:**

There was a 39.4% response rate (n = 266). A greater proportion of the respondents stated that they would treat than assessed treatment to be in the patients best interest, respectively 88% (would treat) vs. 75% (best interest) for the premature, 86% vs. 71% for the term infant, 100% vs. 100% the 2-month-old, 98% vs. 94% for and the 7 year old. For the two newborns 72% and 62% respectively would accept parental refusal.

**Conclusion:**

For Norwegian pediatricians, there is a discrepancy between their assessment of "best interest" and their willingness to treat and accept parental refusal of treatment. This suggests that there are significant ethical and legal challenges in pediatric medicine and biomedical ethics.

In acute medical situations decisions have to be made rapidly and with little time for reflection. Therefore, a presumption in favor of active treatment seems reasonable in many such situations. However, in pediatrics, and particularly in neonatal medicine, information may be available which may make such a presumption open to questioning. Thus, lethal malformations or chromosomal abnormalities may have been detected prenatally, or a discrepancy between the due date and the current date establishes the possible delivery of an immature/extremely low birth weight (ELBW) infant. Parents may also have had an opportunity to express their thoughts on the management of the impending situation.

In such situations, it is conceivable that resuscitation and intubation may not necessarily be the best choice, neither from a medical nor a humanitarian perspective. The legal principle of patient autonomy, which in the case of children is vested in the parents, is established in many countries, and gives the patient a strong right of refusal (1). However, the right of parents to refuse treatment on behalf of their children is more limited than if the decision had applied to themselves, though a significant variation appears to exist between countries in this regard (1-5). Nevertheless, there is unanimous agreement on the need for sensitive dialogue with parents.

While the ethical approach of 'substituted judgment', is often not possible in children, at least not in newborns, the principle of 'best interest' is codified in the UN Convention on the Rights of the Child (6), and is an important guideline for medical practitioners as well as others who are involved in the care of children. Unfortunately, moving from the general concept of 'best interest' to an application of that principle in a concrete case is not always simple. Thus, for caregivers both age, work experience, gender, religious background, fear of litigation, and personal prejudices may color their understanding of what is in the best interest of a given child (7). Parents are influenced by similar variables, and in addition their current psychological situation, which is likely to be characterized both by anxiety and grief, may impact negatively on their competence for making decisions (4, 5, 7). The ability to make decisions in such situations will depend both on having received pertinent information, having understood that information, and being capable of applying the information to the situation at hand. One cannot uncritically assume that such information transfer has been adequate (4, 5, 7).

In 1998, a national consensus conference in Norway concluded that the gestational age limit for active treatment should be 23 to 25 completed weeks, and within this range an individual approach is appropriate (8). In this individualized approach, the opinions of the parents were supposed to play a key role. The neonatologist community in Norway is small, and people know each

other well around the country. On this basis it is reasonable to state that the recommendations from the consensus conference have been quite influential, but there are still variations in practice between various centers as regards the 23-24 week gestation infants. However, attempts to treat infants <23 weeks gestation happen only exceptionally.

In the years since the publication of this conference report, several changes have taken place. The results from the Norwegian extreme prematurity cohort (all extremely preterm infants born in the whole country during 1999-2000) have been published, and follow-up data are under publication (9-12). Thus, we know how such infants fare under currently available therapeutic regimes, with an overall survival of about 80% of those born alive at  $\leq 28$  weeks gestation and/or  $\leq 1000$  grams birthweight (9). Second, new laws regulating both patients' rights and health personnel have been passed (1, 13). Thus the concept of 'patient autonomy' is now a part of the Norwegian codex, as is the duty for health personnel to perform their work 'according to good medical standards' as well as 'considerate/caring'. Finally, Parliament has decreed that all Norwegian hospital must have clinical ethics committees, and such committees currently exist in all somatic hospitals.

