

Beyond healing: three cases, many questions



3 Situations

Extremely preterm infant: Extreme prematurity – uncertain survival – high risk of severe disability – burdensome intensive care – Mother: “do everything you can”; Father: “do not prolong suffering”

Term neonate with severe perinatal complications: Severe hypoxic/perinatal injury – prolonged stabilization – transfer to university hospital versus palliative care – risk of death during transport

Newborn with severe hypoxic-ischemic encephalopathy: Severe asphyxia with profound neurological injury – spontaneous breathing but expected severe disability – parental request to withhold life-prolonging interventions – focus on comfort care

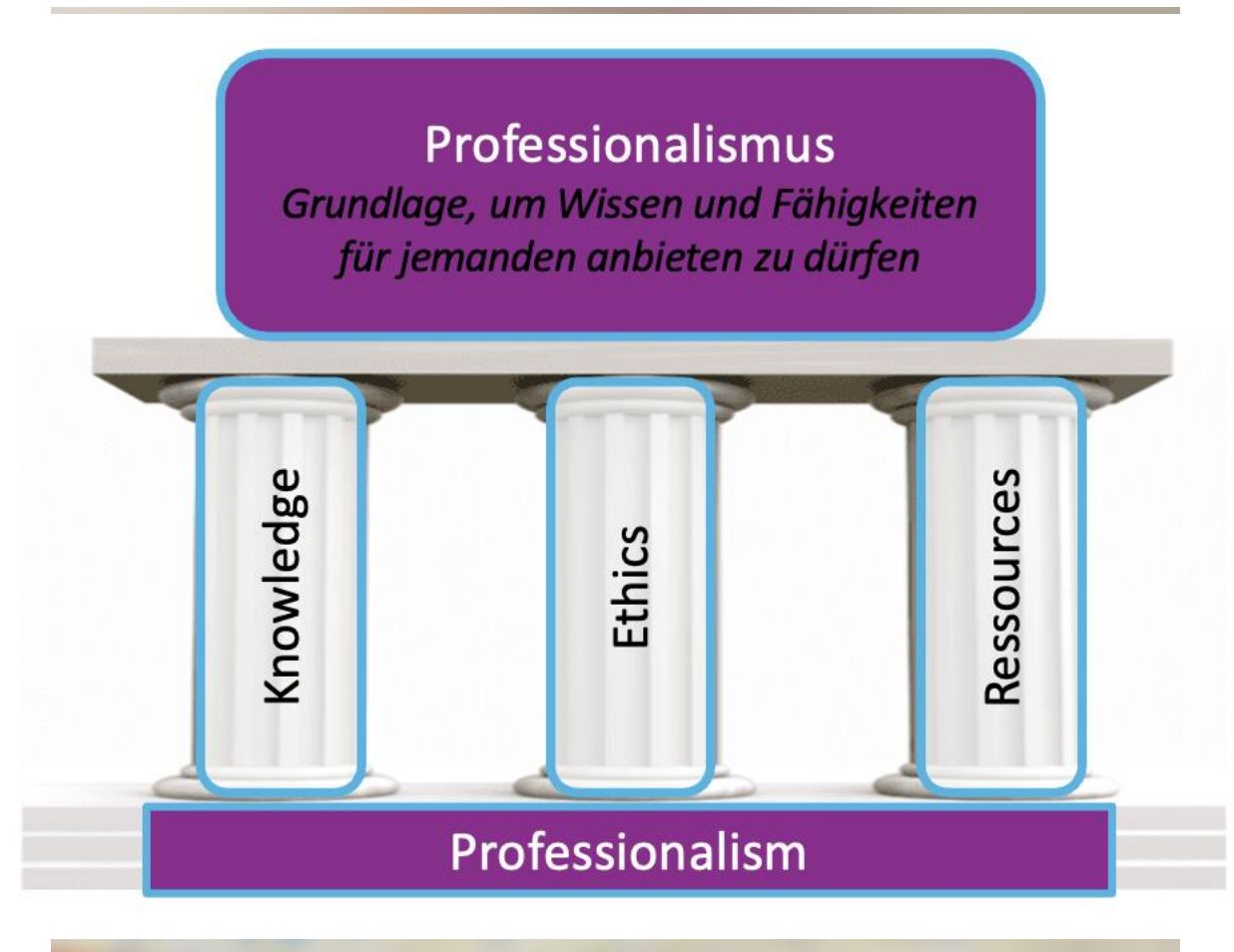
Key Ethical Questions

- Best interest of the child under profound uncertainty
- Survival, suffering, disability, and future quality of life
- Limits and proportionality of intensive care versus palliative care
- Role and limits of parental decision-making
- Conflicting values between parents and professionals
- Ethical distinction between withholding treatment, comfort care, and actively hastening death
- Shared decision-making under conditions of high complexity, emotional burden, and time pressure
- Fair allocation of intensive medical resources



