Experiences from a clinical ethics committee

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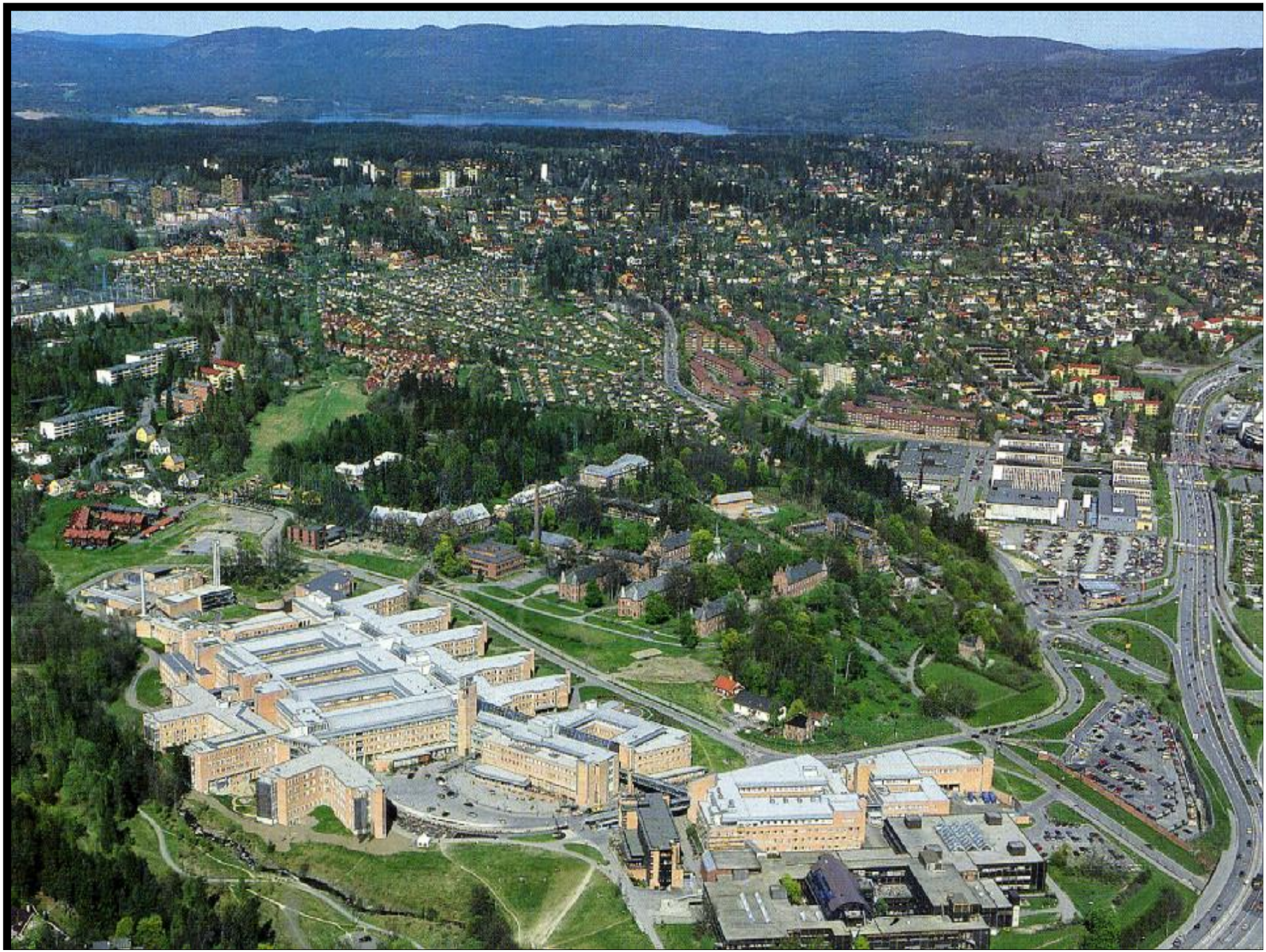
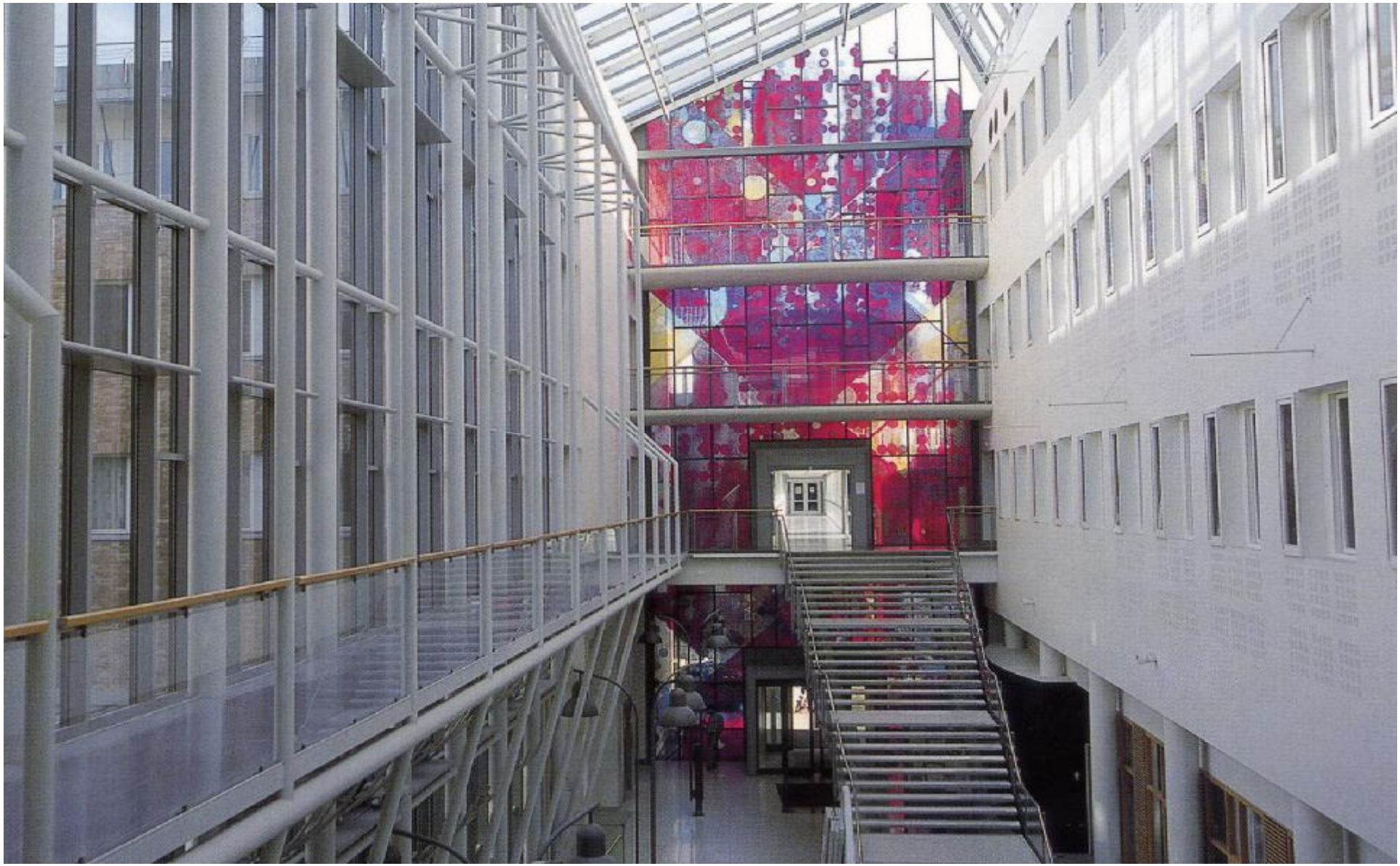