These changes taken together suggested to us that it would be of interest to investigate how Norwegian pediatricians would apply the principles of 'best interest' and 'autonomy' to a series of patients thought to be representative of problems confronted in everyday pediatric practice. The aim of this project was thus to study attitudes of Norwegian pediatricians regarding ethical dilemmas related to acute, life-saving treatment in patients of different ages.

## **METHODS**

Between June 2009 and September 2009, we administered an anonymous questionnaire to all members of the Norwegian Pediatrics association with an e-mail address. A link with the questionnaires was e-mailed to 676 members, using the electronic survey tool QuestBack. Three reminders were sent out to those not answering. The survey was completed anonymous, and different people than those in the study group recorded the whole process (i). The respondents were promised full anonymity. The Norwegian Medical Association and its office assisted us in completing the questionnaire. We obtained authorization from NSD (Norwegian Social Science Dataservice).

Six scenarios were presented, describing currently incompetent, critically ill patients in respiratory failure with a potential for neurological sequelae in case of survival. Family members were not immediately available for consultation. The patients were of different ages, and their

outcomes were explicitly described. All the patients had the same prognosis in percentage of potential outcome.

All six patients were described as having a 50% chance of survival. The first patient was a premature infant at 24 weeks of gestation, who has just been delivered and is not breathing. The prognosis suggested for this patient is representative of expected outcomes in industrialized countries (9, 12, 14). The second patient was an infant born at term with a known brain malformation who is not breathing; the third, a 2-month-old infant with bacterial meningitis who stops breathing. If these patients survived, 50% would be without disability, 15-25% severely impaired, while 25-35% would be mildly disabled. Two other patients were previously disabled, namely the fourth patient, a 7-year-old patient with multiple disabilities (cerebral palsy, hearing loss in need of a hearing aid, learning disability, and hyperactivity) and a new head trauma, who stops breathing; and the sixth patient, an 80-year-old patient with disability from moderate Alzheimer's disease who now has a new stroke and stops breathing. Both patients were noted to have a 50% predicted chance of survival and, if they survived, a 50% risk of having additional disability. The fifth patient was a 50-year-old previously healthy man with severe trauma, including head injury, resulting from a traffic accident, who is semi-conscious and needs intubation. If surviving (50% probability), he would have a 50% risk of quadriplegia.

Table 1: Description of the six patient scenarios:

The patients were presented in order from the youngest to the oldest (table 1). After each patient description, the following questions were asked: (1) Would you give active treatment to this patient? (2) If the parents/family asked you not to resuscitate, would you respect their decision? (3) Do you think active treatment (intubating, ventilation etc) is in the patient's best interest? (4) If the patient were your own child/ you, would you wish for active treatment? (5) If the patient were your spouse/partner, would you wish for active treatment for him/her? (Question five was asked only for scenarios in which the hypothetical patients were adults).

For each of these questions, respondents could respond on a 4-point Likert scale, with the following options: "yes", "probably", "probably not" and "no". In the data analysis 'yes' and 'probably' were combined and counted as positive answers, and 'probably not' and 'no' were counted as negative answers.

After the last question in each patient scenario the respondents were asked to motivate their response to question 1. They were presented with six, respectively seven different response alternatives; a) the expectation for remaining lifetime, b) life has inherent value, c) the risk of increased care responsibilities for the parents/next of kin, d) the risk of impaired quality of life for the patient, e) social costs, f) relations between the patient and the parents/ family are not yet developed, g) there is a time to die (g was only a response alternative for patients 4-6). For each of the different factors (a-f/g), the alternative responses were as follows on a 5-point Likert scale: "Yes, to a large extent", "yes, to some extent", "neutral", "no, to a small extent" and "no, to a very limited extent". In the analysis both yes-answers were combined into a positive answer and both no-answers were combined into a negative answer.

At the end of the questionnaire the respondents were asked: "If you were forced to choose/rank, how would you prioritize these patients? Enter the ordering 1 to 6, 1 being the first patient to be resuscitated and 6 being the last."