Back to Basics: Ethics, Morality and Professionalism

- **Ethics:** Critical reflection on morality and moral decision-making
- **Morality:** The totality of relevant values, norms, and beliefs within a society
- **Professionalism:** Justification of the privilege to act in a professional role based on:
 - knowledge and competencies
 - responsible use of resources and power
 - ethical conduct and accountability



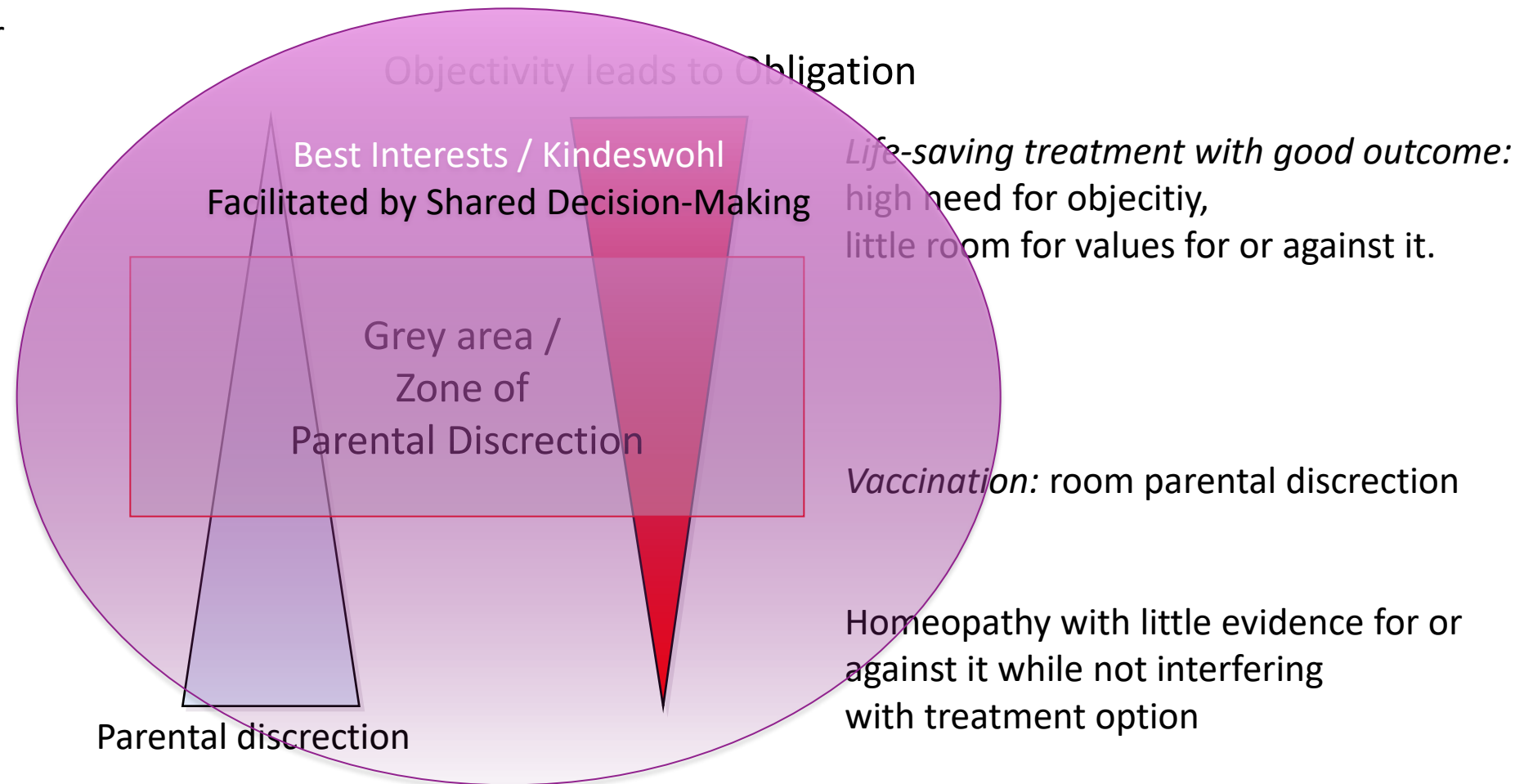
Two central concepts

Best Interests of the Child ("Kindeswohl")

