Dealing with Fairness-Sensitive Issues at the Bedside. Suggestions from a Clinical Ethics Support Project

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Outline

• Fairness-sensitive issues *at the bedside*
  – (N)Ever raised in Ethics Consultation?
• Some insights from our background studies
• What can Clinical Ethics Support offer
  – for dealing with fairness-sensitive issues *at the bedside?*

➤ The METAP project – overview
  – What have we learned?
  – Preliminary suggestions
Fairness-sensitive issues

... at the bedside such as

- under-treatment, rationing ..., 
- discrimination, neglect ..., 
- over-treatment, futility ..., 
- facing DRGs, now also in Switzerland.

- Systemic problems cannot be solved at the micro-level, but affect clinical staff directly and personally.
Fairness-sensitive issues

... at the bedside

may trigger trouble among clinical staff
  – such as moral distress, burnout,
  – leaving the job.

They may also trigger
• cynicism in health care professionals,
• damage trust in patients and relatives and
• challenge the quality of patient care.
Fairness-sensitive issues

... (n)ever raised in Ethics Consultation (EC)?

• Some memories from early ethics consults in Germany
Fairness-sensitive issues raised in EC?

- 1996: ICU, ethics consult:
  - Cancer patient with complications after chemotherapy admitted to the ICU
  - “These patients should not stay in our beds; their prognosis is too bad.”
  - Oncologist explains that this patient has (should have) a chance if treated in the ICU.

- Outcome of ethics consult: patient stayed, recovered.
  - Exchange btw. the depts. (oncology & ICU) was initiated on the conditions of patient transfer
  - Agreement
Fairness-sensitive issues raised in EC?

- And the most recent case from Switzerland
Fairness-sensitive issues raised in EC?

- June 2012: Surgery, ethics consult (retrospective):
  - Tumor patient, multiple operations during the last 10 years, approaching EOL, Qu.L declining
  - Couple needed time to agree with palliative care,
    - were unable to manage at home,
    - did not agree with transfer to Hospice.
  - Patient was allowed to die peacefully in hospital.
  - Due to DRGs, the dept. accepted a financial deficit from this case.

Outcome of ethics consult: decisions acknowledged.
- Suggestion: to engage the hospital in establishing an own unit of palliative care.
The fairness-sensitive issues raised in the ethics consultations have two sides:
• possible under-treatment
  +
  • possible over-treatment
    ➢ disagreement
• Many everyday (repetitive) problems require at least basic knowledge of ethics.
  • Ethics is not yet a core competence of clinical staff
Some insights from our background studies

- paving the way towards the METAP Project
What do we know about the ethical difficulties of clinicians?
Black box
<table>
<thead>
<tr>
<th>Types of Difficulties</th>
<th>Norway</th>
<th>UK</th>
<th>Switzerland</th>
<th>Italy</th>
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<tbody>
<tr>
<td>- experience with ethical difficulties</td>
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<tr>
<td>- treating patients with impaired or uncertain decision-making</td>
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<td>- disagreement among caregivers</td>
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<td>- limiting life-sustaining treatment or Do Not Resuscitate order</td>
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<td>- patient disagreement for reasons other than religious or cultural</td>
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<td>- uncertainty whether to maintain confidentiality</td>
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<td>- uncertainty whether to disclose diagnosis to the patient</td>
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<td>- patient disagreement for religious or cultural reasons</td>
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<td>- scarcity of resources</td>
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<td>- conflict with policies or laws</td>
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<td>- rules for payment of services conflict with chosen course of action</td>
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<td>- request for physician assisted suicide or euthanasia</td>
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<td>- insurance status conflict with chosen course of action</td>
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Percentages shown in valid percent

*Kruskal-Wallis, p<0.01*
Based on your experience, are patients who belong to any of these groups more likely than others to be denied beneficial care on the basis of cost in your health care environment?
Based on your experience, are patients who belong to any of these groups more likely than others to be denied beneficial care on the basis of cost in your health care environment?

*Pearson Chi-Square: p<0.01

Highly accessed
The Values at the Bedside Study

Switzerland – United Kingdom – Italy – Norway
Disagreement about treatment goals …

…. can lead to a breakdown of the conversation between physician and patient.

- Part of Eva Winkler‘s PhD-Dissertation 2010, Basel
- Winning the Award of the Medical Faculty, University of Basel 2012
The role of relatives in decisions concerning life-prolonging treatment in patients with end-stage malignant disorders: informants, advocates or surrogate decision-makers?

