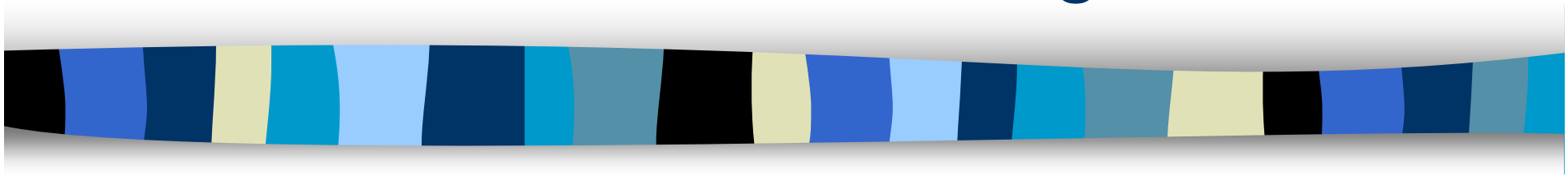
Ethics in neonatal medicine - are newborn infants different from other human beings?



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Ethics in neonatal medicine

- Do neonates merit or need a unique position in medical ethics?
  - Totally dependent on us
  - Unable to hold or express own views
  - Decisions on their behalf will be made by parents in crisis
    - The dream about the perfect baby vs the reality of an infant who is severely ill or malformed

Ethics in neonatal medicine

- Do neonates merit or need a unique position in medical ethics?
  - If they survive, a potentially long life may be marred by handicap and suffering
    - In light of this, being responsible for ”the wrong decision” may seem particularly hard to bear

Ethics in neonatal medicine

- Do neonates merit or need a unique position in medical ethics?
  - On the other hand – most sick newborn babies make a full recovery!
  - Many conditions which are treated without question in adults carry a significantly poorer prognosis than e.g. treatment of 23-24 week premature infants (in Norway)

Ethics in neonatal medicine

- Rights
  - In Norwegian health law newborn infants have the same rights to health care as others
    - I confess ignorance regarding Russian law
  - Official committees who have made suggestions for priorities in health care have both infants and acute care high on their lists
  - However, questions have been raised regarding the ”high cost” of such care
    - Particularly for extremely premature infants
    - In reality, adult intensive care has much higher costs with much lower ”yield”

Ethics in neonatal medicine

- The role of parents
  - In most societies parents have wide-ranging rights relative to their children
  - Such rights are based on the assumption that parents are *i)* capable of and *ii)* willing to care for their child
    - If their will and/or competence fails, society has mechanisms to intervene in order to protect the child
      - Child protection laws and agencies

Ethics in neonatal medicine

- The role of parents
  - Even when both will and competence are present, society may occasionally limit parental rights:
    - The parents will not be permitted to withhold life-saving treatment from the child because of their religious faith or philosophical convictions
      - For example Jehova's witnesses and blood transfusion
    - However, society does not force people to immunize their children against their religious or philosophical objections

Ethics in neonatal medicine

- The role of parents
  - The rights of parents are also based on an assumption that they want to do what's best for their child
  - Sadly, this assumption may not always be justified
    - Child abuse
    - Conflicts between parents when the child/ children may be used as ”weapons” in the fight between mother and father

Ethics in neonatal medicine

- A NICU's relation to parents:
  - Parents are our most important collaborators
  - The parents have rights and duties relative to the child and relative to the law
  - Parents have the right to be fully informed of the diagnosis and the treatment
  - Parents should participate in processes and decisions regarding the range and possible limitations of diagnostic and therapeutic efforts

Ethics in neonatal medicine

- A NICU's relation to parents:
  - We assume a priori that the parents:
    - Are capable and willing to care for their child
    - Want what is best for their baby
    - Are willing and able to reflect on ethical issues
      - Are able to distinguish their own needs and problems from those of the baby
    - Are competent relative to the life of their family
  - We try to be sensitive to signals that suggest that the above may not be true