- No universal definition: must be interpreted case by case based on the child and family situation
- Child as a subject with own rights and needs
- Child-centred and family-oriented approach
- Balance between medical standards and individual values/context

Zone of Parental discretion

Increased direct consequences
leads to increased need for
objectivity



Wilkinson, D., Who should decide for critically ill neonates and how? The grey zone in neonatal treatment decisions. Chapter for When Doctors and Parents Disagree Ethics, Paediatrics and the Zone.
Gillam, L., 2016. The zone of parental discretion: an ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child. *Clinical Ethics*, 11(1), pp.1-8.

Two central concepts

Best Interests of the Child ("Kindeswohl")

- No universal definition: must be interpreted case by case based on the child and family situation
- Child as a subject with own rights and needs
- Child-centred and family-oriented approach
- Balance between medical standards and individual values/context

Shared Decision-Making

- Collaborative decision-making **process and spectrum** between professionals and parents/patients
- Combines:
 - values, hopes, and preferences of the family
 - best available medical evidence
 - professional experience
- Requires empathic, individual and honest communication about prognosis, risks, burdens, and options
 - child-centred and family-oriented, guided by the child's best interests

Shared Decision-Making route planning

Shared Decision Making Spektrum Person-centered und Family-oriented



	Paternalism	Interpretative Phase	Hybrid Phase	Informative Phase	Consumer-oriented Model
Decision-maker	Medical professional	Child / parents indirectly via the medical professional	Shared / balanced	Child / parents	Child / parents
Information flow	One-way	Mostly one-way	Multilateral	Mostly one-way	One-way
Role of the professional	Guardian of medical expertise	Interpretation based on the values of the parents / the child	Partner	Informing, educating expert	Service provider
Role of parents and child	Uninformed, overwhelmed	—	Partner	Competent decision-makers	Competent decision-makers

Why and how structured decision-making?

- Complex clinical situations combine:

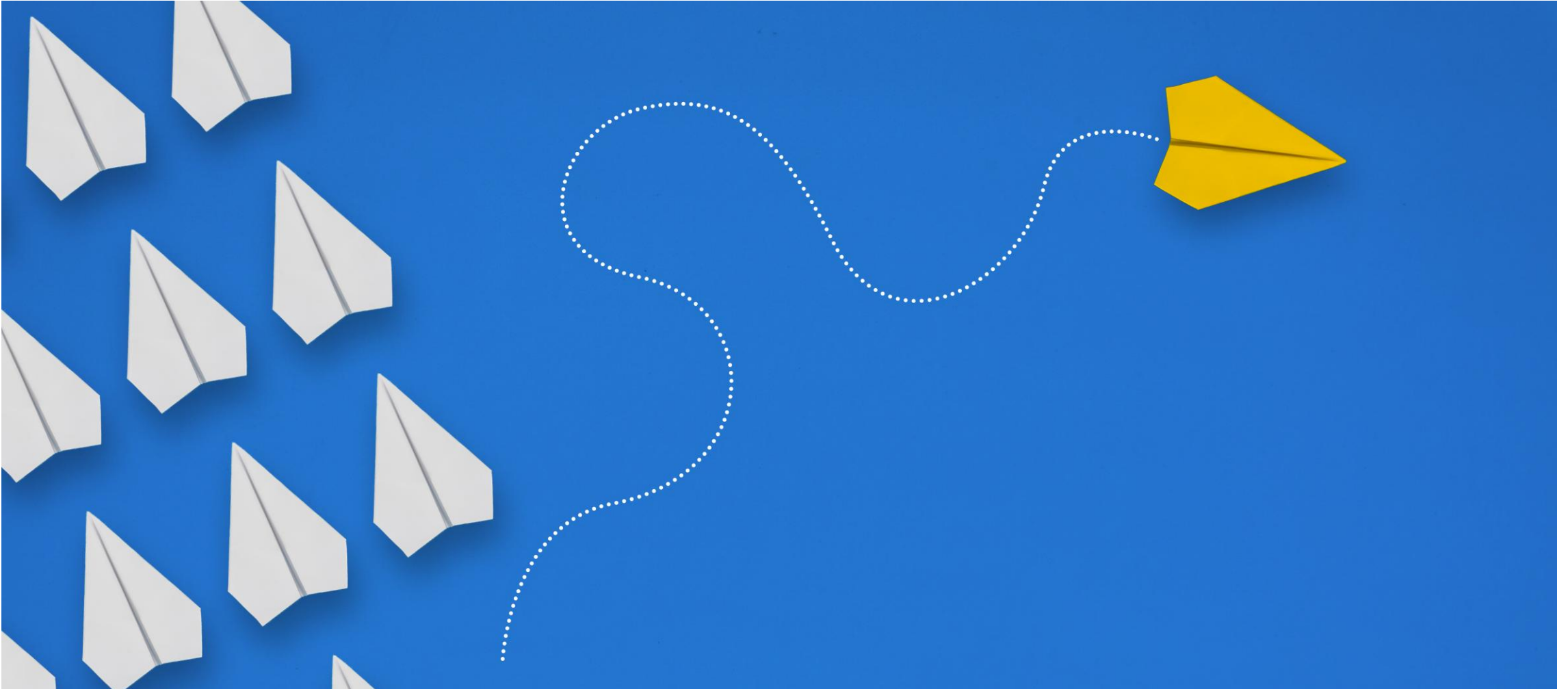
- medical uncertainty,
- emotionally charged relationships,
- conflicting values,
- legal and professional constraints.