D. Hauke, S. Reiter-Theil, E. Hoster, W. Hiddemann & E. C. Winkler

1Department of Internal Medicine III (Haematology and Oncology), University Hospital Grosshadern, Munich, Germany; 2Department of Medical and Health Ethics, Medical Faculty, University Hospital, Basel, Switzerland; 3Department of Internal Medicine III, Institute for Medical Informatics, Biometry and Epidemiology, Ludwig-Maximilians University of Munich, Germany

Received 30 November 2010; revised 12 January 2011; accepted 13 January 2011
In case of „futile“ treatment

.. it is not always the patients or their relatives who prefer medically questionable interventions.

Futility: ein Begriff im chirurgischen Alltag?
Overtreatment (instead of treatment limitation)

... also occurs due to insufficient knowledge / communication in the clinical team

Limiting life-sustaining treatment in German intensive care units: A multiprofessional survey

Ralf J. Jox MD, PhD, Mirjam Krebs MA, Martin Fegg PhD, Stella Reiter-Theil PhD, Lorenz Frey MD, Wolfgang Eisenmenger MD, Gian Domenico Borasio MD, Dipl Pall

- Part of Ralf Jox’s PhD-Dissertation 2008, Basel
- Awarded with: Deutscher Studienpreis 2009, Körber Stiftung
What can clinical ethics support offer … for dealing with fairness-sensitive issues at the bedside?

1. specific approaches missing
2. data (evidence)
3. few experiences reported
4. ?
5. ?
6. ?

1. Education
2. Material
3. Consultation
4. Coaching
5. Ethics Policies
6. Evaluation

METAP Project
Dealing with fairness-sensitive issues in CES
Competences

• Identifying fairness-sensitive issues
• Acknowledging that there is a moral problem
• Motivation to act in an ethically justifiable way
• Reflecting and communicating on options, their pros and cons together with others
• Striving for practical solutions

Knowledge
• “diagnosis”
• Commitment, concern
• Virtues, personality
• Skills of various kinds, environment
• Authenticity
Reporting about METAP –

a clinical ethics support project (started in 2009)

• 6 centers: Departments of University Hospital Basel, Cantonal Hospital, Community Hospital, Private Hospital

- Goals and tasks: guideline development
- Wishes of clinical partners
- Content, procedures and instruments
- What have we learned?
- Suggestions
METAP

M – Modules
E – Ethics
T – Treatment
A – Allocation of resources (incl. time...)
P – Process
METAP — A knowledge-based (evidence) Guideline for supporting ethical competence in patient care with a focus on fairness-sensitive issues

Acknowledgements:

❤ Our clinical partners: AGUK, OIB, Dept. Viszeral-Chirurgie, USB
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METAP Book Co-Authors:
Albisser Schleger, Heidi Mertz, Marcel Meyer-Zehnder, Barbara Reiter-Theil, Stella

Project leaders:
Prof. Dr. Stella Reiter-Theil (Principal Investigator)
Prof. Dr. Hans Pargger (Co-Investigator)

Clinical partners: Prof. Dr. Hans Pargger / OIB, Prof. Dr. Reto Kressig / AGUK, and collab. clinicians

Present team members: Heidi Albisser Schleger, PhD, RN; Dr. Barbara Meyer-Zehnder; Valentin Schnurrer, MA; Jan Schuermann, stud. phil.; Sabine Tanner, MSc
METAP – goals and tasks

• Supporting the competence of clinical staff
  – at the individual level
  – at the interprofessional team level

• Providing
  – decisional procedures with defined ethical criteria

• Training
  – facilitators on the wards

• Evaluation
METAP orientation

• The development of METAP is oriented at international standards of medical guidelines programs
  – AGREE
  – AWMF / ÄZQ
  – Cochrane
  – DELBI

Quality criteria
• Evidence, based on scientific literature
• Interdisciplinary development
• External validation by clinical and academic experts
Ethics Guidelines?

- No agreed upon standard of quality, development or handling exists.
- They are developed in multiple ways by different experts, interest groups or institutions.
- Little is known about procedure, systematic and procedural qualities.
- Even less is known about the practical impact of these guidelines (“paper tigers”?).

Bartels, Parker, Hope, Reiter-Theil (2005) Ethik Med 17,3; 191-205
Concept of METAP / Manual & Guideline

• Foundation by literature
  – Empirical evidence (studies)
  – Normative / ethical validity (law, codes, national guidelines)

• Approval through consensus-building
  – International academic panel
    (for: relevance, consistency, coherence)
  – Local / regional clinical panel
    (for: acceptability, applicability)

• Evaluation through interdisciplinary research
METAP Guideline development

Consolidation of basics (methodology and content) …

Generating drafts …

Validation of drafts regarding scientific basis, methodology, relevance, decisional procedures …
METAP Guideline development