Ethics in neonatal medicine

- The right to live and the right to die
  - A frequent question in neonatal intensive care
    - Is there an unlimited right to live?
      - Some conditions are incompatible with long life at our current state of knowledge:
        - » Trisomy 13 & 18
        - » Anencephaly
        - » Renal agenesis
        - » Some cardiac malformations
        - » Extreme prematurity (<22-23 weeks GA)

Ethics in neonatal medicine

- The right to live and the right to die
  - We may abstain from treatment if it is known prenatally that the baby suffers from a lethal condition
    - The parents must understand and accept this decision
  - If there is diagnostic uncertainty, many would argue for continuation of life support until questions have been answered
    - In this case, consensus needs to be a priori that treatment will be discontinued when reasonable certainty has been attained

Ethics in neonatal medicine

- The right to live and the right to die
  - The meaning of ”futility”
    - Can the parents demand a treatment that from a medical perspective appears futile?
      - A decision from the Norwegian courts in 2007 seems to suggest that a physician cannot be compelled to offer at treatment which, based on present knowledge, appears futile
      - However, another case is currently in process where parents and their lawyer argue the opposite
        - The Norwegian Board of Health Supervision has recently ruled for the hospital in this case

Ethics in neonatal medicine

- The right to live and the right to die
  - The meaning of ”futility”
    - Can there be situations where an a priori futile treatment (relative to survival) may still be offered?
      - For example in order to give parents an opportunity to prepare emotionally for the death of the child
      - Fo give an absent parent the chance to come and see the child before she/he dies?
      - If so, what are the limitations to such treatment
        - Duration?
        - Level of intensity/effort?

Ethics in neonatal medicine

- The right to live and the right to die
  - Does a newborn have a ”right to die”?
    - There is no ”living will”
    - The difficulties of ”substituted judgment”
      - ”To imagine yourself in the place of another”
        - » Food for thought: children with hypoplastic left heart syndrome and their parents assess theiur quality of life significantly higher than their physicians
        - » Food for thought: we are not able to free our thinking from our own background and experiences
        - » The newborn has never communicated, thus we can make no assumptions about what she/he would have thought or wanted

Ethics in neonatal medicine

- The right to live and the right to die
  - Does a newborn have a ”right to die”?
    - Deciding on behalf of others
      - ”Best interest” – difficulties somewhat similar to the preceeding slide
        - » What would the average person have wanted?
      - Prognosis/quality of life
        - » How great a risk for how poor a quality of life may be accepted?
        - » How many children who might have been (reasonably) healthy should be sacrificed in order to avoid how many cases of severe sequelae (the uncertainty of prognoses)

Ethics in neonatal medicine

- Prognosis/quality of life
  - Is it possible to avoid thinking about quality of life in a clinical ethical decision process?
    - Probably only if your standpoint is that life has an absolute value, and that all treatment must be continued until death has been declared

Ethics in neonatal medicine

- The role of society in neonatal ethics
  - Acceptability
    - What we do must appear right and acceptable in the society we serve
      - But we also have a duty to educate that society as to what is achievable
  - Economic responsibility
    - Society has defined certain limits for what they want to spend on health care
      - However, society has for the most part not defined what it is that we should not do in order to stay within our budgets

Ethics in neonatal medicine

- The role of society in neonatal ethics
  - Economic responsibility
    - Could/should individual doctors refrain from offering a treatment because there is no room in the hospital's budget?
      - The doctor as spokesperson for the patient
      - What does neonatal medicine cost relative to other areas of medicine?
        - » In Norway intensive care of old people consumes significantly more resources than neonatal medicine, and with much poorer "yield"

Ethics in neonatal medicine

- The role of prematurity/immaturity
  - In 1998 a ”consensus conference” in Norway recommended that
    - infants born before 23 completed weeks of pregnancy as a rule should not be offered treatment,
    - while infants born between 23-25 weeks should be assessed individually
  - Recently published Norwegian data show that >80% of infants with birth weight 500-1000 g survive