- Without structure, teams risk:

- moral distress,
- Subjectivity and inconsistent decisions,
- hidden normativity,
- overburdening team and families



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



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)

> [Eur J Pediatr.](#) 2021 Mar;180(3):759-766. doi: 10.1007/s00431-020-03756-8. Epub 2020 Aug 18.

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

Jürg Caspar Streuli ¹, James Anderson ², Sierra Alef-Defoe ³, Eva Bergsträsser ⁴, Jovana Jucker ³, Stephanie Meyer ⁴, Sophia Chaksad-Weiland ³, Effy Vayena ⁵

Affiliations + expand

PMID: 32809079 PMCID: [PMC7886834](#) DOI: [10.1007/s00431-020-03756-8](#)



How the SOS is conducted (60–90 minutes)

Step 1: Creating a shared understanding

- **Three perspectives**

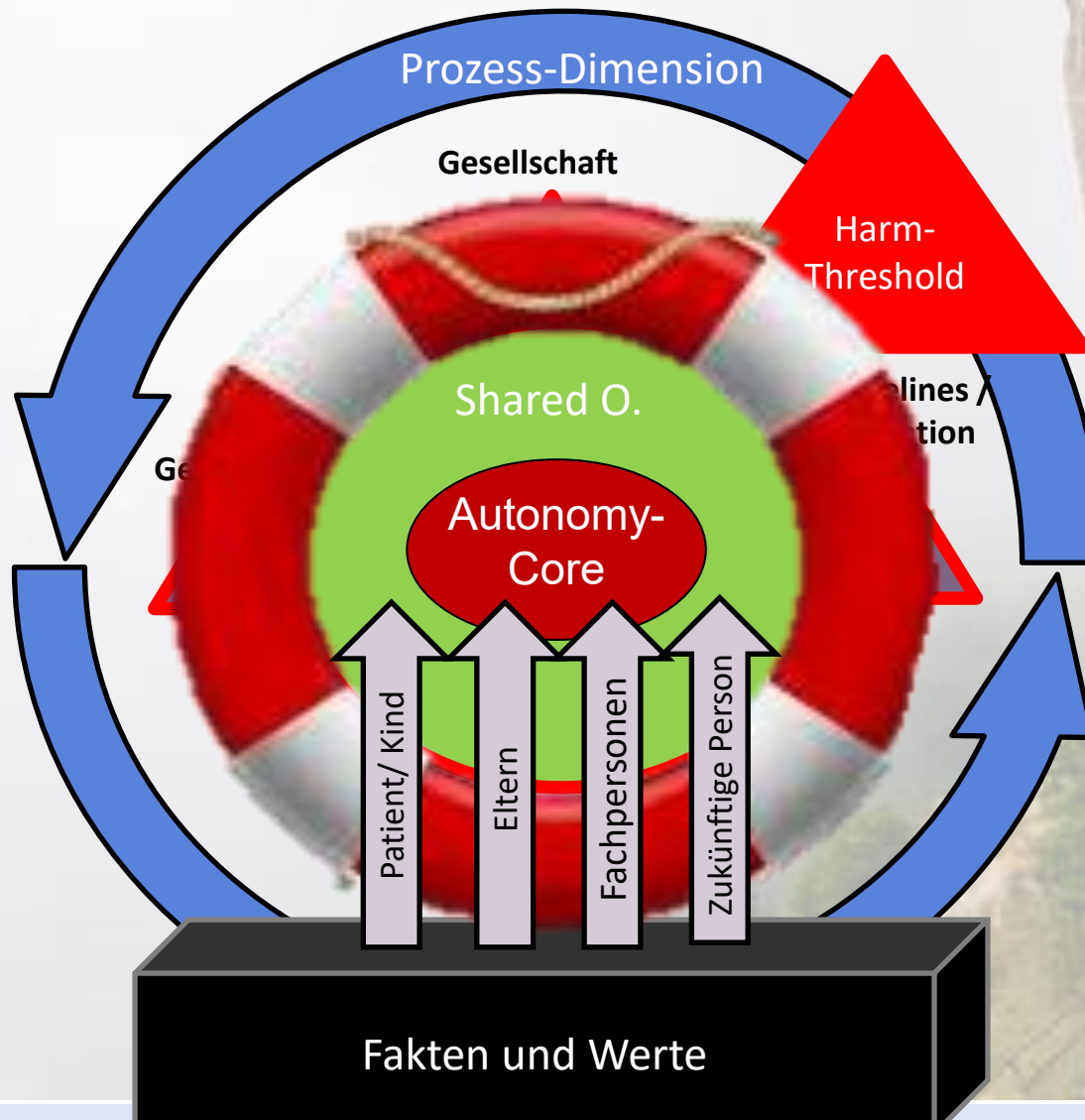
- **We** – medical facts, prognosis, evidence
- **You** – relationships, narratives, roles
- **I** – (personal) values, intuitions, moral concerns but also interpretation (value-based/perspective relevant) of facts and experiences

