Shared Optimum Scheme (SOS) – a structured approach to clinical ethical deliberation

1

Background

2

3 Situations

- **Therapy escalation in a critically ill infant**
  - Parents request maximal intensive care treatment, although the clinical team recommends a palliative approach with limitation of life-sustaining interventions.
    - Shah, S. K., Rosenberg, A. R., & Diekema, D. S. (2017). Charlie Gard and the limits of best interests. JAMA pediatrics, 171(10),

3

3 Situations

- **Treatment refusal in a 17-year-old adolescent**
  - An adolescent with a chronic illness refuses a medically urgent and strongly recommended treatment.
    - Diekema, D. S. (2011). Adolescent refusal of lifesaving treatment: are we asking the right questions?. *Adolescent Medicine-State of the Art Reviews*, *22*(2), 213.

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3 Situations

- **End-stage lung cancer in an older person**
  - The clinical team is divided about the continuation of burdensome interventions; family members insist on "doing everything," although the patient is barely able to express his or her wishes.
    - Schmieg, Gregorowius und Streuli in Stanze, Henrikje, and Annette Riedel. "Moral Distress und Moral Injury." (2025).

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Outline

- Why structured ethical decision-making is needed?
- From models to practice: the Shared Optimum Scheme (SOS)
- How to validate clinical ethics?

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1. Why structured ethical decision-making?

- Complex clinical situations combine:
  - medical uncertainty,
  - emotionally charged relationships,
  - conflicting values,
  - legal and professional constraints.
- Without structure, teams risk:
  - moral distress,
  - Subjectivity and inconsistent decisions,
  - hidden normativity,
  - overburdening team and families

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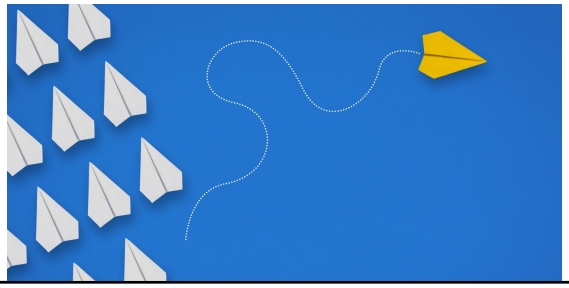
But: Frameworks support decisions — they do not make them.



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2. Many established models of ethical decision-making

1. Principlism (Four Principles – Beauchamp & Childres

- **Core elements**
  - Autonomy
  - Beneficence
  - Non-maleficence
  - Justice
- **Approach**
  - Identify relevant principles
  - Balance and justify trade-offs
- **Strengths**
  - Widely accepted
  - Clear normative language
  - Strong in policy and guidelines
- **Limits**
  - Abstract
  - Weak on relational dynamics
  - Does not specify *how* to weigh principles in concrete cases

2. Four Quadrant Approach (Jonsen, Siegler, Winslade)

- **Quadrants**
  - Medical indications
  - Patient prefereences
  - Quality of life
  - Contextual features
- **Approach**
  - Systematic case analysis
  - Practical bedside orientation
- **Strengths**
  - Clinically intuitive
  - Integrates facts and values
  - Useful for teaching and ethics consultations
- **Limits**
  - Risk of checklist thinking
  - Less explicit about power dynamics and emotions

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2. Many established models of ethical decision-making

3. Casuistry (Case-Based Reasoning)

- **Core idea**
  - Moral reasoning by analogy to paradigm cases
- **Approach**
  - Compare current case to well-understood precedent cases
  - Identify morally relevant similarities/differences
- **Strengths**
  - Highly practice-oriented
  - Sensitive to context
  - Reflects how clinicians often reason implicitly
- **Limits**
  - Depends on quality and selection of reference cases
  - Risk of bias or hidden normativity

4. Care Ethics

- **Core values**
  - Relationships
  - Vulnerability
  - Responsibility
  - Responsiveness
- **Approach**
  - Focus on who is involved and how they are affected
  - Moral importance of care relationships
- **Strengths**
  - Strong in pediatrics, palliative care, disability
  - Addresses emotional and relational dimensions
- **Limits**
  - Less clear normative limits
  - Risk of over-identification or boundary blurring

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2. Many established models of ethical decision-making

5. METAP Model (Nijmegen / Swiss adaptation)

- **Structure**
  - Stepwise ethical reflection
  - Integration of team deliberation
  - Clear escalation pathways
- **Approach**
  - Identify ethical problem
  - Clarify facts and values
  - Explore options
  - Justify decision transparently
- **Strengths**
  - Well established in hospital ethics
  - Process-oriented
  - Supports institutional learning
- **Limits**
  - Time-consuming
  - Requires well-trained and expirienced moderators
  - Can feel formal in acute situations