Rikshospitalet, Oslo, Norway



Brief background

- Clinical ethics appeared on the agenda during 1960-70ies in the USA
  - The Americans have had clinical ethics committees since the 1970ies
    - If U.S. hospitals want to be accredited and get contracts with ”third party payers”, they now need to have such committees
- Clinical Ethics Committees (CECs) were started in Norway in 1996
  - Rikshospitalet was one of a group of 3 hospitals to initiate this work

Brief background

- In 2000 the Norwegian Parliament decided that all hospitals must have a clinical ethics committee
  - Currently there are clinical ethics committees in 38 hospitals in Norway
- Rikshospitalet and the Norwegian Cancer Hospital were merged a few years back
  - A joint CEC for the two hospitals was established on January 1st, 2006

Clinical ethics in the world

- The World Medical Association has published documents dealing with principles of medical ethics
  - Although these do not necessarily represent a true international consensus, I believe they are quite representative of current thinking. A link to these documents may be found at:
  - WMA Ethics Unit http://www.wma.net/e/ethicsunit/

Clinical ethics in the world

- The British Medical Association has a very active medical ethics unit
  - The following link is to their handbook of 2004:
  - BMA Handbook on ethics and the law: http://www.bma.org.uk/ap.nsf/Content/MET2004
  - Some updates to the chapters were published in 2007: http://www.bma.org.uk/ap.nsf/Content/MET2007updates

Clinical ethics in the world

- The American Medical Association also has very useful medical ethics documents on the web:
  - http://www.ama-assn.org/ama/pub/category/2416.html
- This includes their 9 principles of medical ethics:
  - http://www.ama-assn.org/ama/pub/category/2512.html
- The Russian Medical Society has a Committee for Medical Ethics
  - I have not been able to find a web link for this committee

Tasks and mandate of a CEC

- A CEC should identify, analyze, and if possible solve ethical problems connected to the clinical activities of a hospital
- A CEC should work to make the staff more aware of the ethical issues involved in resource utilization, and should present a holistic perspective when it comes to prioritizing between the diverse needs of the patients served by the hospital
- A CEC should work to enhance the quality of the encounters between the hospital and the patients

Tasks and mandate

- A CEC
  - takes cases under consideration
  - evaluates the questions raised by the case
  - attempts to shed light on unclear points
  - gives advice to the clinical team in charge of patient care
    - may occasionally formulate quite strong opinions
- However –
  - Clinical responsibility always rests with the physician in charge of the care of the patient

CECs vs RECs

- CECs do not, as a rule, deal with questions concerning research ethics
- Separate committees for research ethics are constituted in all Norwegian health regions (Regional Ethics Committees = RECs)
  - All research protocols involving human study subjects must be approved by a REC*
    - *or its designated representative

How is a CEC composed?

- A clinical ethics committee should be composed of representatives of the different professions working in the hospital
- A lay person or representative of the public is also often included in the committees

The CEC at Rikshospitalet

- We have 12 members as follows:
  - Chair – MD, professor of pediatrics
  - Assistant chair –MD, oncologist
  - Secretary – clerical staff and patient/family representative
  - MD - clinical oncologist
  - MD – professor of medical ethics
  - Nurse - neurology
  - Nurse – oncology
  - Nurse – oncology
  - PhD – professor of physical therapy
  - JD – lawyer/legal councel
  - Social worker – child psychiatry
  - DD – hospital chaplain

How does a CEC work?

- Patient cases may be evaluated prospectively or retrospectively
  - The goal is to achieve a comprehensive characterization of the ethical questions involved, and to discuss these in a multidisciplinary forum
- Tematic meetings in hospital departments or divisions
  - Emphasis on insight, understanding, and attitudes
- General questions or questions of overarching principles may be discussed without relation to concrete patients
  - For example questions concerning prioritization
- Open seminars which focus on specific problems and challenges

Who may attend CEC meetings?

- Members of the CEC
- Those who have requested evaluation of a case or question
  - Possibly also others from the department/division involved
- +/- Patient and/or next of kin, alternatively a representative appointed by the patient
  - If a concrete/recognizable patient is discussed, the patient must be aware and should give consent to disclosure of sensitive information
  - Cases may also be discussed anonymously
    - This appears to be becoming less common

Typical plan for deliberations

- Presentation of the case
  - Which questions are asked?
- Explanation of those medical facts necessary to understand the case
- Identification of the involved parties
  - ”Who owns the problem?”
- Attempts to identify the ethical problems raized by the case
  - Deciding which aspects need to be evaluated
  - Which alternative answers/solutions are possible?

Typical plan for deliberations

- This is followed by an open discussion in the committee
- Proposals are put forward for possible solutions
- The CEC chair then summarizes the discussions and attempts to formulate a conclusion
    - There may be consensus or divergent views

What does a CEC not do?

- A CEC is not a court of law!
  - We have no power to sanction
  - We do not pass judgments on ”bad ethics”
    - Obviously we sometimes express views that diverge from the way in which a case was managed
      - Ideally the individual or department which receives this type of opinion would use this as a tool to improve their management when/if a similar situation occurs again
    - Occasionally we are also able to give a ”pat on the shoulder” to individuals and departments
  - A CEC is not out to ”get” somebody!

What does a CEC not do?