- **Goal:** a transparent, shared picture of the situation.

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)

SOS-Shelter (Shared Optimum)



> Eur J Pediatr. 2021 Mar;180(3):759-766. doi: 10.1007/s00431-020-03756-8. Epub 2020 Aug 18.

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

Jürg Caspar Streuli ¹, James Anderson ², Sierra Alef-Defoe ³, Eva Bergsträsser ⁴, Jovana Jucker ³, Stephanie Meyer ⁴, Sophia Chaksad-Weiland ³, Effy Vayena ⁵

Affiliations + expand

PMID: 32809079 PMCID: [PMC7886834](#) DOI: [10.1007/s00431-020-03756-8](#)

We/Wir:

You/Du:

I/Ich:

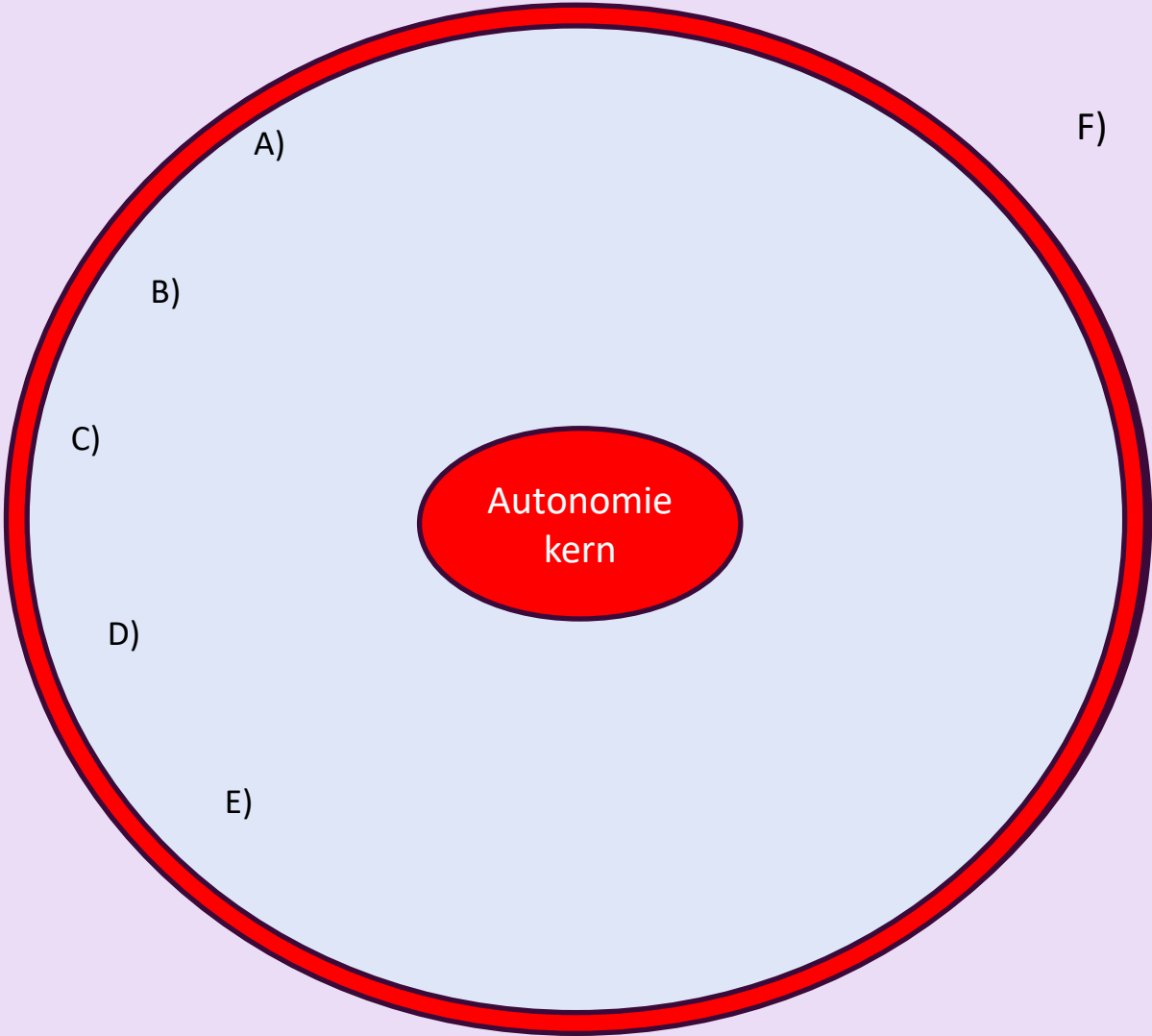
A)

B)

C)

D)

E)



G).

1) Extremely preterm infant:

Extreme prematurity – uncertain survival – high risk of severe disability – burdensome intensive care – Mother: “do everything you can”; Vater: “do not prolong suffering”

2) Term neonate with severe complications: Severe hypoxic/perinatal injury – prolonged stabilization – transfer to university hospital versus palliative care – risk of death during transport

■ Limits

- Extremely poor prognosis with high resource use and potential suffering without a plan: objectified clinical findings may create professional obligations
- Prolongation or induction of suffering based on parental dissensus

■ Shared Optimum

- Time-limited intensive care with continuous reassessment
- Family counselling with grieve support and mediation
- Focus on best interests of the child
- Honest communication under uncertainty without final outcome message (the child will die within...)
- Balance between hope and suffering - **“A meaningful and sustainable ‘yes’.” (Victor Frankl)**
- Early NICU + PPC collaboration *“Doing Everything Purposeful”*
 - i.e. Do not harm or prolong harmful interventions

Newborn with severe hypoxic-ischemic encephalopathy:

Severe asphyxia with profound neurological injury – spontaneous breathing but expected severe disability – parental request to withhold life-prolonging interventions – focus on comfort care

■ Limits

- Avoidance of discrimination based solely on disability or predicted quality of life
- No active life-shortening / euthanasia despite parental request to avoid prolongation of life
- Not prolongation of life with invasive treatment without a treatment and support plan (after hospital care)
- No decisions based solely on time pressure without continuous support