Adaptation and modification of drafts according to validation

Pilot implementation and pilot evaluation

Optimization according to evaluation

(Regional) Dissemination
Wishes of our clinical partners regarding ethics support

**Immediate support**
- Prospective case discussion = “ethics consultation”

**Mid- and long-term help**
- Basics for ethical decision making
  - Relevant empirical data, criteria, methods
- Overview: normative framework
  - Ethics, law, guidelines
- Transfer into practice: education and support – translational research
PATIENTENGERECHTE VERSORGUNG
Ein Handbuch für ethische Problemanalyse und Lösungsstrategien

Leporello / Kurzfassung von: Heidi Alibas Schieger,
Marcel Merz, Barbara Meyer-Zehnder, Stelia Reiter-Theil
(Stand: Februar 2010)

Manual, long version,
1./2. internal working edition
Wishes of our clinical partners?
Klinische Ethik - METAP

Leitlinie für Entscheidungen am Krankenbett


Wie hilft Ihnen METAP?


- METAP geht auf die gerechte Zuteilung von Ressourcen am Krankenbett ein.
- METAP ist ein klinisches Ethikkonzept, das medizinische Fachpersonen für ethische Fragen sensibilisiert.
- METAP unterstützt mit seinem Instrumentarium klinisch Tätige aus dem ärztlichen, pflegerischen und therapeutischen Bereich ebenso wie andere Helfer in der Weiterentwicklung ihrer ethischen Kompetenz.

Neben dem umfassenden Handbuch, das Grundlagen und Empfehlungen enthält und detailliert erläutert, liefert der beigefügte Leporello eine Übersicht zur ersten Orientierung.


2012. XX, 317 S. Softcover ▶ 69,95 € (D) | 71,91 € (A) | SFr. 87,50 ISBN 978-3-642-11127-3
METAP

PATIENTENGERECHTE VERSORGUNG

Ein Handbuch für ethische Problemanalyse und Lösungsstrategien

Lapreteke / Kurzfassung von: Heidi Albiesser-Schlegel, Marcel Mertz, Barbara Meyer-Zehnder, Stella Reiter-Theil

(Stand: Februar 2010)

Pocket version
Direct order: barbara.meyer@unibas.ch
Instrumentarium, Summary („Leporello“)
www.klinischeethik-metap.ch
Content of the Manual

- Empirical
- Ethical, normative
- Practical approaches and tools

  - Empirical basics of under-treatment, over-treatment and unequal care
  - Ethical basics - values, norms, principles - and specific topics
  - Psychological and communicative basics of decision-making
  - Procedural rules of decision-making and ethical case discussion
  - Relevant legal basics and official guidelines
- Checklists
- Recommendations
Abbildung 1: Vier Eskalationsstufen bei einer Therapieentscheidungssituation mit ethischen Fragen, Unsicherheiten oder Konflikten

Problemwahrnehmung

1. Stufe
Kurzfassung

2. Stufe
Langfassung

3. Stufe
Ethische
Fallbesprechung

4. Stufe
Ethikberatung mit zusätzlicher Hilfe von Fachpersonen aus der Projektgruppe

Procedures

How does METAP work?

Steps and escalating model

Zeit
Abbildung 1: Vier Eskalationsstufen bei einer Therapieentscheidungssituation mit ethischen Fragen, Unsicherheiten oder Konflikten

Problemwahrnehmung

1. Stufe: Kurzfassung
2. Stufe: Langfassung
3. Stufe: Ethische Fallbesprechung
4. Stufe: Ethikberatung mit zusätzlicher Hilfe von Fachpersonen aus der Projektgruppe

Consult within team
Level 3:
Guide for ethical case discussion
- team -

ORGANISATION EINER ETHISCHEN FALLBESPRECHUNG
- Die ethische Fallbesprechung wird durch ein Mitglied der Steuergruppe organisiert.
- Das verantwortliche Steuergruppenmitglied kann einzelne Aufgaben an andere Mitarbeitende delegieren.
- Die unten abgebildete Checkliste soll bei der Organisation helfen.

CHECKLISTE ZUR ORGANISATION EINER ETHISCHEN FALLBESPRECHUNG

- Informationssammlung vor der Fallbesprechung
  - Welche Informationen liegen bereits vor?
  - Welche Informationen fehlen noch?
  - Wer holt fehlende Informationen ein?

