Ethical issues in Pediatric SCT

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Agenda

• Clinical ethics- a mini refresher
• What is special about SCT?
• What is special about pediatric ethical issues?
• What is special about ethical issues in pediatric SCT?
• (probably) one clinical ethics best practice example: Advance care planning – also for children/adolescents
A mini „refresher“
Clinical ethics
It is mostly about **deciding** and **acting** best in **problematic or complex dilemmatic** (no win win) situations

(decisional criteria, process, evaluation)
2 central questions with regard to therapy

1. What are our central goals of care? (including all alternatives)?
2. What does the patient want? (and does the patient/his/her surrogates have sufficient information on all alternatives?)

- Central questions to be answered before any procedure to answer the central ethical question
  - „What should we do“?
  - (Be careful if someone says „its obvious“)
Goals of Medicine

1) Avoidance of premature death
2) Prevention of disease
3) Care of the ill
4) Relief of suffering

•=> Quality of life – and death
Historical development of central disease stage specific goals

![Diagram showing Different Stages of Therapy](image)

- Therapy
- Maximal Therapy
- Curative Therapy
- Palliative Therapy
- Minimal Therapy

Courtesy of Ralph Jox Munich
Ethics is the twin of evidence based medicine

- In evidence based medicine, suggestions of treatment alternatives do not (solely) rest on experiences from good old boys but from best available evidence.
- Treatment decisions are also value based.
- A rational approach to ethics (not only in medicine) demands that we root value based decisions impacting other persons not (solely) in experience from good old boys but on transparent reflections and good reasons.
Indication- no (clear) objective basis e.g. life prolonging therapy...

Futility/ extreme pain, imminent death, brain death

Persistent vegetative State

End stage lung disease

Severe COPD

Blood with a HB under 6 g/dl
Shared decision making (SDM) and evidence based medicine (EBM)
Characteristica of intervention/therapy
Whitney 2003

Lumpectomy versus mastectomy in a small Mamma Ca

Blood Jehovas witnesses

Priority decision
Patient

Conflict ↑

SDM

Importance of values ↑

Evidence not clear or Equipoise

Bioethics ↑

Priority decision physician

Certainty ↑ clear evidence

Antibiotics for pneumonia of a young patient
What is special about SCT?

• Highly specialized procedure only performed in certain centers
• „all or nothing“ feeling while waiting for an adequate donor
• Isolation
• Different indications and situations
• Considerable risk of immediate death during procedure
• Some severe long term effects
• Highly different cost effectiveness (QALY gain) of SCT for different indications
Sucessfull in the virtual emergency room in 75-90% …
And in reality

19% on average in hospital arrest

>1% Survival of cardiac arrest in Aplasia
5. What matters most to me when I consider this decision?

The information presented below is based on a thorough review of the scientific literature. Blocks of 100 faces show a ‘best estimate’ of what happens to 100 people who choose different options in the decision about CPR. Each face ☻ stands for one person. The shaded areas show the number of people affected. There is no way of knowing in advance whether your heart will stop or what will happen to you if you have CPR.

<table>
<thead>
<tr>
<th>Staying alive longer</th>
<th>✓ Have CPR</th>
<th>☻ Decline CPR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some patients want to have CPR to stay alive longer, even with the small chance of survival. People might have unfinished business that they would like time to attend to, for example they want to see a child married or get their affairs in order.</td>
<td>About 5 patients will survive out of every 100 patients who have CPR when their heart stops. This means that 95 people who receive CPR die. It is not possible to know what will happen to you if you have CPR.</td>
<td>If you do not have CPR when your heart stops, then you will die.</td>
</tr>
<tr>
<td><strong>Serious Brain Injuries</strong></td>
<td><strong>Have CPR</strong></td>
<td><strong>Decline CPR</strong></td>
</tr>
<tr>
<td>---------------------------</td>
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<tr>
<td>Some patients who survive CPR live with serious brain injuries like paralysis, speech, memory, language, and personality problems. This means that they need a lot of care from family and/or caregivers. For some patients, the risk is acceptable and they may feel that nothing is worse than death itself. Others do not want to live with disabilities, especially with serious brain injury.</td>
<td>About <strong>5 patients will survive out of every 100 patients</strong> who have CPR when their heart stops. So about <strong>95 people who receive CPR die</strong>. Of the <strong>5 who survive 2 will have serious brain injuries</strong>. It is not possible to know what will happen to you if you have CPR.</td>
<td>If you do not have CPR when your heart stops, <strong>then you will die</strong>.</td>
</tr>
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</table>
Indications/treatment situations

SCT

• high chance of healing very severe diseases leading to premature death
• Step of a complex treatment plan maybe leading to healing the disease
• Rescue therapy to gain some more months of life
Indication- no (clear) objective basis of e.g. life prolonging therapy...

Resuscitation in Aplasia, Sepsis and on Vasopressors in SCT

Re SCT after second relapse

Re – SCT after first relapse

SCT for SCID

Blood with a HB under 6 g/dl during therapy induced anemia

Palliative Therapy

Curative Therapy
Risk of SCT e.g. Immediate death

Medical, psychological and social Side effects Child family

Symptoms of disease

Values of the child e.g. limits of suffering

Values of the family e.g. limits of enduring suffering of the child

Short/long term prognosis regarding prolonging life QOL
What is special about Pediatric ethical issues?

