Advanced clinical medicine requires advanced clinical ethics

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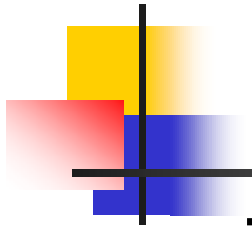
Patrick Bouvier Kennedy
August 7.-9.,1963

- Youngest son of Jaqueline B and John F Kennedy
- Delivered by caesarean section at 34½ weeks of gestation, BW 2112 g
- Died at Boston Children's Hospital 2 d old due to "hyaline membrane disease"
- Buried next to his father at Arlington National Cemetery, Washington DC

Louis Washkansky (1913-1967)

- Recipient of the world's first (human) heart transplant at Groote Schuur Hospital in Cape Town, South Africa, December 3., 1967
- He died after 18 days due to bilateral pneumonia

Medical progress



- Today (2009) deaths due to immature lungs at 34½ weeks of gestation is extremely rare in the industrialized world
  - but 46 years ago not even the son of the arguably most powerful man in the world could be saved
- Today about 30 patients a year receive heart transplants at Rikshospitalet
  - 1 year survival is 85%

Medical progress

- Reports of attempts to mechanically ventilate newborn infants started to appear towards the end of the 1960ies
  - In 1976 neonatal ventilators were simple & ”primitive”
  - In 2009 we have ventilators which may be controlled by infants as small as 500 G
- The first experience with surfactant for treatment of RDS was published in 1980 (Fujiwara T et al, Lancet)
  - I 2009 surfactant therapy is ”standard of care” and is given to thousands of infants each year

Medical progress

- In my ”lifetime” as a physician:
  - Treatment of respiratory failure in neonates has gone from experimental science fiction to (quite) reasonable and widely available care for the ”masses”
  - Treatment of terminal cardiac disease with heart transplantation has gone from being a very expensive, experimental therapy for a few – to a very expensive, established therapy for a few

Advanced clinical medicine

- ” Advanced clinical medicine” is a result of progress in many areas
  - A few ”quantum leaps”
  - + many small steps

Advanced clinical medicine

- For (almost) all progress a price has been (and is being) paid
  - Personal/humanitarian
    - Death ”om the learning curve”
      - Louis Washkansky and many others
    - Suffering
      - Anticipated side effects of intensified cytostatic- and radiation treatment
        - Those who might have survived with less intensive therapy pay a price with more suffering so that more may survive
      - Unexpected/unanticipated side effects
        - Progressive deterioration of CNS function in children given CNS radiation for cancer at a young age

Advanced clinical medicine

- For (almost) all progress a price has been (and is being) paid
  - Economical
    - For the individual
      - Permanently reduced working ability for those who remain disabled by their illness
      - Close to ruin in countries with self-paying health care systems
    - For society
      - Rapidly escalating costs of health care delivery
      - Increased costs of disability
    - Alternative costs
      - What would the same money have bought if used differently?

When we are seduced by our success

- Modern medicine can in many areas take pride in it's success
  - But what did we have to do to achieve this?
    - Change our historical understanding of health and disease:
      - Analyze disease by emphasizing the universal aspects – the epidemiological approach
      - Treat illness based on the same population centered understanding
      - To achieve this we had to downgrade the importance of the individual's history, beliefs, and characteristics
    - Change the curriculum in training of health care workers:
      - We no longer learn to understand "the meaning" of health and disease
      - Rather, we learn to diagnose and intervene to cure disease

The price of success

- ”When disease cannot be cured, or when suffering can no longer be relieved, doctors are no longer sure what to do or whether they still have a role to play”
  - John D.Lantos: Do we still need doctors? 1997

The road travelled

- Approaches to medical ethics
  - Benevolence
    - To help, cure, palliate, comfort
  - Avoid causing harm (non-maleficence)
    - Medical treatment has always been associated with risk
  - Justice
    - Not treating the commoner differently from 'King Solomon'

The road travelled

- Approaches to medical ethics
  - Legal rights
    - The Norwegian Law of Patients' Rights gives patients the right to
      - Choose their hospital
        - with certain limitations
      - Contribute to and make decisions regarding their own treatment
        - "…. the right to participate in choices between available modes of investigation and treatment, as long as these are based on sound professional practice"
        - Implicit in this is the need for patient consent
      - To receive an "individual plan" for therapy
      - To receive information about the disease as well as the plans for investigations and therapy