- Einschätzen der Risikokonstellation
  - Überprüfen, ob Hinweise für Unter- oder Ungleichbehandlung vorliegen
  - Überprüfen, ob Hinweise für Übersorgung bestehen

- Organisation
  - Zeitpunkt der Fallbesprechung:
    - Zeitpunkt festlegen
    - Raum reservieren
  - Teilnehmer:
    - Wer soll an der Fallbesprechung teilnehmen?
      - Pflege
      - Ärzte
      - Andere Fachpersonen
      - Hausarzt
    - Teilnehmer informieren über:
      - Zeitpunkt
      - Ort
    - Ablösung für Teilnehmer organisieren, wenn notwendig
  - Moderation:
    - Moderator organisieren
  - Protokoll:
    - Festlegen, wer Protokoll schreibt
  - Material bereitlegen:
    - Flipchart oder Tafel
    - Protokollbogen
    - Patientenunterlagen

Abbildung 1: Vier Eskalationsstufen bei einer Therapieentscheidungssituation mit ethischen Fragen, Unsicherheiten oder Konflikten

Problemwahrnehmung

1. Stufe
   - Kurzfassung
2. Stufe
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3. Stufe
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4. Stufe
   - Ethikberatung mit zusätzlicher Hilfe von Fachpersonen aus der Projektgruppe

Zeit
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<thead>
<tr>
<th>Medical infos</th>
<th>Nursing / therap. infos</th>
<th>Prognosis</th>
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<tr>
<td>Pt. values / biography</td>
<td>Patient wishes</td>
<td>Risk constellation</td>
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Knowledge-based ethics support
### Risk constellation for under-/ unequal care – patient is

- ≥ 71 years old
- Multimorbid
- Chronically ill
- Terminally ill
- Needs much nursing care
- In social difficulties
- Female
- Migrant
- Single
- Demented

### Risk constellation for over-care

- Subjective judgment
- Private insurance
- Difficult treatment decisions
- Incentives?
- Other?
Clinical ethics as partnership—or how an ethical guideline on fair resource-allocation can be developed and implemented in the clinic

Stella Reiter-Theil · Marcel Mertz · Heidi Albisser Schleger · Barbara Meyer-Zehnder · Reto W. Kressig · Hans Pargger
EVIDENCE – COMPETENCE – DISCOURSE: THE THEORETICAL FRAMEWORK OF THE MULTI-CENTRE CLINICAL ETHICS SUPPORT PROJECT METAP

STELLA REITER-THEIL, MARCEL MERTZ, JAN SCHÜRMANN, NICOLA STINGELIN GILES AND BARBARA MEYER-ZEHNDER
What do we try to evaluate?

- **Product**
  - User friendliness, acceptability

- **Process**
  - Consistency (content-wise, formal), social influence

- **Structure**
  - Influence of time, staff, leadership on METAP

- **Outcome**
  - Effect on patient (quality of care) / on staff (+competence, -distress)
Evaluation strategy – Mixed method

(Status, June 2012)

Qualitative:

• semi-structured interviews with staff of collaborating wards
  • Single interviews (n=26)
  • Group interviews (n=7; 33 persons)

• Non-participant observation
  • Ethical case discussions (n=17 cases)

Quantitative:

• Questionnaire (n=86) pre / post
What have we learned?

- Preliminary suggestions from the METAP evaluation
Preliminary results 1

• The METAP **low-threshold forms** of clinical ethics support (level 1,2) are welcomed by clinicians.

• The **material** (esp. the Leporello and the instruments / checklists) is appreciated and used in practice.

• **Ethical case discussions** (level 3) require special training and guidance for facilitators.
  
  – Once established, ECD / level 3 is appreciated and supports the clinicians’ competence & self-esteem.
Preliminary results 2

- **Participation** plays a key factor for the acceptability of METAP.
- **Implementation** has to be carried out carefully acknowledging obstacles and resistances.
- Activity (of both sides) seems to be focused on levels 1, 2, 3; level 4 (EC) requires an effort of its own.
- Clinicians need practical **experience** to evaluate the usefulness of a certain CES form.
  - Wards with frequent ethics consults do not request anything else.
Open questions

• The **choice** between having an escalating model such as METAP or clinical ethics consultation alone needs investigation.

• How do we know what is good for which clinical specialty, team or leadership?

• Should we rely on clinicians’ wishes (only)?

• Or should we formulate “indications” for – certain forms of – clinical ethics support?
Conclusion

- The perspective of bedside care is limited.
  - However, individuals, their intentions and actions count, both in ethics and in healthcare.

- The METAP concept is limited, too.

- It is an approach that tries to make a little difference in every day patient care,
  - perhaps it will become possible to document an effect on institutional resource allocation at a later stage.
Hans-Joachim Schwager Award for Clinical Ethics
Named after German pioneer in clinical ethics (1929-2004)
Award: 5,000 €; plenary lecture, ICCEC
Activities of implementation, development, or research achievements in clinical ethics
Deadline: October 1st, 2012
Contact: s.reiter-theil@unibas.ch
Clinical Ethics international …
Website www.clinical-ethics.org/

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