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• June – High court rules life-sustaining treatment should be withdrawn.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

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

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

• Respect for Charlie’s autonomy
• Maximize benefits and minimize harms.
• Justice?
Additional Ethical Analyses

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