- A CEC does not handle personell or staff issues
  - If colleagues behave badly or do not exhibit a reasonable professional standard, these are issues for personell management or for the clinic/department leadership
    - However, if bad behavior or inadequate standards result in ethical conflicts, a CEC may reasonably be asked to handle the issue

The legal situation in Norway

- Several laws in Norway impact upon the practice of clinical ethics
  - The law of patients' rights
    - Patients have the right to have their condition evaluated
    - Patients have the right to be informed of their illness
    - Patients have the right to shared decision-making as regards their treatment
      - This includes the right to refuse treatment
      - And the right to chose between alternative treatments
        - » Limited to a choice between treatments which are documented or accepted by the medical community

The legal situation in Norway

- The health personell law
  - This law describes the rights and responsibilities of doctors, nurses, and other people with training in the medical field
  - Persons without medical training are not permitted to offer medical care to sick people
  - Medical/nursing professionals are held to a professional standard of care
  - Medical/nursing professionals must respects the patient's right to confidentiality
    - Sign an "oath of silence"

The legal situation in Norway

- The child protection law
  - Society and it's representatives must safeguard the welfare of children
  - If parents are not competent to take properly care of their children, society has a duty to step in
    - This may be temporary or permanent, depending on circumstances
  - All communities in Norway have a publicly appointed child protection board whose duty it is to look after the welfare of children

The legal situation in Norway

- The UN Convention on the Rights of the Child
  - Art.3: ”In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.”
- Having signed the Convention, Norway is obliged to consider the articles of the convention, also as they may pertain to health care
  - The question of what constitues ”the best interest” of a child occasionally comes up in the weighing of treatment alternatives

Children in clinical ethics

- Parents have the right and the duty to make decisions on behalf of their child.
  - Children have a right to be heard, which increases with age.
    - Between the ages of 12-16 years children's right to be heard increases. After the age of 16 it would take a lot to override the opinion of the youngster.
- Parents must be included in medical decision-making which concerns their child
  - However, parents cannot demand treatment which the responsible physician finds to be professionally or ethically improper
  - Also, they cannot refuse treatment which the responsible physician finds to be in the child's best interest
    - For example, parents who are Jehova's Witnesses cannot refuse a blood tranfusion to an underage child

Children in clinical ethics

- Example of a recent CEC case involving a child
  - NN was a 4 week old baby with Trisomy 18
    - He started to have apneas and was initially resuscitated with bag-and-mask ventilation
    - The hospital informed the parents that such apneas usually lead to the death of babies with trisomy 18
    - Therefore the hospital determined that further resuscitation was futile in this baby with poor prognosis
      - Further resuscitation would not be undertaken
    - The father demanded that the child be kept alive by repeated resuscitation

Children in clinical ethics

- Example of a recent CEC case involving a child
  - The case of NN was brought before the Rikshospitalet CEC by the hospital where he was being treated
    - The hospital's case was presented to the CEC in writing
    - The father and his lawyer met the CEC in a 2-way phone conference from the city where NN was being treated
    - The father and his lawyer presented their views on the case verbally and answered questions and comments from CEC members

Children in clinical ethics

- Example of a recent CEC case involving a child
  - The Rikshospitalet CEC gave the following opinion:
    - The medical facts are indisputable
      - The diagnosis of trisomy 18 has been established beyond doubt
      - Pure (non-mosaic) trisomy 18 carries an extremely poor prognosis – very few children with this diagnosis live beyond the age of 1 year, and these children are without exception severely retarded
      - Further resuscitation is likely to be painful for the infant

Children in clinical ethics

- Example of a recent CEC case involving a child
  - The interested parties in this case are:
    - The infant – it is not clear that he has an "interest" in prolonging a life of which he is likely not aware
    - The mother and father – though their interest was not shared. Thus, the mother did not agree with the father's wishes for resuscitation.
    - An older sibling of the infant, who needed a lot of care because of developmental issues
    - The hospital staff, who felt that resuscitating this infant was incompatible with their view of medical ethics and with a caring attitude to the child
    - Society at large, which has an interest in protecting the welfare of children, preventing child abuse, and limiting the use of medical resources for a treatment that appeared futile

Children in clinical ethics

- Example of a recent CEC case involving a child
  - The ethical questions appear to be:
    - What constitutes the ”best interest” of this infant?
    - Is a ”substituted judgment” possible?
    - Can parents demand continued treatment which may be painful for the child, regardless of the prognosis?
    - When parents disagree, do the wishes of one parent take presedence over those of the other parent?
    - Do ”sanctity of life” considerations demand that life support be continued in all such situations?
    - What role can/should ”quality of life” considerations play in weighing the alternatives?

