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Charlie Gard in the Media: Lessons for Clinical Ethics?

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Charlie Gard's Story

- Born in August 2016
- Initially healthy
- After lack of growth, diagnosed in Fall with mitochondrial DNA depletion syndrome.
- Deteriorates – by Winter is blind, deaf, immobile, and seizing on occasion.
- January – nucleoside therapy is considered, but not given. Parents initiate public appeal for support
- Spring – several court reviews by now – all supporting palliation.

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- June – High court rules life-sustaining treatment should be withdrawn.
- Early July – pope and president make statements.
- Late July – Charlie passes away after ventilator withdrawal.

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Media Coverage

- Extensive in the connected world of 2017.
- Hundreds of articles and comments.
- Pope and President
- Polarization – division into “teams”. (“pro-life” vs. opponents)
- Political
- Serves the public good?
- Courtrooms and public drama.

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Decision-making challenges

- Do decision-makers trust each other?
- How can we define what is “reasonable?”
- Is grief complicating clarity of thought?

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Shared Decision-making

- Patient and physician
- Family
- Other physicians, nurses, therapists, and caregivers.
- Reasonable compromise between old-style medical paternalism and excessive patient autonomy
- Second opinions. And third, sometimes.
- Negatively affected by extreme publicity.

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Clinical Experimentation

- Potential for exploitation.
- Protections for subjects, due to histories of shocking abuse.
- Creates compelling “what-ifs?”

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Analysis by Ethical Principles

- Respect for Charlie's autonomy
- Maximize benefits and minimize harms.
- Justice?

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Additional Ethical Analyses

- Optimizing outcomes? Benefits and costs.
- Narrative ethics – what should Charlie's story be?
- Rights questions?

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Surrogate Decision-making and moral burden

- Imagining what other humans would want is difficult.
- Uncertainty is common.
- Need to feel that all reasonable avenues have been explored.
- Possibility of regret usually works both ways.
- Reflective equilibrium among decision sharers is goal.

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Possible Lessons for the Future?

- Improve problem solving mechanisms within hospitals.
- Consider altering the way courts intervene in such cases.
- Reduce incentives for media to over-sensationalize.
- Greater physician focus on the importance of earning patients' trust.
- When death is inevitable, focus on quality of final days, not quantity.
- Regard intensive care as a harm that ought to be balanced by a reasonable prospect for improvement.
- Formalize time-limited trials of therapy to reduce disagreements about prognosis.

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Promise and Potential of Clinical Ethics practice?

- On site, face-to-face communication in complex cases.
- Practical problem solving by consensus.
- Facilitation of shared decision-making.
- Non-adversarial.
- Timely.
- Ethicists supported closely by ethics committees (community of peers).
- Reduces burdens of decision-making for patients and families, and clinicians.

Your Thoughts?

- Thanks

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