ISPN
INTERNATIONAL SOCIETY FOR PEDIATRIC NEUROSURGERY

ISPN Statement: Limitations of Care – An Ethical and Professional Framework

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The decision to withhold or withdraw care for a child is a complex and challenging situation for both treating clinicians and families. As paediatric neurosurgeons, the typical duty of care involves life-sustaining or health-restoring care; however, this duty is not an absolute obligation to preserve life by all means. Where preservation of life is not possible or not in the child's best interests, there is a defining duty to comfort and prevent pain and suffering.

Because there are significant global differences in legal definitions and regulations regarding the limitation or foregoing of life-sustaining medical treatment, neurosurgeons must remain highly aware of the regulations relevant to their local area of practice. This statement serves as an ethical guide and practical framework for navigating these difficult shared decisions, noting that local clinical ethics committees and legal advice should be sought whenever available.

Guiding Ethical Principles

The decision-making process in pediatric neurosurgery must be anchored in core ethical principles, executed within a shared decision-making partnership:

- **Beneficence:** Acting in the child's best interest, which includes alleviating suffering and actively promoting well-being.
- **Non-maleficence:** Avoiding harm to the child, which remains a core principle in pediatric care.
- **Autonomy:** Respecting the child's developing autonomy and involving them in decisions about their care whenever possible.
- **Parental Autonomy:** Recognizing the parents' role as protectors and decision-makers for their child, while emphasizing open communication and collaboration with healthcare professionals.
- **Veracity and Fidelity:** Providing complete, honest, and unbiased information to children and families.
- **Confidentiality and Privacy:** Strictly adhering to the ethical boundaries of privacy throughout the decision-making process.
- **Justice:** Ensuring fair and equitable access to care and resources. Aside from extreme circumstances (such as conflict, disaster, or extreme resource limitation), treatment limitation decisions must be formulated solely on the needs of the child and family, not on healthcare costs or resource limitations.

> **Right to Process:** *Acknowledging the deeply challenging nature of these decisions, neurosurgeons may decline to participate in withholding or withdrawing life-sustaining care. In these circumstances, their professional duty is to arrange for care by another neurosurgeon and continue providing care until the transition is complete.*

The Core Principle: "Best Interests" vs. Sanctity of Life

Modern paediatric ethics consensus dictates that the duty to preserve life is not absolute. When a treatment ceases to provide a net benefit or instead prolongs severe suffering, the ethical imperative shifts from a duty to prolong life to a duty to comfort and alleviate suffering.

Major medical bodies agree that deciding which interventions to apply requires a careful balancing of the **benefits versus the burdens** of treatment from the perspective of the child and family:

- **The Royal College of Paediatrics and Child Health (RCPCH):** Their framework outlines specific scenarios where withholding or withdrawing LST is ethically permissible, such as when life is limited in quantity (e.g., brain stem death, imminent or inevitable death) or limited in quality (e.g., where the child cannot derive benefit from continued life or the treatment burden is too high).
- **The American Academy of Pediatrics (AAP):** The AAP Committee on Bioethics emphasizes that a "best interests" standard must guide these decisions, moving away from technological imperative (doing something simply because it is possible) toward goal-directed care.

Advanced Care Planning

Advanced care planning is a vital way to seek to do the right thing for children with life-limiting conditions. It involves thinking ahead and making decisions about what treatments would or would not be in the best interest of a patient if they were to suffer an acute deterioration.

Key Characteristics of Planning

- **Focus:** It remains strictly focused on the individual child and family.
- **Flexibility:** Advanced care plans are not immutable and may be revised at any future time.
- **Ethical Basis:** The planning is grounded in promoting the child's and family's values, respecting the child as a developing person, and respecting the parents' role as protectors.
- **Distinction from Euthanasia:** Advanced care planning is explicitly ***not*** euthanasia (defined as knowingly and intentionally directly causing the death of a person to relieve suffering). Withholding or withdrawing treatment under this framework is ethically and legally accepted when it does not provide net benefit, and does not constitute euthanasia.