Ethics in neonatal medicine

- The role of prematurity/immaturity
  - Could we imagine any other group of patients in whom a treatment that would change 100% mortality to 80% survival would be the subject of a ”consensus conference”?
  - In reality we have no survival in Norway at <23 weeks gestation
    - Attempts to treat such infants appear to occur rarely, if ever

Ethics in neonatal medicine

- How do we as medical caregivers prioritize premature infants?
  - Recent studies by Annie Janvier, Canada, suggest that our decisions may not be entirely logical
  - Example from Acta Paediatrica publication 2008
    - Pediatric residents and nurses were asked:

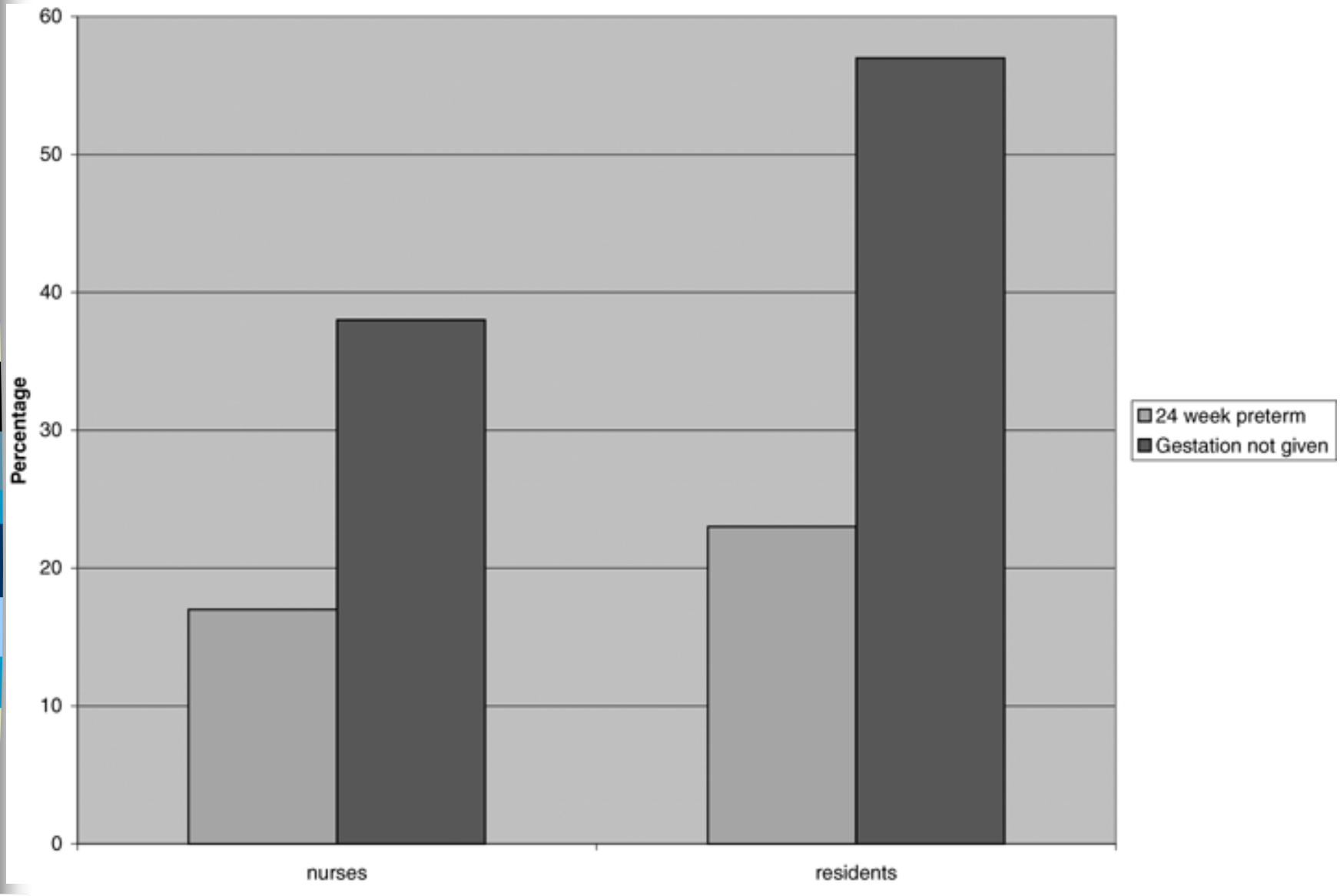
Ethics in neonatal medicine

- **RESUSCITATION OF A 24-WEEK DEPRESSED INFANT**
  - Do you think it is reasonable to resuscitate (in the delivery room) an AGA depressed infant at 24-week gestation?
  - The possible responses were: always, generally, exceptionally,never. ‘Always and generally’ were counted as positive answers.

Ethics in neonatal medicine

- **HYPOTHETICAL INFANT**
  - There is an impending delivery of a preterm infant with a 50% predicted survival and a long term outcome as follows if the baby survives:
    - 1. 50% development ‘within normal limits’
    - 2. 20–25% serious handicap rate
    - 3. 40% with behavioural and/or learning disability
    - 4. Do you think such baby, if born depressed, should be aggressively resuscitated in the delivery room?
  - The possible responses were: always, generally, exceptionally, never. ‘Always and generally’ were counted as positive answers.
  - NB! This question regarding a hypothetical newborn infant did not mention the gestational age in the scenario.

The Answers:


60
50
40
30
20
10
0
Percentage
nurses
residents
24 week preterm
Gestation not given

A conundrum

- The baby described as a 24-weeker and the premature baby of unspecified gestational age really had the same prognosis for outcome
  - But caregivers were more inclined to resuscitate the baby with unspecified gestational age
    - Because they unconsciously associated the 24-weeker with a much worse prognosis?

An answer to the conundrum?

- A fair decision and a fair allocation of resources must be based on a solid knowledge and understanding of the biological and medical facts

Ethics in neonatal medicine

- Family oriented neonatal care*
  - Is based on open and honest communication between parents and medical staff
