Dilemmas of a Neonatologist

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Dilemmas of a Neonatologist

- Modern medicine has evolved rapidly the last decade.

- This has directed the neonatologist into different scenarios of dilemmas.

- Along with technological developments in neonatology there has been a continuing debate about ethical issues.
Dilemmas of a Neonatologist

To be or not to be that is the question

William Shakespeare
Dilemmas of a Neonatologist

To start or not to start

To end or not to end

?
When to start, when to withhold?
Treatment, do we do more harm than good?
When is enough–enough?
A number of ethical theories and principles are relevant.
Sanctity of Life Doctrine

“All human life has worth and therefore it is wrong to take steps to end a person's life, directly or indirectly, no matter what the quality of that life.”
Should life be preserved at all costs?
Is there no place for consideration of quality of life?
This distinction argues that there is a difference between actively killing someone and refraining from an action that may save or preserve that person's life.
A translation of this would imply that withholding/withdrawing treatment is regarded as legal and regarded differently than actively killing.

This would be an important point in the discussion between withholding/withdrawing treatment and euthanasia.

In many countries withholding/withdrawing treatment would be accepted legally, however euthanasia will not be acceptable by the same legal system.
The doctrine of double effect argues that there is a moral distinction between acting with the intention to bring about a person's death and performing an act where death is a foreseen but unintended consequence.
Doctrine of Double Effect

- This is an important ethical principle very often used in palliative care and end of life decisions.

- An example is the use of morphine to ease pain and discomfort although we know that in the end it may have fatal effect on the respiration.
Guidelines recently published by the Norwegian authorities it states:
- When life prolonging treatment has been withdrawn, palliative treatment should be continued or augmented.
- The patient (neonate) must have adequate pain relieve even if it cannot exclude hastening death
Respect for autonomy

- The principle for respect for autonomy acknowledges the right of a patient to have control over their own life, including decisions about how their life should end.
Respect for autonomy

- For the neonate it would be decision in proxy, meaning someone else will act in their best interest to make these decisions.

- In most instances it would be the Parents, however health workers may also act in proxy
Respect for autonomy

- Is it so that a parent can demand treatment where death is inevitable.
- Deny a decision to stop treatment when continued treatment just prolong the death process.
- Can parents deny treatment for their infants or demand respirators turned off.
A common belief is that a parent do NOT have an absolute right to demand treatment, nor prolongation.
An important question is whether the parent always acts in the best interest of their child even although they do believe so.
A duty to act in the patient's best interest—Beneficence

- The duty of beneficence, that is to act in a way that benefits the patient, is an important ethical principle in health care.
The concept of nonmaleficence – an obligation not to inflict harm intentionally.

How much harm caused by the treatment needs to be considered, as does the question of whether death itself is always a harm.

Many medical treatments may have harmful side effects but save or improve lives.
Legal considerations
Common dilemmas as in “end of life decision”

However

- These situations may be matter of there and then decisions.
- The neonatologist will be very alone in the decision making.
The intention is to save the newborn infant’s life and minimize morbidity.
Initiation, when to start, when to withhold

- In some circumstances no effort is made to save the life of the newborn
  - Providing peaceful death for the child and emotional support for the parents
Is this approach never ethically justified?
The parents should decide?
In some settings resuscitation should not be attempted?
The AAP Committee on Fetus and newborn emphasize the importance of basing decisions on an assessment of the child’s best interest.

- An intervention is generally considered to be in a patient’s best interest if the overall benefit to the patient outweighs the overall burden to the patient.
A duty not to harm—Nonmaleficence

A duty to act in the patient's best interest—Beneficence
Possible clinical settings

- GA – when is young too young?
- Congenital abnormalities?
- Chromosomal abnormalities?
If there is a reasonable chance it will provide the patient with an overall net benefit and does not represent an injustice or unfair burden to the infant.
What unfair burden to the infant implies is discussable:

- But if death is inevitable even if treatment is started
- That the prospect to survive without major handicaps is extremely poor

It would be regarded as an unfair burden.
To start

- Based on Relevant data
  - Predicted survival
  - Morbidity
- Application of ethical reasoning and analyses of these data
Application of available data

- Which data are available?
- Are they valid?
- Are there any consensus based on the available data?
- Do they apply to our clinical setting?
- Are the data relevant?
Previously neonatology was advancing so fast that outcome data reported as “new” were already out of date.

However, for the last decade there has been a more steady state in the development in neonatology, thus outcome for premature infants borne in 2000, is still valid for infants born in 2011.
GA – when is young too young

- GA used as guidelines
  - Based on outcome data
The UK, Nuffield Counsel on Bioethics published guidelines in 2006.

- Resuscitation should not be standard practice at 22 completed weeks, unless requested in written by the parents.
- Parents should be given a choice at 23 completed weeks.
- And possibly at 24, but at 25 resuscitation should be done.
Norway have similar consensus, but put 23 completed weeks in their recommendation, others have 24 completed weeks
GA – when is young too young

- How certain is it that the GA is correct
- How to validate outcome
  - Quality of life measurements?
Choice of treatment, do we do more harm than good
Choice of treatment, do we do more harm than good

- New treatments have been initiated without good evidence based foundations.
- Unexpected side-effects, despite clinical trials
- Off-label drugs
Choice of treatment, do we do more harm than good

“Organ targeted” approach:

- Catch-up growth or beneficial under-nutrition
- Perceptive hypercapnia – good or bad?
- “high” vs “low” oxygen approach
Withdrawal of treatment, end of life decisions

- An important question that needs to be considered is whether the neonatologist’s obligation is to preserve life for whatever costs?
- Is there any obligations to provide life sustaining treatment if the benefits of that treatment no longer outweigh the burden to the patient?
- Do we prolong life or just delay death?
Withdrawal of treatment, end of life decisions

- Who decides
  - Doctor?
  - Parents/Family?
  - Child?
  - Nurses?
  - Others?
Withdrawal of treatment, end of life decisions

- Guidelines/laws
- Communication “health workers/parent”
- Aim “joint” decision
- Ethical committees
- Outside “second opinions”
Acknowledgement/References

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Thank you