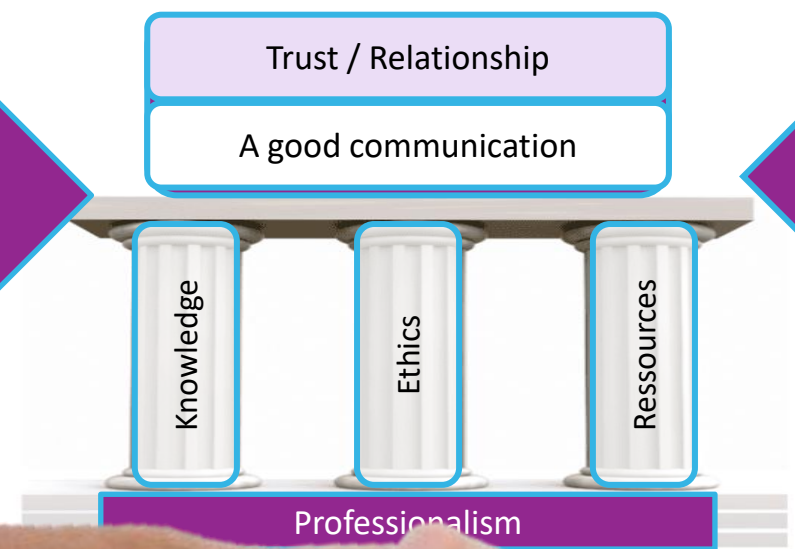
■ Shared Optimum

- Child-centred comfort-oriented care with ongoing reassessment and support
- Family and grieve counseling without time pressure; if needed raise option of KESB/adoption
 - Shared exploration of parental fears, suffering, values, and hopes
 - Close **Calman gap**: potential discrepancy between hope or expected quality of life and lived experience
- Honest communication under uncertainty without reduction of the child to neurological outcome predictions
 - Balance between protection, dignity, suffering, and relational meaning — striving for “a meaningful and sustainable ‘yes’” (Viktor Frankl)
- Early collaboration between NICU, PPC, and neurology – maybe with other parent groups, school.

Within
Questions

healing: three cases, many

“Medicine was once simple, ineffective, and relatively safe. Today it is complex, effective, and potentially highly dangerous.”



- The Good Healthcare Professional — From the Patient’s Perspective
1. Takes time
 2. Empathetic and honest
 3. Explains information clearly
 4. Competent and trustworthy
 5. Supports my autonomy and participation

Ill / Krank—
Old High German *kranak*: “suffering”
Therapy aimed at treating
underlying causes
and controlling symptoms

Integrated Neonatal Care

Healthy, gesund, heil
Indo-European *ghans*:
“whole, intact, healthy”
Comprehensive care and
support aimed at healing

... (2012). DSD and professionalism from a patient perspective. *Journal of Medical Ethics*, 26(2), 101-106.
... (2019). The Promise, the Reality and the Future of Professionalism in Health Care. *Bioethica Forum*, 4.
van Mook, W. et al. (2009). Professionalism: Evolution of the concept. *European Journal of Internal Medicine*
Chantler, C. (1999). The role and education of doctors in the delivery of health care*. *The Lancet*,

Uncertainty remains.
Healing prevails.

**Many thanks for your
attention and your work!**

juerg.streuli@gesundheitskompass.ch

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.