In addition, the questionnaire contained questions about gender, age, place of employment, whether they were pediatric specialists or under specialization, and about experience from neonatal medicine and care. The informants' ages were divided into 3 groups: under 40 years, between 40 and 60 years, and above 60 years. Place of employment was divided in 4 different categories: university clinic, other pediatric wards, private practice, and other.

For the statistical calculation we used Chi square test, Fisher's exact test 2-tailed, and normal 'student t-test' in SPSS. P value less than 0.05 was reported as significant.

## RESULTS

676 received an email and there were 266 respondents, for a response rate of 39.4 percent. In this paper we focus primarily on results pertaining to the four pediatric patients. A graphic presentation of the results is shown in fig.1.

Figure 1

As shown, for the 24 week premature baby, 72 percent would abstain from treatment on parental wish. 62 percent of the doctors would abstain from treatment on parental request for the term infant. For the 2 month old 9 percent would accept parental refusal of treatment, while 23 percent would respect parent refusal for the 7 year old.

Table 2 Pediatricians' ranking of the six patients (1 being the first patient to be resuscitated and 6 being the last)

Table 3 gives the answers to the respondents' motivation for their willingness to treat the different patients or not.

For patient 2, the term infant, the most important factors were; the risk of impaired quality of life for the patient, life has inherent value, the remaining expected lifetime and the risk of increased care responsibilities for the parents. Social costs and undeveloped relations between the patient and the parents are less important factors, according to the respondents in the survey. The most important factor for both patient 3 and 4 (the 2 month old and the 7 year old) was "life has inherent value". Furthermore, the remaining expected lifetime and relations to the family (parents/siblings) were also important factors, while the risk of impaired quality of life for the patient was not so important for patient 3 and 4 according to the respondents. This factor is placed in 4<sup>th</sup> place for the 2 month old and 3<sup>rd</sup> place for the 7 year old patient. "Social costs" was clearly the least important factor for all the four pediatric patients.

## **DISCUSSION**

Our study indicates that pediatricians seem to be driven by the "therapeutic imperative", they choose to treat although they do not necessarily consider the treatment to be in the patient's best interest. In emergency situations like the ones we have presented, when the outcome is uncertain and the decision must be made very rapidly, the decision favors life.

It is hardly controversial that the patient's best interest is the most important criterion on which to base difficult end of life decisions. However, what should be included in the concept "best interest" is not an easy assessment (15-18). In addition other, often non-explicit, factors and values may influence the caregivers' willingness to treat.

If equal cases are treated differently, this may be a threat to the principle of justice (19). Accordingly, it is important to explore which other factors than the patient's best interest that may influence ethically challenging life and death decisions. Janvier and coworkers in Canada claim that preterm newborns may not receive treatment which is according to their best interests and that they are prioritized lower than other patients with the same prognosis (15, 20). They conclude that the best interest standard is not always applied for neonatal resuscitation decisions



Deciding when limitation of life prolonging treatment can be justified, and what constitutes the patient's best interest, are not the only ethical challenges in pediatrics. Another pressing question is - who should assess the patient's need of treatment and decide what is in the patient's best interest? (15, 16, 20-22).

Our study shows that when parents ask pediatricians to abstain from treatment, a significant proportion of the respondents accept and withhold treatment, even though they judge treatment to be in the patient's best interest. This is most clearly shown with the two newborn patients.

### **Need for clarification - best interest vs. parental exercise of autonomy**

For all the children there was a highly significant difference between the proportion who believed treatment to be in the child's best interest and those who would not accept parents' refusal of treatment. In other words, although the majority of the Norwegian pediatricians thought treatment was in the patient's best interest, many would nevertheless abstain from care on parental request. If a physician believes a life-saving treatment to be in the child's best interest, it would seem logically consistent to refuse to follow the parents' desire to abstain from care. It is therefore quite surprising that 2 in 3 of those who believed being treated was in the 24 wk premie's best interest, would accept a parental decision not to provide life saving treatment. This phenomenon was shown as early as 1977 as well as in more recent studies (23-26). In Norway today this may in fact be a violation of both the law and existing guidelines.

