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Thou Shalt Not Kill, But….. The Right to Die and How to Die: Some Thoughts in Light of Recent Cases of Infants with Severe Brain Damage/Dysfunction

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Introduction

- Over the last decade the issue of life support for seemingly intractable brain-damaged patients has come to the forefront.
- This is due to the technological advances in diagnostics, brain imaging, and life support.
- Patients who previously would have died from their brain damage are now easily supported for extended periods of time, at home or in specialized units.
- Functional MRI and other diagnostic procedures can show varying levels of brain function in those patients.
- Both family and medical staff face greater uncertainty and thus greater dilemmas.
- Decisions are further complicated due to the mingling of cultures, religions, and legal systems when cases cross borders.
- Nowhere are these issues more fraught with emotion and uncertainty than in infants or children.
- Two recent high-profile cases in the UK have brought the question of continuing or discontinuing life support to the forefront.

Charlie Gard (4 August 2016 – 28 July 2017)

- An 11-month-old infant who was diagnosed with infantile onset encephalomyopathic mitochondrial DNA depletion syndrome (MDDS).
- Infants suffering from MDDS typically develop early-onset muscle weakness and rapid symptom progression, reflecting severe multi-organ dysfunction, followed by death within a short time.
- When Charlie was diagnosed, he was ventilator dependent. The hospital wished to withdraw life-support due to the poor quality of life with a very poor prognosis.
- The parents wished to keep him alive and try an experimental treatment.
- The hospital concluded that this treatment would be futile and may prolong suffering.
- Charlie's case was brought to court and it was decided to withdraw life support.

Verdict, Great Ormond Street Hospital v Yates & Gard

- "Some people may ask why the court has any function in this process. Why can the parents not just make the decision for themselves?"
- "As the Judge whose sad duty it is to have to make this decision, I know that this is the darkest day for Charlie's parents, who have done everything that they possibly can for him, and my heart goes out to them. … I can only hope that in time they will come to accept that the only course now, in Charlie's best interests, is to let him slip away peacefully and not put him through more pain and suffering."

Great Ormond Street Hospital v Yates & Others [2017] EWHC 972 (Fam).

Alta Fixsler (23 December 2018 – 18 October 2021)

- A 2-year, and 4-month-old girl suffered from a severe hypoxic-ischemic brain injury from birth.
- The parents of Alta are Orthodox (Chassidic) Jews and Israeli citizens.
- The hospital wished to withdraw life support, but Alta's parents wished to maintain treatment, claiming that withdrawing such treatment is not allowed according to their religious beliefs.
- The parents wanted to transfer Alta to Israel, at their own expense.
- The court, in an in-depth discussion, accepted the hospital's request to withdraw treatment.

Verdict, Manchester University NHS Foundation Trust v Alta Fixsler & Others

- "I make a declaration pursuant to the inherent jurisdiction of the High Court that it is not in the best interests of Alta for life-sustaining medical treatment to be continued, and that it is in her best interests for a palliative care regimen to be implemented. ….
- That, with immense sadness, is my judgment."

Manchester University NHS Foundation Trust v Alta Fixsler & Others [2021] EWHC 1426 (Fam).

Discussion

- Central to such cases are the criteria for "Futility", "Suffering," and "Best Interest."
- Cultural and religious values affect these criteria and confound the deliberations.
- Decisions are impacted by the jurisdiction where the deliberations occur.
- In the UK courts, where these cases were tried, the weight given to these criteria differs from the weight in other jurisdictions.
- In Israel, for multiple reasons, court approval to terminate life support is almost unheard of, although courts may grant approval for "non-intervention" when a disease or other complications intervene.

The Dying Patient Act, 2005, Israel

The law distinguishes between two types of treatments:

- Continuous life-sustaining therapies (cardiac pacemakers or respirator), which cannot be stopped because this is viewed as an act that shortens life.
- Intermittent life-sustaining therapy (hemodialysis, chemotherapy), which can be stopped if they are directly related to the dying process.

Steinberg A, & Sprung C.L. IMAJ 2007;9:550-2.

The Certainty of Parental Love vs. the Uncertainty of a "Best" Decision

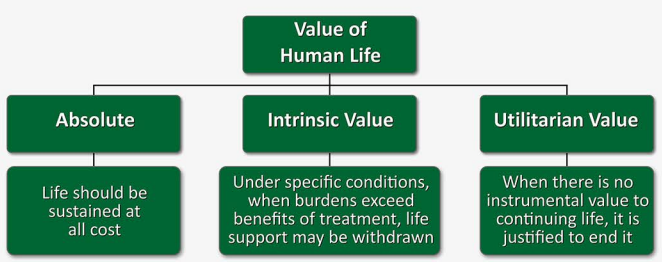
- "As intensivists, we strive to make decisions in the best interest of our patients and in line with parental wishes and beliefs."
- "What does it mean to make a decision for another person out of love? ... Are decisions made out of love always the right ones for the child?"
- "Parental love and guilt are universal, just like death is always filled with regrets, … parents will live with these decisions for the rest of their lives. But why do some parents make different decisions? Why do some of them clearly follow a path of extreme invasiveness that is clearly not beneficial to the child? Parents always want their children to live, but what makes that life meaningful in the circumstances? ... "
- "As intensivists, we know how to manage the pain, breathlessness and anxiety of our patients. Our ability to alleviate the suffering of their parents is often inadequate."

Haj-Hassan T & Mema B. Intensive Care Medicine 2023 Mar 1

The Suffering Child: Claims of Suffering in Seminal Cases and What To Do About Them

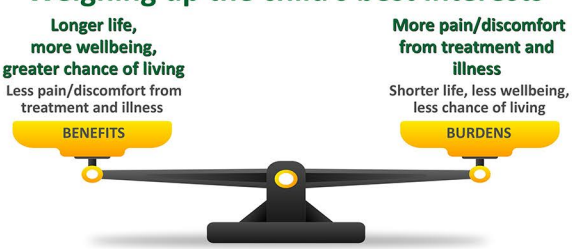
- "Veiled under the nebulous claim of alleviating suffering, clinicians are making judgments about what type of life is not worth living."

Friedrich AB. Pediatrics 2020, 146(S1) e20200818M



Pellegrino ED. Decisions to withdraw life-sustaining treatment: a moral algorithm. JAMA. 2000 ;283:1065-7

Weighing up the child's best interests



Wilkinson D, Savulescu J. Ethics, conflict, and medical treatment for children: From disagreement to dissensus [Internet]. London (UK): Elsevier; 2018

Thou shalt not kill; but needst not strive officiously to keep alive

Arthur Hugh Clough (1819–61)