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

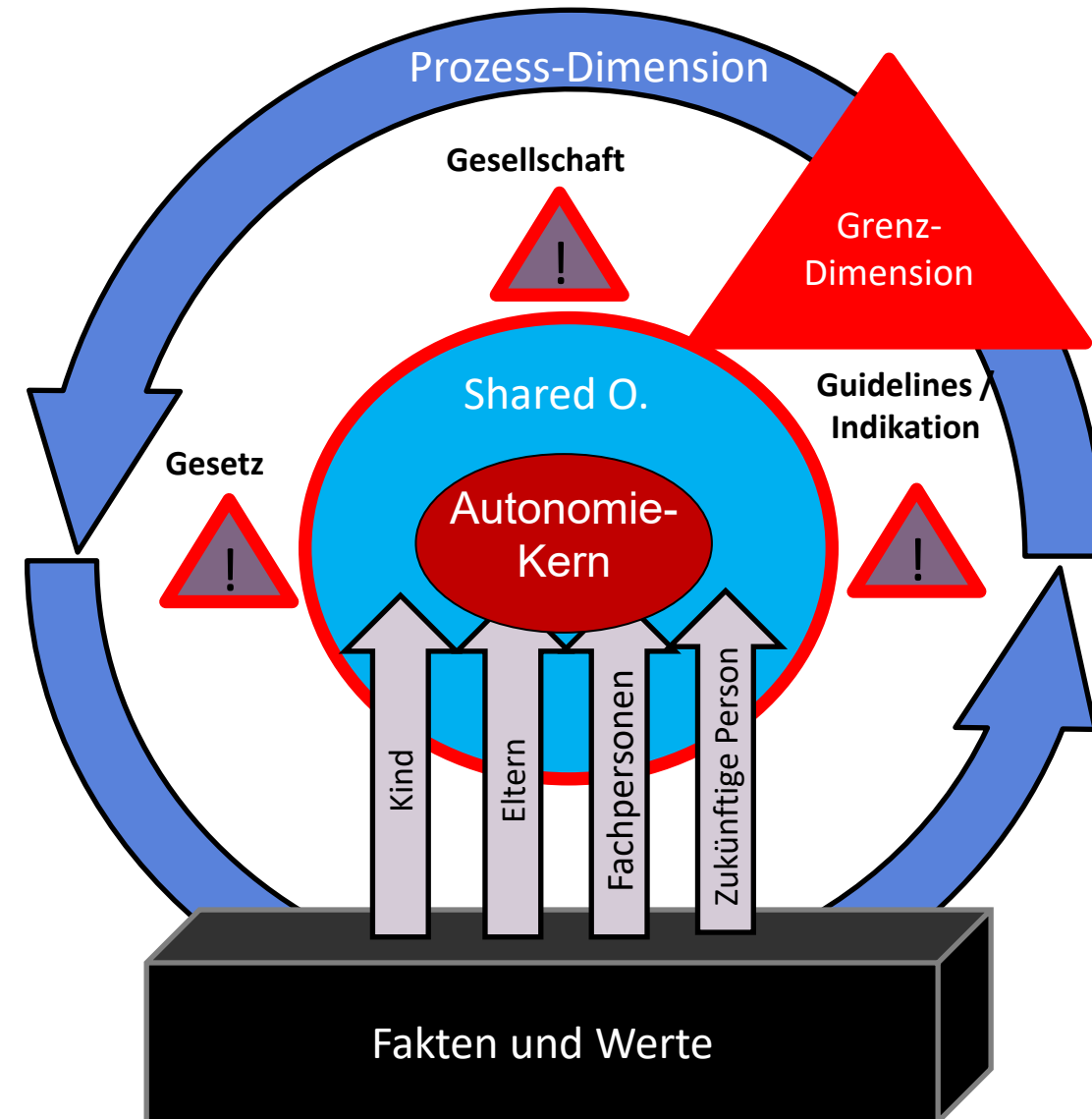
- Anerkennung elterlicher Pflichten, Sorgen und Hoffnungen (Eltern haben Recht und Pflicht für ihr Kind eine Entscheidung zum Wohl des Kindes zu fällen)
- Offene, nicht wertende Kommunikation über Prognose, Unsicherheiten und mögliche Wege und objektive Zeichen des Kindes – weniger über konkrete Nicht-Massnahmen 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.

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.



Moralischer Kompass und weshalb wir oft über die richtige Richtung streiten

Aufgaben

Beziehung

Ergebnis

Begegnungen

Care-Ethik

Menschenwürde

Moralische Pflichte

Deontologie

Einzelfall-Erfahrungen (Kasuistik)

Utilitarismus

Menschenrechte / Körperintegrität

Evidenz-basierte Medizin

Tugendethik

Richtlinien

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.



1) Extremely Preterm

Clinical Situation

- 23+0 weeks gestation, premature rupture of membranes and intrauterine infection
- Male infant born weighing 480 g
- Severe resuscitation required:
 - intubation
 - chest compressions
 - resuscitation drugs
- Admission to NICU

Complications

- Bilateral intraventricular hemorrhage Grade III
- Severe respiratory failure
- Necrotizing enterocolitis, systemic infections
- Complete ventilator dependency

Prognosis

- Very low probability of survival
- Extremely high risk of severe neurological disability
- Continuous painful and burdensome interventions
- **Ethical Tension**
- Mother: “do everything possible”
- Father: fears treatment is prolonging suffering
- Medical team divided:
 - continuation of intensive care
 - versus limitation of treatment

Shah, S. K., Rosenberg, A. R., & Diekema, D. S. (2017). Charlie Gard and the limits of best interests. JAMA pediatrics, 171(10),

2) Term Neonate with Perinatal Complications

Clinical Situation

- Full-term male infant after uncomplicated pregnancy
- Vacuum-assisted delivery due to fetal bradycardia
- Severe postnatal deterioration:
 - respiratory failure
 - DIC
 - cardiovascular instability
 - multiple transfusions and coagulation support

Approximately 10 hours of intensive stabilization

Decision Point

- Two options discussed with the parents:

- Transfer to tertiary NICU:
 - small chance of survival
 - risk of deterioration or death during transport without parents present
- Remain at local hospital with palliative care focus

Outcome

- Parents chose transfer
- Infant died the next day in NICU in presence of both parents

Ethical Tension

- Giving a small chance of survival versus
- Avoiding burdensome treatment and suffering