Although the prognoses of these patients were described in identical terms, the judgment of best interest as well as willingness to accept parental refusal were significantly different between the patients. This may have been partly influenced by the age and preexisting condition of the patients. The caregiver's implicit values may also affect the attitudes. It is possible that the information given about the different patients in the survey was filtered through preexisting but false knowledge among the respondents. This might partly explain why the caregivers accept parental refusal, as they might assume the prognosis to be worse than actually stated. This hypothesis is supported if one considers that our results show the respondents worrying about the risk of impaired quality of life for the two newborns, but this concern is apparently not applied to the same extent for the older patients.

Norwegian guidelines (27) and law (1, 13, 28) state that parents can both give consent to and refuse treatment on behalf of their own children. However, this assumes that decisions are made in accordance with the child's best interests. Thus, if a physician judges a treatment or conversely,

withholding/withdrawing treatment, to be in the child's best interest, she or he should override the parents if they have conflicting perceptions. Our study suggests that this may not happen often, as 72 percent of the pediatricians would accept parental refusal of treatment even though they found treatment to be in the patient's best interest. Perhaps pediatricians misinterpret the guidelines or the law, giving too much weight to the parents' opinion?

Patient autonomy, in our cases exercised by the parents, is a central concept in Norwegian law and guidelines. During the last decades the principle of autonomy has been strongly emphasized, as for example in the Nuremberg Code, the Helsinki declaration, and Beauchamp and Childress's *Principle of Bioethics* (19). One may perhaps argue that the caregivers overemphasize the concept of autonomy (19, 29). This excessive emphasis may be a threat to other fundamental principles, such as the Hippocratic oath: "To impose treatment on the patient overwhelmed by disease is to display an ignorance akin to madness". One could argue that the focus on autonomy may be a threat to children's best interests.

To what extent should the parents be heard? There is no doubt that many families of disabled children experience great challenges in their everyday life (8, 30). Ingstad and Sommerschild use the term 'disabled families' (30). There is a general perception in the literature and in the guidelines that it is important to involve the parents in the process, and try to build a common understanding of the situation between the medical caregivers and the family (8, 29). Our results suggest that the balance best interest vs. parental exercise of autonomy is in need of legal and ethical clarification.

### **Discrepancy between best interest and willingness to treat**

There seems to be an abrogation of the best-interest principle with the two newborn patients, especially the 24 week preterm infant, when a greater proportion of respondents state that they would treat the patients actively than those who find such treatment to be in the patients' best interest.

Why do some Norwegian pediatricians treat actively although they do not find treatment to be in the patient's best interest? There will be more or less uncertainty in the assessment of the patient's best interest and what is truly the right action. This uncertainty may speak in favor of treatment. From a moral-philosophic point of view one may state that it is better to do wrong by acting in order to save life than not to act when death is imminent (8).

### **Prioritizing the patients**

The survey presented this question; “If you were forced to chose/rank, how would you prioritize these patients?” In general, the respondents would start to give active treatment/resuscitation to the 2-month-old patient first, the 7 year old patient second and the 50 year old third. It was almost a tie between the 24-week preterm and the term infant in fourth place. The 80 year old patient was definitively placed last. This supports the impression that newborn infants are being systematically devalued, consistent with the results from Annie Janvier and colleagues (15, 20, 21). One interesting difference from the results of Janvier et al, compared with our results, is that we could not find any clear difference between the two newborns. Janvier et al concludes that “*newborn infants and particularly preterm infants are systematically devalued, in comparison with older patients...*” (15). Do Norwegian pediatricians think differently about premature infants than Canadian physicians? If so, why is this?

Why are the newborn infants being systematically devalued? Janvier et al have asked “Is the systematic devaluation of the newborn due to deeper rooted anthropological, cultural, social and evolutionary factors?” (20). Newborns may be classified in a special and less valuable moral category (21). The change from the intrauterine to the extrauterine condition is rapid and the neonate is suddenly granted the same legal rights as everyone else (1). This shift is perhaps so quick that the caregivers are unable to relate to this enormous increase in the baby’s ‘moral status’?