The road travelled

- From quiet acceptance of the doctor's decisions to active, informed, demanding participant
  - Democracy enters health care:
    - People ask more questions
    - They want more details
    - They may seek 2nd and 3rd opinions
    - They recognize that our knowledge is limited
    - They do not accept the doctor's words as the final truth

Rights imply challenges

- Henrik Ibsen about ”user involvement” (in Rosmersholm):
  - *Johannes Rosmer:* ”It is my impression that in recent years there is evidence of more independence in the thinking of the individual”
  - *Principal Kroll:* ”Now, and is it Your opinion that this is a significant benefit?”

Rights imply challenges

- Prerequisites for user involvement
  - Ability/competence for decision making
    - Age
      - When should children be involved in decision making?
    - Cognitive changes
      - How demented is *too* demented?
  - Understanding
    - Information must be conveyed in a way that can be understood by the patient
      - Disparity in intellectual and educational background
      - Differences in cultural background
      - Differences in thinking about health and disease
      - Language barriers

Rights imply challenges

- Prerequisites for user involvement
  - Voluntarism
    - How real is it?
      - Remnant of the old doctor's authority?
        - Differences between specialties?
    - Need to document?

Rights imply challenges

- Risks in user involvement
  - We may deny responsibility for unfortunate results
    - ”You made the decision – you are responsible for the outcome”
  - Covering up/avoiding difficult ethical dilemmas
    - ”It was the patient who wanted it”
  - Shirking responsibility for resource allocation
    - Carrying out expensive, non-indicated exams and studies just because ”the patient asked for it”

Ref.: Bjørn Hoffmann, Section for Medical Ethics, UiO

Rights imply challenges

- The patient's right to choose
  - We probably still have more terrain to cover
    - "Living will"
      - Suggest that some people fear that the health care system may continue to treat them beyond what they perceive to be the limits of reason and humanity

Rights imply challenges

- The patient's right to choose
  - Limitations
    - The right to abstain from treatment is extensive
      - However, there are significant limits in the rights of parents to abstain from treatment of their children (Norwegian Law of Patients' Rights)
    - The right to "positive choice" is limited by
      - Lack of documentation ("evidence base")
      - Requirements for "sound professional practice"
      - Cost/benefit ratio
        - The cost must "have a reasonable relationship to the effect of the intervention" (Norwegian Law of Patients' Rights)

Advanced ethics in advanced clinical medicine

- What do we do when...
  - Our therapies become more expensive while our budgets are limited?
  - Our therapies become more burdensome and our patients no longer want a part of it?

Advanced ethics in advanced clinical medicine

- When resources are limited .....
  - We must assume responsibility for prioritizing
    - We cannot possibly do ”everything for everybody”
      - Sometimes we have to look patients in the eyes and say ”no”
      - We must ask if everything that is offered at ”St.Elsewhere” should necessarily be standard of care at our hospital
      - May be we have a right to expect that our political and administrative authorities have the guts to own up to the limitations which they have decided on?
    - We must ask whether the result of an intervention is worth the cost
      - Which effects on survival at what price?
      - Which effects on quality-of-life at what price?

Advanced ethics in advanced clinical medicine

- When resources are limited .....
  - We must assume responsibility for prioritizing
    - This may involve greater attention to the concept of ”alternative cost”
      - Do we get ”more” out of a given amount of money by investing it in high-cost care of a small group of patients with (possibly) marginal effect on survival and health?
        - At recent example might be multivisceral transplantation.
      - Or do we get ”more” out of the same amount by investing it in time, attention, and dialogue with patients in existential crises?
      - Our should we perhaps invest the same amount in better palliative care and symptom relief for those patients who we cannot cure?