6. Shared Decision-Making (SDM)

- **Core idea**
  - Decisions made *with* patients/families, not *for* them
- **Approach**
  - Exchange information
  - Explore values and preferences
  - Reach a shared decision
- **Strengths**
  - Strong empirical backing
  - Respects autonomy
  - Improves satisfaction and trust
- **Limits**
  - Lack of competence (fig leave problem)
  - Underestimates professional responsibility
  - Risk of shifting moral burden to families
  - Needs clear boundaries

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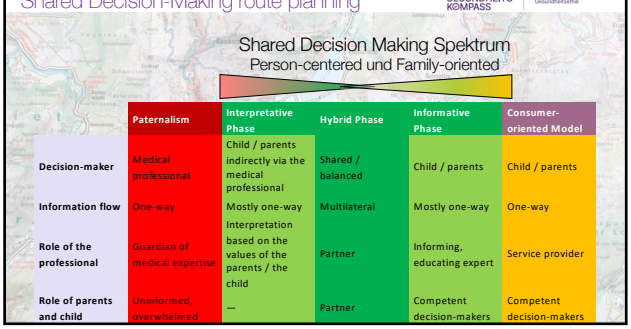
Shared Decision-Making route planning



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From models to practice: the Shared Optimum Scheme (SOS)

- Conceptual position of SOS
- The **Shared Optimum Scheme (SOS)** integrates:
  - Principlism (normative boundaries),
  - Care ethics (relationships),
  - Casuistry (case sensitivity),
  - SDM (participation),
  - Professional responsibility (clear limits).
- SOS explicitly distinguishes between:
  - **Non-negotiable boundaries** (red zone)
  - **A shared space of ethically acceptable options** (green zone)

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How the SOS is conducted (60–90 minutes)

Step 1: Creating a shared understanding

- Three perspectives
  - **We** – medical facts, prognosis, evidence
  - **You** – relationships, narratives, roles
  - **I** – (personal) values, intuitions, moral concerns but also interpretation (value-based/perspevtice relevant) of facts and experiences
- Goal: a transparent, shared picture of the situation.

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How the SOS is conducted (60–90 minutes)

- Step 2: Defining boundaries and the shared optimum
- Red zone (non-acceptable): basically acute self-harm / harm to others (including justice)
  - Medically non-indicated treatments
  - Disproportionate harm
  - Legal or professional violations
  - Abandonment of professional responsibility
  - Competent autonomous decisions (not necessarily rational)
- Green zone (Shared Optimum) powered by Shared Decision-Making
  - A wide range of ethically justifiable options
  - Co-created with patient/family
  - Re-evaluated over time
  - Anchored in a shared goal (e.g. time-limited trial)

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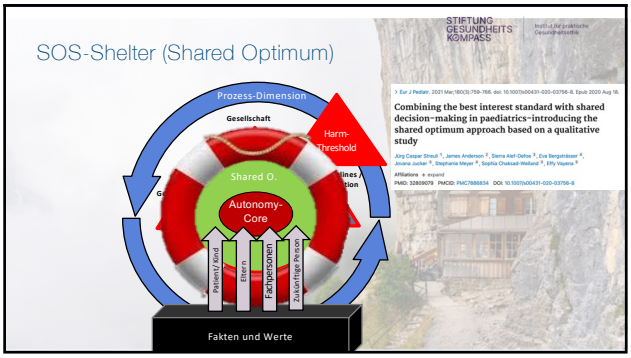
SOS-Shelter (Shared Optimum)



Combining the best interest standard with shared decision-making in paediatrics–introducing the shared optimum approach based on a qualitative study

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Ethisches Gespräch "Shared Optimim Schema" Teil 1

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Du:

Ich:

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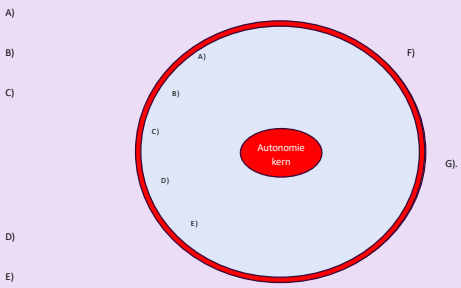
Ethisches Gespräch "Shared Optimim Schema" Teil 2



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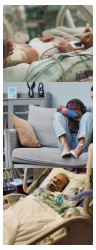
- **Case 1: Severely ill infant – therapy escalation**
- Clear boundary against harmful non-beneficial escalation
- Shared goal focused on the child's well-being
- Making plans, giving time, within limits
- PPC as *new pathway*, not "giving up"

- **Case 2: 17-year-old refusing treatment**
- Careful assessment of decisional capacity
- Respect for veto rights
- Supportive containment instead of coercion

- **Case 3: Advanced lung cancer**
- Professional responsibility to structure choices
- Avoid delegation of "no-decisions" to family
- Transparent limits with openness to reassessment



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Conclusion 2

- The **Shared Optimum Scheme** aims for
- clear boundaries,
- a protected space for shared decision-making with a acceptance of uncertainty
- and a practicable model for complex questions in clinical ethics.