Ethical dilemmas may be inevitable this field. It is challenging to note that a baby who was just born at 24 weeks of gestation could be said to have more rights than a fetus still in utero at 40 weeks. The difference in gestational age between a just-born extremely premature infant and a late abortion may be minuscule. Do we therefore define an infant born at 24 weeks gestation as a person? If our answer is affirmative, it could well be argued that this person must have the same rights as everyone else, and be entitled to special protection. Most people would agree that it is unacceptable not to give the 2 month old patient treatment and let the child die. This raises the challenging question of what constitutes the difference between the 2 month old and the premature infant. In our study they were described as having the same chances of survival and the same risk of sequelae. Personhood, or lack of personhood, will be a good argument for many. Another may be that a child who has lived outside the uterus has developed social relations, which are stronger than those of a fetus. Evolutionary mechanisms that protect us against feeling grief over the death of newborns may be another. Janvier proposes this as a possible explanation (15). Are some lives more valuable than other lives?

**Less inclined to treat own child**

For the two newborns, and the 7 year old, there were significant differences between willingness to treat somebody else's child vs. one's own. This suggests that the reasoning behind the decisions must involve more than a weighing of best interest for the child (15). One may speculate that professional knowledge about treatment options and prognoses, which were not mentioned in the scenarios, may nevertheless have contributed to the decisions. However, Markestad et al (9) and Gargus et al (14) have shown that our hypothetical scenarios are quite close to real life.

Thus, a perception that serious functional deficits are more common than described for the two newborns, may explain a desire to spare one's own child from such potential suffering. Another possible explanation is that many pediatricians have met families with children with handicaps and know the burdens that these families endure.

**Functional guidelines?**

In Norway, a national consensus conference in 1998 concluded that the gestational age limit for offering resuscitation should be 23 to 25 completed weeks and that within this range an individual approach was appropriate (8). In April 2009 the Norwegian Health Directorate published 'Limiting life-prolonging treatment for critically ill or dying patients – National guidance for decision making processes' (27).

Briefly these guidelines discuss three important aspects. First, treatment decisions must be in the patient's best interest, and the patient's best interest is the first priority. Second, all decisions should be discussed with the parents if the patient is a child. Third, it is the responsible doctor who makes the final call. When the patient is incompetent to make his or her own decisions, the most important consideration is to consider the patient's best interest and give treatment or non-treatment according to the patient's wishes, if they can be reasonably assumed.

We believe the guidelines in themselves are functional, but whether they are applied in clinical practice is more uncertain. Our findings suggest that they may not be applied as they probably should. It is therefore a great challenge to implement these guidelines to a greater extent in everyday clinical practice than what is currently the case.

**Limitations of the study:**

As in other questionnaire studies, the present study may have limitations. Thus, we do not know whether opinions would translate into actions if the respondents were actually in the situations described. A questionnaire is not real life, but a hypothetical, constructed situation.

The scenarios were presented in the order of the patient's age because this would seem logical and unbiased to the participants, but we cannot rule out the possibility that a different order of presentation could have produced differences in the results.

Our response rate was roughly 40%, which might have given a response bias. However, our response group seems to be a representative group for pediatricians in Norway, regarding age and gender. Recent data show declining response rates for questionnaire studies, suggesting that a 40% response rate is good (31).

**CONCLUSION**

The question of best interest vs. parental exercise of autonomy, as well as the reasons why pediatricians are less inclined to apply a treatment considered to be in a child's best interest to their own children than to the children of others, suggests that significant ethical and legal challenges exist in pediatric medicine and biomedical ethics. These challenging questions appear worthy of further study and clarification. Increased training in ethics and the law appear to be needed for Norwegian pediatricians, and perhaps also increased national dialogue. Other studies suggest that this is likely to be true in other countries as well.