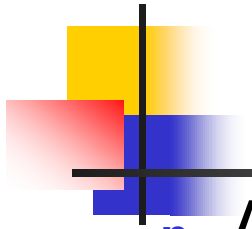
Advanced ethics in advanced clinical medicine

- When resources are limited .....
  - Equality in distribution becomes important
    - Democratic and egalitarian traditions may be a help in this context
  - We must be well reflected and transparent as far as how and why we make our choices
    - Maybe we need mechanisms in our organizations to assist in these decisions?
      - But we must avoid a bureaucracy that might kill innovation

Advanced ethics in advanced clinical medicine

- When resources are limited .....
  - The Norwegian Law of Patient's Rights states:
    - "The right to health care only applies if the patient can benefit from care, and when there is a reasonable relationship between the cost and the effect of the intervention."

Advanced ethics in advanced clinical medicine



- Advanced clinical medicine is often tied to research
  - Requires us to be attentive to our possibly hidden agendas
    - Are we primarily looking for more recruits for our study, or are we primarily focused on healing our patient?
    - When are we scientists and when are we doctors?
    - Is our research conducive to health or (mostly) conducive to our career?

Advanced ethics in advanced clinical medicine

- ”Practice makes perfect.....”
  - Your can only master advanced clinical medicine if you practice at it
    - To become a specialist requires 5-6 years of training after medical school
    - To become a ”sub-specialist” requires additional years
      - And to become a ”star” requires even longer!!
  - Everybody understands and accepts that this is how it is!
    - Who would be a passenger in a jumbo-jet if the pilot were only licensed for and experienced with small, single-engine aircraft?

Advanced ethics in advanced clinical medicine

- ” Practice makes perfect.....”
  - Ethics also requires knowledge and training
    - Basic knowledge about medical ethics
    - Knowledge about the law and about patients’ rights
    - Knowledge about human psychology and emotions
    - Training in communication
    - Training in sensitivity
    - Self-knowledge and ability to reflect on who and how you are
    - Ability to control your own emotions face-to-face with the suffering of others
  - Most of this can be learned!

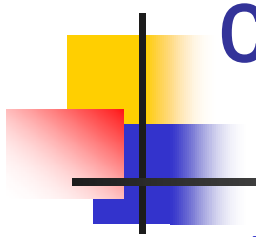
Advanced ethics in advanced clinical medicine

- ” As health workers we must be willing to face the challenge of working on our reactions and emotions confronted with these patients, so that, when our knives, radiation, and drugs have forfeited their role, we can be at their side with humanity and empathy. If we are unable or unwilling to do this, we should look for other employment..”
  - Hansen TWR & Liavåg A, Tidsskr Nor Lægeforen 1999

Advanced ethics in advanced clinical medicine

- When innovation ”pushes the envelope” ...
  - And things do not go well for the patient, we may
    - Continue ”ad infinitum” and play ignorant
      - Because our self-image cannot stand losing?
      - Because we dare not look the patient in the eyes and admit our limitations?
      - Because we are not reconciled to our own mortality?
      - Because avoidance is the easier course?
    - Enter into dialogue with the patient and kin
      - What are the patient’s own understanding and expectations?
      - What are the patient’s own limits?
      - What support and help from us would the patient need if we decided to withdraw or limit active therapy?

Advanced ethics in advanced clinical medicine



- When innovation ”pushes the envelope” ...
  - We need to reflect in advance on where to ”draw the line”
    - The Norwegian Law of Health Personnel §4 states that the treatment we offer must be
      - i) In accordance with sound professional practice, and
      - ii) Considerate/caring!
        - The ”considerate and caring” bit is easy to forget!
  - The patient needs to know that she/he is participating in a journey into unknown territory
    - And should be invited into advance dialogue as far as the limitations

Advanced ethics in advanced clinical medicine

- Ethics and communication
  - Recognize that ethical problems and communication problems are not the same
  - Recognize that a communication problem may develop into an ethical problem
  - Develop mechanisms to deal with communication problems
    - Between health workers (”internal”)
    - Between health workers and patient
    - Between patient and kin

Advanced ethics in advanced clinical medicine

- Parliamentary report. 26 (1999-2000) On values for Norwegian health services
  - ”The encounter between patient and health worker is at the core of health care delivery. This encounter must be based on respect and on love for your neighbor.”

Advanced ethics in advanced clinical medicine

- In the end, avanced clinical medicine can be practiced using a simple set of ethical rules:
  - Put yourself in the patient's place
  - "Do unto others as you would wish done unto yourself"