    - Parents have a right to know
    - There are no acceptable reasons to withhold information
  - If parents are to participate in meaningful dialogue with the medical staff, they must have access to the same information as them

» *From Pediatrics 1993

Ethics in neonatal medicine

- Family oriented neonatal care
  - In situations where there is great likelihood of death or great suffering, or where there is significant disagreement between physicians, the parents must have the right to abstain from aggressive treatment

Ethics in neonatal medicine

- Family oriented neonatal care
  - If information about serious disease or risk of serious disease in the infant becomes available during pregnancy, the parents should be given the opportunity to express their wishes regarding treatment in advance

Ethics in neonatal medicine

- Family oriented neonatal care
  - Parents and health personell should work together to develop meaningful follow-up programs that will permit early recognition of sequelae in the child

Ethics in neonatal medicine

- Modern neonatal medicine provides wonderful opportunities to save and prolong life
- Because we can do som much more, it has become even more important to be aware of the limits
  - Our ability to help is much greater today because old boundaries were move
  - But somebody always pays a price when boundaries are moved!

Ethics in neonatal medicine

- In the NICU at Rikshospitalet University Hospital 15-25 newborns die every year (out of 700-750 admissions)
  - 2 out of 3 die as an immediate consequence of withdrawal of life support
  - When we are getting close to the limits for what technology and medical science can offer, we must be increasingly cautious so that we don't overstep the limits of humane care

Ethics in neonatal medicine

- When we have come to the limits for what technology and medical science can offer, it is tempting to say:
  - ”There is nothing more we can do!”
- But that would be wrong:
  - In is in those situations that our ability to exercise empathy, loving care, and humanity are truly challenged
  - And in that arena we can still do important work!

Ethics in neonatal medicine

- When we have made a decision to stop life support, how can we be certain that we have done the right thing?
  - There is unlikely to be an absolute guarantee
  - But if together we have used our heads and our hearts a tried to find the answer which we think is best
  - Then the best is good enough!