

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Critical Care Decisions in Fetal and Neonatal Medicine: Ethical issues during March to June 2005. The views expressed are solely those of the respondent(s) and not those of the Council.

K.A. Bergman MD, Consultant Neonatologist

1. In a case where a fetus may suffer from serious abnormalities that are likely to be disabling in the long term, measures to sustain the life of the fetus, or where possible, to correct those abnormalities before birth might be appropriate when
 - the benefits of treatment for the fetus outweighs the risk to the fetus and improves the long term prognosis
 - the benefits of treatment for the fetus outweighs the risk to the mother
 - the risk for the mother is within reasonable limits
 - there is informed consent from the mother

By law we cannot override the wishes of the pregnant women as long as she is mentally competent

(i.e. she has no psychiatric condition or mental retardation and has not been sanctioned).

In Dutch law the fetus does not acquire legal personality until born alive.

Only after the baby is born a court order can be obtained if the mother has seriously harmed her unborn baby during pregnancy and there is still concern about the babies well being.

In my opinion this should not be changed. The wishes of pregnant women should be respected.

2. It would not be appropriate to prolong the life of a new-born if there is a condition of “no chance” (i.e. the new-born would die regardless of interventions) or a condition of “no purpose”(i.e. thought the new-born would be able to survive, the prognosis for future health is very poor with only dim changes for a liveable life)
To me there is no difference between “not start” and “terminating” life-lengthening measures in the situations as mentioned above.

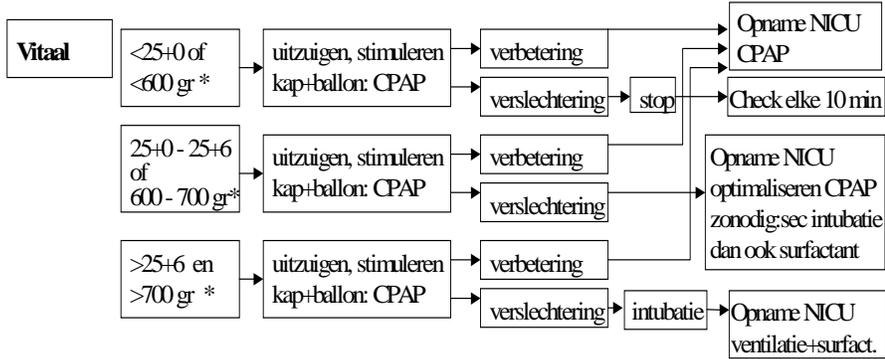
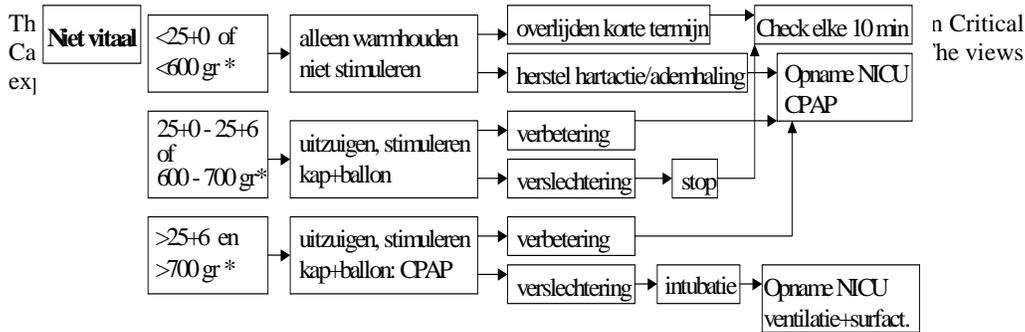
In my opinion intensive care treatment should not be offered to