**ACKNOWLEDGEMENTS**

- i) Cecilie Normann, consultant at the medical department at The Norwegian Medical Association
- ii) No specific funding.

**REFERENCES**

1. Pasientrettighetsloven. 1999. Lov om pasientrettigheter m.v. av 1999-07-02 nr 64.(Act relating to patients' rights). Available at: <http://www.lovdatab.no/all/hl-19990702-063.html>
2. Orfali K, Parental role in medical decision-making: fact or fiction? *Soc Sci Med* 2004; 58:2009-22
3. AAP, Bell EF, Noninitiation or withdrawal of intensive care for high-risk newborns *Pediatrics* 2007;119:401-3;
4. Schroeder J, Ethical issues for parents of extremely premature infants. *J Paediatr Child Hlth* 2008; 44:302-4;
5. Paris JJ, Schreiber MD, Moreland MP, Parental refusal of medical treatment for a newborn. *Theor Med Bioeth.* 2007; 28:427-41
6. United Nations, UN. Convention on the rights of the child, 1989 available at: <http://www2.ohchr.org/english/law/crc.htm>
7. Belline C V, Buonocore G. Flaws in the assessment of the best interests of the newborn. *Acta Paediatrica* 2009; 98: 613-617.
8. Konsensuskonferanserapport nr 13. *Grenser for behandling av for tidlig fødte barn* (Limitations in treatment of preterm infants).Oslo, *Norges forskningsråd*, 1999
9. Markestad T, Kaaresen PI, Rønnestad A, Reigstad H, Lossius K, Medbø S et al. Early death, morbidity, and need of treatment among extremely premature infants. *Pediatrics* 2005; 115: 1289-1298.
10. Rønnestad A, Abrahamsen TG, Medbø S, Reigstad H, Lossius K, Kaaresen PI et al. Septicemia in the first week of life in a Norwegian national cohort of extremely premature infants. *Pediatrics* 2005; 115: e262-8
11. Rønnestad A, Abrahamsen TG, Medbø S, Reigstad H, Lossius K, Kaaresen PI et al. Late-onset septicemia in a Norwegian national cohort of extremely premature infants receiving very early full human milk feeding. *Pediatrics* 2005; 115: e269-76
12. Leversen KT, Sommerfelt K, Rønnestad A, Kaaresen PI, Farstad T, Skranes J et al. Prediction of neurodevelopmental and sensory outcome at 5 years in Norwegian children born extremely preterm. *Pediatrics* 2011; 127: (Unpublished report)
13. Helsepersonelloven. 1999. Lov om helsepersonell m.v. av 1999-07-02 nr 64 (The Health Personnel Act ). Available at: <http://www.lovdatab.no/all/hl-19990702-064.html>;
14. Gargus RA, Vohr BR, Tyson JE, High P, Higgins RD, Wrage LA et al. Unimpaired outcomes for extremely low birth weight infants at 18 to 22 months. *Pediatrics* 2009; 124: 112-121.