- **Situation**: a 12 year old boy is having a lung transplant. Due to logistics and specialization, he is hospitalized in an adult ICU.

- What problems might he, the parents, the family, the team face? What does the team have to think about? Provide? Are there different procedural and ethical issues compared to an adult? Specific needs and rights?
Childrens rights, needs and relations
Childrens rights...

- E.g. Right, not to be separated from his/her parents; Right to education (...)

and needs translated into pediatrics...
Table 3 Practical implications of the UNCRC

<table>
<thead>
<tr>
<th>Deduced questions (related article)</th>
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<tr>
<td>Do I try my best to arrange all conversations with children and parents undisturbed in a likeable atmosphere with sufficient time? (Art. 3, 9, 16, 23, 31)</td>
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<tr>
<td>Do I rather talk with the child than only about the child as soon as possible? (Art. 12, 13, 16)</td>
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<tr>
<td>Do I explain the whole purpose of a treatment or an intervention to the child in an age-appropriate manner? [duration, speed, pauses, word choice, demonstration with drawings, toys, videos or computer] (Art. 12, 13, 30, 31)</td>
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<tr>
<td>Do I indicate to the child that he or she can know everything, even if it could be difficult to understand everything? (Art. 13)</td>
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<td>Does the child have enough time and support for a proper decision making process? Are there repeated opportunities to raise questions? (Art. 5, 13, 31)</td>
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<td>Do I let the child feel that it would not be alone with his or her problems? (Art. 9, 19, 24)</td>
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<td>Am I of sufficient openness and impartiality for a proper dialog? (Art. 2, 12, 13)</td>
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<td>Does the child with linguistic and/or symbolic communication make a contribution to the decision making process? (Art. 3, 12)</td>
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<td>Do I try to understand arguments and decisions even if they seem wrong to me? Do I appreciate the cultural background as a part of the child’s interests? (Art. 12, 24, 27, 22, 30)</td>
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<td>Do we determine the child’s best interests interdisciplinarily by a broader consultation including children and parents or merely from the biomedical perspective? (Art. 3, 5, 9, 18, 24, 31)</td>
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<td>Do I allow the child to acquire experience with the decision making process in well-considered and appropriate situations, and in such cases do I even allow the child to make the wrong decisions? (Art. 6, 12, 13, 30)</td>
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<td>Do I provide and plan with the same professionalism curative as well as supportive, palliative, and comfort therapy? (Art. 3, 19, 23)</td>
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<td>Do I take into consideration the basic needs of the child and his or her family? (Art. 6, 18, 19, 22, 27)</td>
</tr>
<tr>
<td>Do I advance my communication skills through appropriate training? (Art. 2, 3, 6, 12, 13, 24)</td>
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Caring (balancing relations, responsibilities for self and others)

Family crucial for the child: Living, treating, healing and dying in relations

Family entire „sense giving“ world;
Decision making
Support

Supporting the caregivers is crucial for treating the child
Pediatric ethical issues in SCT

• Protect the rights and needs of the child – very crucial and intensive during conditioning and isolation (e.g. no/reduced body touch during most vulnerable phase)

• Care for the child and for the care giver differently in different stages of the treatment process and sometimes hard to achieve (distance, job loss, transitions)

• As far as possible shared decision making and advance care planning
Do you want to…

- Be intubated or not???
- Be transferred to the ICU or die???

What is the problem??
What is missing???
US Physicians wanting terminal sedation vs intubation in end stage lung disease

US Physicians talking with patients facing end stage lung disease about terminal sedation versus intubation
Bad news....
Enough

THE FAILURE OF THE LIVING WILL

by Angela Fagerlin and Carl E. Schneider

In pursuit of the dream that patients’ exercise of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned.
...and good news
• Ethical-legal strengthening of AD
• Well structured conversation with trained physicians
• Well structured conversation with trained Health care professionals into the care process

Not effective

Effective

Highly effective
The impact of advance care planning on end of life care in elderly patients: randomised controlled trial.


CONCLUSIONS:

Advance care planning improves end of life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives.
• Early palliative care for patients with metastatic non-small-cell lung cancer.

**CONCLUSIONS:**

• Among patients with metastatic non-small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival.
ACP for adolescents


Family-Centered Advance Care Planning for Teens With Cancer.

CONCLUSIONS:
Family-centered advance care planning by trained facilitators increased congruence in adolescent/surrogate preferences for end-of-life care, decreased decisional conflict, and enhanced communication quality. Families acknowledged a life-threatening condition and were willing to initiate end-of-life conversations when their adolescents were medically stable.

Lotz et al (2013)
Pediatric Advance care planning: A systematic review.

CONCLUSIONS:
There are few systematic pACP programs worldwide and none in Europe. Future research should investigate the needs of all stakeholders. In particular, the perspective of professionals has so far been neglected.
We have some fantastic international and Australasian speakers covering the topics of ACP and end of life care in:

- Paediatrics and Adolescents
- Aged Care and Dementia
- Mental Health
- Intensive Care and High Technology Medicine
- Primary and Community Care
- Palliative Care
- Chronic Disease
- Ethics
- The Law
‘neither science or economics (nor ethics or law, TK) will resolve the pain of choice. The best we can hope for is to strive to improve the process by which we reach the decisions’