- Extremely premature neonates i.e. less than 25 weeks gestational age because of poor survival rates and the very high risk of serious neurodevelopmental disabilities in neonates who survive. On the other hand a viable 24-week-old preterm infant with no signs of respiratory distress syndrome will be admitted to the unit for fluids, nutrients, CPAP, antibiotics and caffeine. The baby will be kept comfortable but further treatment, such as respiratory support, will not be started. This regime is evaluated daily by medical staff taking the child's current condition in account. If necessary it is changed. This will be discussed with the parents on a daily base.
- premature infants between 25 and 26 weeks who are not viable at birth
- severely growth restricted infants, weighing less than 500-700 gram, who have poor prospects for survival at birth.
- New-borns with congenital malformations or genetic conditions with “no change” (for example Potters syndrome) or “no purpose” (for example trisomy 18) in which there is a definite diagnosis at birth.
- New-born with acquired brain damage in whom the prognosis for future health is very poor with only dim changes for a liveable life.

This should be discussed with the parents before birth is possible.

In our hospital guidelines are used for extremely premature neonates by obstetricians and neonatologists. Please find enclosed as a PowerPoint file (sorry it's in Dutch).

Discussie-Concept: Eerste opvang extreem prematuren en extreem pre-dysmaturen(24-28 wkn*)



Dijk april 2004

Discussie-Concept: Eerste opvang extreem prematuren en extreem pre-dysmaturen(24-28 wkn*)

<24 wkn of <500 gram	24+0 - 24+6 of <600 gram*	25+0 - 25+6 of <700 gram*	26+0 - 26+6 en >700 gram	27+0 - 27+6	>28 wkn
geen prenatale steroiden	wel prenatale steroiden				
geen sectio op foetale indicatie	i.p. geen S.C op foetale indicatie	i.p. wel S.C. op foetale indicatie		wel S.C. op foetale indicatie	
i.p. bij opvang geen kinderarts	neonatoloog voor / bij opvang aanwezig			kinderarts bij opvang	
i.p. geen IC- behandeling	bij vitaliteit wel IC- behandeling		wel IC behandeling		
Niet-vitaal:	geen actieve handelingen warmhouden	stimuleren, kap en ballon, niet prim. intuberen	stimuleren, kap en ballon,CPAP zo nodig: wel primair intuberen		
Vitaal:	stimuleren, kap en ballon:CPAP. NIET intuberen				
Secundaire verslechtering:	behandeling stop	behandeling i.p. niet intensiveren		behandeling i.p. wel intensiveren	

Dijk april 2004

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Critical Care Decisions in Fetal and Neonatal Medicine: Ethical issues during March to June 2005. The views expressed are solely those of the respondent(s) and not those of the Council.

3. In my view all the ethical questions should be considered and are of equal importance. The question about quality of life is the most difficult one to consider. What is a meaningful life? After a thorough diagnosis and prognosis other criteria have to be applied in the evaluation. Taken in to account are often:
- Communication potential
 - Prospect for an independent lifestyle
 - Likelihood of dependence on medical facilities
 - Eventual suffering
 - Life expectancy

But estimating the severity of a handicap is often very difficult and in many cases there is no certainty. It's also difficult to estimate the magnitude of the handicap and the burden its places on the child and family.

4. Quality of life is often seen in relation to the prospect of a meaningful life. But what is a meaningful life? This depends on the religious background and the spiritual influences of the medical professionals involved and the child's family and always influences the process of decision making.

In the discussion about "meaningful life" communication potential, prospect for an independent lifestyle, likelihood of dependence on medical facilities, eventual suffering and life expectancy are taken into account as are the burden on the child and the family. But one should always consider the importance of religious and spiritual influences in the discussion and decisions. In religion life is often seen as a gift from God and therefor should be respected and protected. But, in my view, this should not leave the child in a situation of inhumane and irresponsible suffering.

Mass media attention might influence the public opinion and as a consequence the process of decisions to some extend. This might be critical as modern society is hardening; pressure on people is high, as are expectations. What is happening if people cannot meet them because they are disabled? Individualism is common, there is less solidarity and cuts in social security and resources are normal at the moment.

All those aspects should be taken into consideration. The quality of life question is a very important and difficult one to answer.