15. Janvier A, Leblanc I, Barrington KJ. The best-interest standard is not applied for neonatal resuscitation decisions. *Pediatrics* 2008; 121: 963-9.
16. Janvier A, Barrington KJ, Aziz K, Lantos J. Ethics ain't easy: do we need simple rules for complicated ethical decisions? *Acta Pædiatrica* 2008; 97: 402-406.
17. Kopelman LM. Children and bioethics: Uses and abuses of the best-interests standard. *J Med Philos* 1997; 22: 213-217
18. Kopelman LM. The best-interests standard as threshold, ideal, and standard of reasonableness. *J Med Philos* 1997; 22: 271-289
19. Tom L. Beauchamp, James F. Childress. *Principles of Biomedical Ethics*. 6<sup>th</sup> ed. New York, Oxford: Oxford University Press, 2009
20. Janvier A, Leblanc I, Barrington KJ. Nobody likes premies: the relative value of patients' lives. *J Perinatol* 2008; 28: 821-6.
21. Janvier A, Bauer KL, Lantos J. Are newborns morally different from older children? *Theor Med Bioeth* 2007; 28: 413-425.
22. Janvier A, Nadeau S, Deschênes M, Couture E, Barrington KJ. Moral distress in the neonatal intensive care unit: caregivers experience. *J Perinatol* 2007; 27(4) :203-8.
23. Shaw A, Randolph J, Manard B, Ethical Issues in Perdiatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons, *Pediatrics* 1977; 60; 588-589
24. Todres I D, Krane D, Howell MC, Shannon DC. Pediatricians Attitudes Affecting Decision-Making in defective Newborns, *Pediatrics* 1977; 60;197-201
25. A. Janvier, Neonatologists Do Not Apply the Best Interest Principle for Resuscitation Decisions, *PAS* 2008; 4305.3
26. J.Harai et al, The infant's Best Interest- A German Perspective, *PAS* 2009; 46
27. Helsedirektoratet. Nasjonal veileder for beslutningsprosesser for begrensning av livsforlengende behandling hos alvorlig syke og døende. (The Norwegian Health Directorate. Limiting life-prolonging treatment for critically ill or dying patients – National guidance for decision making processes) Oct. 2009. Available at:  
[http://www.helsedirektoratet.no/vp/multimedia/archive/00117/Nasjonal\\_veileder\\_f\\_117069a.PDF](http://www.helsedirektoratet.no/vp/multimedia/archive/00117/Nasjonal_veileder_f_117069a.PDF)
28. Barneloven. 1981. Lov om barn og foreldre av 1981-04-08 nr 07.(Act relating to Children and Parents ) Available at: <http://www.lovdato.no/all/hl-19810408-007.html>



29. Paris J. J. Autonomy Does Not Confer Sovereignty on the Patient: A commentary on the Golubchuk Case. *Am J Bioeth* 2010; 10:54-74
30. Benedcte Ingstad, Hilchen Sommerschild. *Familien med det funksjonshemmede barnet*. Kolbotn: Tanum-Norli, 1984
31. Johannessen A., Tufte P, Kristoffersen L. Introduksjon til samfunnsvitenskapelig metode. Oslo: *Abstrakt forlag*, 2007: 209.

## Tables;

**Table 1:** The prognosis for the patients was described in identical terms as far as survival and likelihood of sequelae. All numbers are in percentages. NA = not applicable.

Age of patient	Previous disability	Probability, %		
		Survival	Normal outcome among survivors	New major disability among survivors
24 week preterm	NA	50	50	25
Term	NA	50	50	25
2 month	No	50	50	25
7 years	Yes	50	0	50
50 years	No	50	50	25
80 years	Yes	50	0	50

**Table 2:** “Total of the ranks” refers to the summarized score; one respondent answering rank 1 to a given patient gives 1 “point”, one respondent answering rank 2 to a given patient gives “2 points” and so on. The lower the “total of the ranks”, the earlier resuscitation would have been offered.

Ranking	The patients	Total of the ranks	Mean rank
1	2 month	394	1,5
2	7 year	500	1,9
3	50 years	956	3,7
4	24 week preterm	995	3,9
5	Term	1002	4
6	80 years	1531	6

Table 3:

<b>Factors</b>	<b>Positive</b>	<b>Neutral</b>	<b>Negative</b>	<b>RANK</b>
The expectation for remaining expected lifetime	53,8%	22%	24,3%	4
Life has inherent value	71,6%	15,9%	12,5%	2
The risk of increased care responsibilities for the parents	55,9%	20,7%	23,4%	3
The risk of impaired quality of life for the patient	84,1%	9,8%	6,1%	1
Social costs	15,2%	14,8%	70%	6
Relations between the patient and the parents/family are not yet developed	25,4%	22,3%	52,3%	5

Figures;

Figure 1: Response to the different questions in percent with 95% confidence intervals, focusing on the four pediatric patients. The indicated p-values are based on two-tailed Fischer's exact tests. N=266