Documentation and Communication

Advanced care plans are designed primarily as communication tools rather than strict legal documents, and they are often left unsigned. Because discussions progress over time, it is vital to document all topics covered, clear goals of patient care, and any specific decisions made—including identifying decisions that have not yet been made. Tools like the “Thinking ahead Framework” utilise forms specifically designed for this purpose.

Once formulated, advanced care plans should be clearly and concisely communicated and shared across relevant parties:

- Medical records (local, state, or national)
- Parents
- Emergency services
- Other key health professionals and facilities involved in the child's care

Note: Some institutions require parental signatures for specific plans or Do Not Resuscitate (DNR) orders; clinicians must understand local requirements and remain sensitive to the triggering nature of these requests.

Determining Goals of Care: Benefit vs. Burden

Deciding which interventions should be provided requires a continuum of care assessment, ranging from the prolongation of life at one end to comfort and symptom management at the other. The explicit aim of clinical discussion is to find the "zone" where patients and families find a comfortable balance.

Medical interventions should not be undertaken simply because they are technically possible. They should only be provided if they align with the agreed goals of care and are expected to produce a net benefit to the child. All interventions must be subject to a rigorous analysis of potential benefit versus burden, assessed from the perspective of the child, the family, and the treating medical team. Having shared goals significantly helps reduce conflict and distress during these moments.

Framing and Language

Talking to families about the likelihood of death is one of the most difficult tasks for medical professionals, often arousing feelings of sadness, guilt, and fear of causing further pain. The framing and language used are highly important:

- Avoid clinical or triggering terminology abruptly (e.g., DNR, Allow Natural Death (AND), Palliative Care) without proper context.
- For a dying child, rather than asking a family if they want their child resuscitated, it is better to compassionately explain the process of dying and explore the means of comfort for the child and family through the end-of-life process.

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Ethical Framework for Withholding or Withdrawing Interventions

Ethically and legally, no distinction is made between withdrawing and withholding life-sustaining treatment. There is no ethical or legal obligation to continue an intervention simply because it has already been started. However, clinicians must recognise that the active withdrawal of treatment is frequently more emotionally and psychologically challenging for parents and health professionals than withholding it.

Permissible Circumstances for Forgoing Treatment

1. When Life is Limited in Quantity

- Brain Stem Death: As determined by agreed professional criteria appropriately applied via local legal definitions.
- Imminent Death: Where clinical deterioration is actively occurring irrespective of medical treatment.
- Inevitable Death: Where death is not immediately imminent but will inevitably follow, and where prolongation of life by artificial means confers no overall benefit to the child.

2. When Life is Limited in Quality

- Treatment Burden: Where the medical treatments themselves produce sufficient pain and suffering to outweigh any potential or actual benefits.
- Underlying Condition Distress: Where the severity and impact of the child's underlying condition is sufficient to produce such pain and distress that it overcomes any potential benefits of sustaining life.
- Inability to Derive Benefit: Where the severity of the condition makes it difficult or impossible for the child to derive any benefit from continued life.

Involving Children and Families

Parents are universally recognized as the primary decision-makers and protectors of their children. However, this authority is not unchecked.

- Bioethicists often refer to the **"Zone of Parental Discretion."** This concept suggests that healthcare providers should respect parental choices even if they don't align perfectly with the clinician's optimal recommendation, provided the parents' decision does not cross into the threshold of causing significant, unmitigated harm or prolonged suffering to the child.
- When conflict arises—such as over varying perceptions of prognosis, quality of life, or deep-seated spiritual beliefs—a tiered resolution strategy is recommended: starting with multi-disciplinary facilitated discussions, seeking independent opinions, involving institutional clinical ethics committees, and utilizing legal intervention strictly as a final resort

The rights of the child as an individual must be recognized within the complex inter-dependency of the family unit.

