

Case Study – Aaron’s Siblings Need to Make a Tough Decision



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September 2024

Bioethics case study on shared decision making.

Aaron Jacobson was a 63-year-old man who was admitted to the hospital for a bowel obstruction. He came to the hospital from his long-term care facility a few days ago. In addition to his bowel obstruction, he is also suffering from cancer, and he has a very poor prognosis.

There are many factors that make this situation particularly challenging. For one, Mr. Jacobson suffers from profound intellectual disability. He has lived in an assisted facility and supported by caregivers his entire life. He has never had decision making capacity and has never been able to make his own healthcare decisions.

Because of Mr. Jacobson's inability to make healthcare decisions, the medical team has been speaking with his family members for assistance in decision making regarding the goals of care.

His brother Russ and his sister Helen have both served as his decision maker for most of his life. They both live out of town and are not always the most responsive or timely in getting back to the medical team, but in general they have been there and have been supportive of their brother.

When Aaron was admitted, his family wanted the medical team to be as aggressive as possible. This meant starting tube feedings, starting antibiotics and establishing full code status.

Unfortunately, Aaron has some difficulties with his feeding tube and this caused respiratory duress. Now Aaron has been intubated and can only breathe with assistance from a ventilator. He has lost all consciousness and is likely to never wake back up. His siblings, who are wanting aggressive measures, are now unsure about what is the right path forward. Either Aaron is going to need a trach and a surgically implanted feeding tube so that he

can go to a long-term care facility, or he will need to be taken off the ventilator and allowed to likely pass away.

Helen and Russ have started arguing over this, with neither side confident of which is the right decision. On the one hand, Russ does not want to give up on his brother. He knows Aaron has had a challenging life and he feels some regret for not being there more often for him. He thinks going forward with the trach and the PEG would give his brother more time to recover.

Alternatively, Helen believes that Aaron's prognosis is too poor, and he would not want to linger like this. Aaron was a very social person at his care facility and really thrived on being around others. If his only future is being in a bed hooked up to machines, Helen says that is not a life that he would find worth living.

Because of this conflict and uncertainty, the medical team has requested an ethics consult.

Questions

This case suggests some particularly important questions, including:

- What should the patient's code status be?
- Should the medical team go forward with the trach and PEG or should they prioritize only comfort?
- Who is the most appropriate person to speak for Aaron and uphold his autonomy?
- What is the value of patient assent when the patient is not able to give informed consent?
- How important are non-verbal means of communication?
- Does a patient's history impact the team's decision making?
- If you were the ethicist in this case, what would you do?
- What would you feel are the most important steps in this situation?
- What information is missing that you would need to come to a recommendation?
- And what do you feel is the most important first step in making these recommendations?

This is a challenging scenario, but one that could certainly benefit from the involvement of a clinical ethics team.