- **Structured ethical decision-making:**
- needs plural ethical perspectives,
- must combine clarity with humility,
- and requires validation focusing on **process quality** rather than moral certainty.

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How to validate clinical ethics?

- **Process indicators**
- Transparency of reasoning
- Explicit handling of values and conflicts
- Consistency across similar cases

- **Participant-based evaluation**
- Moral distress (pre/post)
- Perceived fairness
- Trust and satisfaction (families, professionals)

- **Educational outcomes**
- Improved ethical competence
- Better articulation of ethical reasoning

- **Institutional outcomes**
- Reduced conflict escalation
- Fewer ethics-related complaints
- Better interprofessional collaboration

- **Qualitative methods**
- Observations of ethics meetings
- Thematic analysis of discussions
- Narrative interviews

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Planned mixed-methods validation strategy for SOS

- **A. Observational analysis (N=10)**
  - Structured observation of SOS sessions
  - Coding of:
    - clarity of boundaries
    - participation balance
    - integration of values
- **B. Retrospective surveys (N=20)**
  - Professionals: moral distress, clarity, feasibility
  - Families: understanding, trust, perceived involvement
- **C. Case comparison**
  - Literature search
  - Similar cases with and without SOS
    - Focus on process differences, not outcomes alone
- **D. Reflexive documentation**
  - Written ethical reasoning
  - Anonymized, internal peer review of decisions

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Conclusion (2)

- **EDM models lack rigorous empirical validation** comparable to evidence-based clinical interventions
  - *(Cottone & Claus, 2000; Suarez et al., 2022)*
- **There is no agreed gold standard or "correct outcome"** for validating ethical decision-making models across contexts
  - *(Hill, 2004; Johnson, 2020)*
- **Evaluation therefore focuses on process quality** (transparency, clarity of reasoning, consistency, perceived usefulness) rather than outcomes. However, outcome matters.
  - *(Jonsen et al., 2010; Schildmann et al., 2016)*
- **A mixed-methods approach is therefore essential**

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Literature

- **Cottone, R. C., & Claus, R. E. (2000).** Ethical decision-making models: A review of the literature. *Journal of Counseling & Development*, 78, 275–283.
- **Hill, A. L. (2004).** Ethical decision making in social work: A process model. *Journal of Social Work Values and Ethics*.
- **Johnson, M. K. (2020).** *Making a decision on ethical decision-making models.* Doctoral dissertation, Utah State University.
- **Suarez, V. D., et al. (2022).** Examination of ethical decision-making models across disciplines. *Behavior Analysis in Practice*, 16, 657–671.
- **Jonsen, A. R., Siegler, M., & Winslade, W. J. (2010).** *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine.*
- **Schildmann, J., et al. (2016).** Evaluation of clinical ethics support services: A systematic review. *Journal of Medical Ethics*, 42, 8–16.

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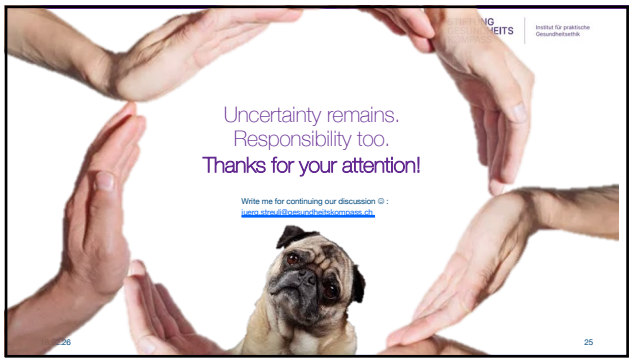

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Fall 1: Therapie-Eskalation bei schwerkrankem Säugling