- **Informed Competent Refusal:** An older child or mature minor may be assessed as having the capacity to competently consent to the withdrawal or withholding of life-sustaining treatment. Where the competent child is supported by their parents and clinical team, there is no ethical obligation to provide life-sustaining treatment.
- **Involvement of Non-Competent Children:** Even when children are not deemed legally "competent" for major medical decision-making, children of any age and cognitive level retain a role in determining their quality of life, including preferences regarding their environments, relationships, and circumstances.
- **Developmental Considerations:** Children frequently develop the cognitive abilities to evaluate their circumstances and wishes before they develop the ability to articulate them. The use of pediatric-appropriate aids, such as books and visual aids, can significantly enhance a child's ability to communicate preferences.
- **Cultural Sensitivity:** Many families and cultures find direct discussions challenging and may instinctively wish to protect their children from difficult concepts and conversations. Clinicians must navigate this with care while balancing individual patient rights.

Special protocols and extra caution must be applied in cases involving patients with limited capacity, including neonatal protocols, children without established communication, newborns with an uncertain prognosis, and instances where children disagree with their parents over medical treatment.

Managing Conflict and Mitigating Distress

Disagreement, or even the perception of disagreement, is a frequent source of severe stress to families. Conflict can manifest at all levels: within care teams, within families, and between families and professionals. Common triggers include conflicting spiritual beliefs or concerns regarding the accuracy of a prognosis.

While it is important to gain wide opinions for robust decision-making, this multi-disciplinary approach should not be allowed to increase the family's sense of disagreement.

Conflict Resolution Pathway

1. Facilitated Discussion: Open, structured meetings to clear up miscommunications.
2. Independent Opinions: Seeking outside clinical perspectives to verify prognosis.
3. Clinical Ethical Committees: Engaging institutional ethics boards for multi-disciplinary guidance.
4. Legal Opinions: Utilized strictly as a last resort.

Mitigating Factors

To minimize distress, decision-making must remain transparent, areas of clinical uncertainty must be openly acknowledged and debated, and families must be allowed adequate time for reflection. Comprehensive bereavement support should be integrated into the care pathway from the outset.

Special Circumstances and Areas of Caution

Neurosurgeons must exercise extreme caution and careful ethical contemplation in specific clinical scenarios, including the forgoing of medically administered nutrition and hydration, cases of suspected abuse or neglect, determinations of death by neurological criteria, and organ donation processes. Additionally, care must be tailored appropriately when treating children with developmental disabilities to avoid biased metrics of worth.

Analytical Cautions

- **Subjectivity of Quality of Life:** Quality of life is an inherently subjective concept. Clinicians must avoid projecting their own personal views about life, constantly asking "how does life feel for this child?" rather than "how would I feel if I were this child?".
- **Negative vs. Zero Quality of Life:** Teams should differentiate between a baseline of no capacity to experience anything versus a state dominated by negative experiences (such as unremitting pain).
- **Futility of Treatment:** Futility is a relative concept judged against a specific goal. Rather than using "futility" as a blanket term, clinicians should consider whether treatments are likely to achieve the desired goal or produce an outcome that is genuinely worth aiming for from the patient's perspective.

References

- **RCPCH Guidance (UK):** Search for "Royal College of Paediatrics and Child Health (RCPCH) Making decisions to limit treatment in life-limiting and life-threatening conditions" to find their updated ethical framework and clinical criteria.

- **AAP Bioethics Policy (US):** Search for "American Academy of Pediatrics Committee on Bioethics: Pediatric Palliative Care and Quality of Life" or their statements on "Forgoing Life-Sustaining Medical Treatment" in the journal Pediatrics.

- **Canadian Paediatric Society (CPS):** Search for the CPS bioethics status statement on "Treatment decisions regarding infants, children and adolescents at the end of life."

- **Nuffield Council on Bioethics:** Search their reports for international overviews on the ethical complexities of neonatal and pediatric critical care decision-making.

- Ethical principles of decision making in the paediatric setting. Royal Children's Hospital Melbourne Clinical Practice Guidelines