5. The physician (due to expertise, objective evaluation, and responsibility for medical treatment) and the parents (due to involvement with and responsibility for the child) are best placed to judge the quality of life for a child.

When parents are involved the view of both parents should be clear. In case of disagreement between parents the physician should offer help to the parents to resolve the difference or refer parents for counselling (social worker, minister/ priest, Stichting Dilemma)

Nurses might have an important integrating and advising role but authority lies with the physicians and the parents.

The question whether or not to initiate and continue intensive care treatment can be brought up for discussion by the medical team (i.e. physicians, nurses, and social worker) or the parents. The medical staff needs information to support and clarify the decision:

- Relevant medical data and the results of diagnostic tests/ investigations used to establish the diagnosis
- Treatment so far and the results
- Availability of alternative treatment options
- The prognosis regarding long term health and how it was assessed
- The degree of suffering
- Life expectancy and how it was assessed

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Critical Care Decisions in Fetal and Neonatal Medicine: Ethical issues during March to June 2005. The views expressed are solely those of the respondent(s) and not those of the Council.

This should be brought forward during a meeting in which all physicians directly involved in the care of the patient are present, as are a senior nurse and the family's social worker. In the child's medical notes there should be a summary, a list of all the participants in the decision-making process, all opinions expressed, and the final consensus. The final consensus then should be discussed with the parents by the consultant looking after the baby. Both the parents and the medical team should be convinced that treatment is not in the best interest of the child because the outlook is extremely poor.

After the decision has been made, treatment was not initiated or continued and the child has died, an outside body should determine whether the decision was justified. So far this is not the practice in The Netherlands at the moment.

If there are any disagreements between the parties this can be resolved by asking a second opinion. Help can also be offered by the Stichting Dilemma, a 24 hour-helpline run by senior professionals in the field which is available for medical staff, parents and families. If this does not resolve disagreement any other team, if available, is asked to take over the child's care.

I don't think that people should use the law to challenge medical advice but sometimes it's the only way out in a conflict between parents and medical staff. It is very rare in the Netherlands.

6. I find it very difficult to give any weight to economic considerations in determining whether to prolong the life of fetuses or the new-born. What the price of a life? In case economic considerations are taken into account they should be applied to everyone. It is not right that treatment should be available for the people who can afford it.
7. Yes it should be my opinion. I cannot/ and will not value the life of a person depending on their age. Every life is precious.
8. It can be helpful to draw up more directive professional guidance to parents and professional as we do in The Netherlands. It is clear for Obstetricians and Paediatricians from what gestational age/ birth weight one treatment will be available for preterm infants at the edge of viability. At the moment there are no big differences between centres. I think it is wise to set a minimum age below which resuscitation normally would not be permitted to prevent cases as recently discussed in *The New England Journal of Medicine* (2004; 351(20):2119-23)
9. I'm not sure if further legislation is needed if there are professional guidelines set up by Obstetricians and Paediatricians which have the approval of the Colleges.

Comments

In the Netherlands there is discussion about euthanasia in severely ill new-borns. This applies to infants with a hopeless prognosis who experience what parents and physicians deem to be unbearable suffering and who are not dependent on intensive medical treatment. When both parents and physicians are convinced that there is an extremely poor prognosis, they may consider that death would be more humane than continued life. For this situation the Groningen Protocol for Euthanasia in new-borns is under discussion. (*N Engl J Med* 2005; 352(10): 959-962)

I cannot support euthanasia for this group. In my view there is a difference between whether or not to initiate and continue intensive care treatment and deliberately ending the life of a baby who is not depending on intensive medical treatment and who cannot ask for euthanasia. As a doctor I will take care of alleviating suffering in those patients and accept the risk that they may die as a consequence of that treatment. But deliberately ending the life goes against my conscience taken my religious and family background (I have a sister with spina bifida and hydrocephalus) into account. At this point I don't share the view of some of my colleagues.