- Nicht akzeptable Grenzen – roter Bereich
  - Fortführen von **medizinisch nicht indizierten Massnahmen** (Behandlung ausschliesslich aus Angst vor Schuld oder Konflikt) mit **Verlängerung von Leid** ohne objektive Ziele im Wohl des Kindes
  - **Unverhältnismässige / nichtindizierte Massnahmen** mit klarem und signifikantem Schadenspotenzial
  - Komplette **Entscheidungslast an Eltern abgeben**, ohne professionelle Orientierung und Vermittlung
- Shared Optimum – grüner Handlungsraum
  - Anerkennung elterlicher Pflichten, Sorgen und Hoffnungen (Eltern haben Recht und Pflicht für ihr Kind eine Entscheidung zum Wohl des Kindes zu fällen)
  - Offene, nicht wertende Kommunikation über Prognose, Unsicherheiten und mögliche Wege und objektive Zeichen des Kindes – weniger über konkrete Nicht-Massnahmen und Therapie-Abbrüche
  - Erarbeitung eines tragfähigen Kernziels (z. B. Time-Limited Trial)
  - Kontinuierliche Reevaluation: Was dient dem Kind – was belastet? Keine Massnahmen ohne Plan.
- Weiterer Verlauf:
  - PPC-Team wird zum Teil eines neuen Weges, anstatt einer Begrenzung. Versterben zu Hause im engen Familienkreis unterstützt durch PPC-Team.

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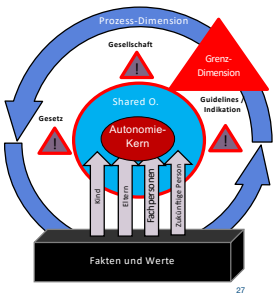
Fall 2: Therapieverweigerung bei 17-jährigem Jugendlichen

- Nicht akzeptable Grenzen – roter Bereich
  - Akute Selbstgefährdung
  - Zwang unter Nichtbeachtung des Vetorechts
- Shared Optimum – grüner Handlungsraum
  - Urteilsfähigkeit wird ernst genommen mit Definition des Autonomiekerns unter Klärung der Urteilsfähigkeit und Bedeutung des Vetorechts
  - Unterstützung der Familie hin zu einem Weg für und mit dem Jugendlichen anstatt gegen den Jugendlichen
- Weiterer Verlauf:
  - Nein wird akzeptiert, qualitativ hochwertige Zeit im familiären Umfeld, darunter Änderung der Meinung des Jugendlichen mit Entscheid für Therapie.



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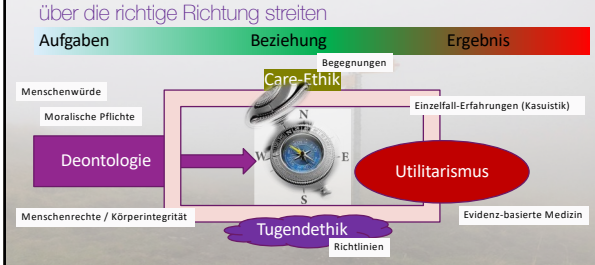
Moralischer Kompass und weshalb wir oft über die richtige Richtung streiten



Klein, Sabine D. et al. „Sources of distress for physicians and nurses working in Swiss neonatal intensive care units". SMW, 2017
Streuli JC et al. „Five-year experience of clinical ethics consultations in a pediatric teaching hospital". EJP, 2014
Streuli, JC et al. Ethik in der Pädiatrischen Palliative Care. 2023, Palliative.ch.

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Fall 3: Endstadium Lungenkarzinom bei älterer Person

- Nicht akzeptable Grenzen – roter Bereich
  - Nein-Entscheidungen an Familie delegieren ohne Einordnung
  - **Überforderung aller Beteiligten** durch widersprüchlich Signale des Teams
  - **Verlust des Fokus auf das Wohl des betroffenen Menschen: Intensivmedizin ohne Plan mit objektiven Fakten**
  - **Missachtung professioneller und gesetzlicher Standards** (z. B. Zwang, Übergriffe, Übertherapie)
- Shared Optimum – grüner Handlungsraum
  - **Einbindung der familiären Narrative** (Herkunft, Werte, Erfahrungen, Hoffnungen)
  - **Professionelle Verantwortung aktiv wahrnehmen**: Orientierung bieten, Optionen einordnen
  - **Grenzen transparent und klar kommunizieren**
  - **Kooperative Entscheidungsprozesse** innerhalb des SOS mit **sinnvollen Kompromissen**
- Weiterer Verlauf:
  - Planung des Austritts mit Offenheit für weitere Massnahmen. Kurz vor Austritt Lungenentzündung mit nochmaliger Verlegung auf IPS mit Therapiebegrenzung. Dort Versterben nach 3 Tagen.

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