Children in clinical ethics

- Example of a recent CEC case involving a child
  - The opinion of the CEC:
    - It is difficult to see that an infant with a confirmed diagnosis of non-mosaic trisomy 18 can have any ”interest” of its own in prolonging a life without possibility of meaningful cognition
    - Repeated resuscitation of this infant in reality prolongs death rather than prolonging ”life”
    - Parents do not have a right to insist on painful procedures which do not have a potential for prolonging a life from which the child itself can derive benefit
      - » In fact, it is quite possible that the child will not even be aware of its life
    - The wishes of one parent for prolonging ”life” can have no presedence against the other in circumstances like these

Children in clinical ethics

- Example of a recent CEC case involving a child
  - The opinion of the CEC:
    - A ”sanctity of life” argument in this situation would appear to demand continued life support with currently available technology in all dying persons
      - » Clearly, the available equipment and personell resources would be exhausted very quickly in caring for patients for whom no hope of cure is possible with our current knowledge
    - Quality of life considerations will need to be factored in when prioritizing scarce resources
      - » Thus, in a hypothetical scenario where only 1 respirator is available with 2 patients needing ventilatory support, expected quality of life needs to be part of the discussion - though it is not necessarily the only relevant argument!
    - Conclusion: The hospital is under no legal or ethical obligation to resuscitate or provide other types of life support for this infant

Children in clinical ethics

- Example of a recent CEC case involving a child
  - The father of the child would not accept the hospital's decision or the opinion of the CEC.
  - He therefore brought this case before the courts, claiming that the infant's rights to emergency medical treatment had been violated.
  - The opinion of the CEC was subsequently supported by courts of law up to the Supreme Court

Another problem handled by the CEC

- Case scenario
  - A woman who had a sterilization procedure by tubal ligation some years ago requests recanalization
    - There is a new man in her life, and she wants a child by him
  - The gynecologist is concerned because:
    - The local social services office has expressed concern about this woman's parenting ability
    - The "new man" is currently in prison because of a narcotics offence

Another problem handled by the CEC

- The gynecologist's question:
  - Does this woman have a right to demand that this procedure be performed?
- The opinion of the CEC
  - Recanalization at public expense after sterilization is request for public assistance to have a child
  - There are two possible analogies to this situation:
    - Requests for adoption
    - Requests for in vitro fertilization

Another problem handled by the CEC

- The opinion of the CEC
  - Norwegian law determines that people who want to adopt a child, as well as people who request in vitro fertilization to have a child, must be evaluated as far as their ability to care for the child
    - Information must be sought from sources such as the social service agency
  - If the applicants are not deemed able to properly care for a child, adoption and IVF will be denied

Another problem handled by the CEC

- The opinion of the CEC
  - It would seem reasonable that requests for recanalization be judged by the same criteria
    - As the purpose is the same – to have a child
  - The CEC suggested that the woman and her partner be evaluated following to the same rules that apply to IVF and adoption
    - And that recanalization not be offered unless the criteria were satisfied

Resolving disagreement

- Interpretation of the medical situation
  - The patient/parents/next-of-kin and the medical experts do not always have the same understanding of the facts
    - The patient is improving or a miracle will occur, vs
    - The patient is dying and/or has no long term survival chances
  - It is important to try to understand the basis for the patient's/parents' interpretaton
    - What are their thoughts on health, disease, body, and function?
    - What is the impact of religion or life philosophy?

Resolving disagreement

- Use of ”second opinion”
  - If patients in Norway do not agree with the opinions or advice of the physician, they are entitled to a second opinion by another expert
    - This can occur either by transferring the patient to another hospital, or by having an external expert see the patient in the hospital where she/he is currently hospitalized

Ethical decisions in medicine

- ”Practice makes perfect…..”
  - Advanced clinical medicine demands a lot of training if you want to get good at it
    - In Norway medical school takes 6-7 years, and most specialties require 5-6 additional years of training
    - Becoming a ”sub-specialist” requires 2-3 years of additional training
      - if you want to be ”a star” you have to work even harder!!
  - Everybody understands and accepts that this is the case!

Ethical decisions in medicine

- ” Practice makes perfect …..”
  - Clinical ethics also requires a lot of study and practice
    - You need basic knowledge about medical ethics
    - Knowledge about the law and patients’ rights
    - Knowledge about the range of human emotion
    - Training in communication
    - Training in sensitivity
    - The ability to reflect on who you are and to know yourself
    - The ability to control your emotions when confronted with the sufferings of others
  - It is possible to learn this!!

Thank you for your attention!