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## When a Parent Overrides Their Child's Best Interests

### Jacob Needs a Baclofen Pump



By [Ryan Pferdehirt, DBe,HEC-C](#)

January 2026

Bioethics case study on autonomy and beneficence.

Patient self-determination and personal autonomy is a central part of ethically appropriate care. If patients have decision-making capacity, are able to understand the consequences of those decisions, and accept the risks that might occur, it typically holds that it is ethically appropriate to support those decisions. Of course, each patient situation is unique and needs to be reviewed as such, but the concept holds more often than not. If a patient is requiring of aggressive medical intervention and a high level of life-sustaining treatments, that patient's preferences should be respected and followed.

But how far does this principle extend? At what point does the best interest of the patient, and thus the principle of beneficence, overcome the patient's right to autonomy? And how does this principle apply to the pediatric realm, when it is the parents making the decision regarding what is best?

#### **Demanding Mom**

Let's look at the case example of the Morton Family. Jacob Morton was an eight-year-old male who suffered from severe medical complications his entire life. He has very bad epilepsy, which would cause neuro-storm and daily seizures. This was further complicated due to another condition that caused his body to remain constantly stiff. It was described to the ethics team as the equivalent of rigor mortis. He was only able to lay on his back, completely stiff. But when he would have a seizure, he would break bones due to the severity of them.

His condition is likely to worsen due to his family's naturopathic medical beliefs, believing that all modern western medicine is "poison" and should be avoided. Jacob has been living in a pediatric nursing facility, where he is able to receive constant care and attention, but Mom is remaining highly involved in all medical decisions. Mom had been constantly demanding particular interventions be stopped, monitoring IV medications and the amount given. Jacob's mother believes that he simply requires breast milk and is pushing for all medical interventions be stopped. This is causing severe moral distress among the medical team, as they continue to care for his constant seizures and broken bones.

### **Overriding the Parent**

A recent conversation came up between the medical team and Jacob's mom regarding a surgically implanted baclofen pump. The medical team believe that this would relax his muscles so that the next seizure would not be as severe and not cause as many fractured bones. But Mom is adamantly refusing, saying that the medical team cannot abuse and batter her son. The medical team is now torn and distress, reaching out to ethics as to whether they can do the baclofen pump over mom's demands because doing nothing is only furthering harm to Jacob.

It is these situations that really highlight the modern difficulties with the principles of respect for autonomy and beneficence. Medically, the team knew what was in the best interest of Jacob but also wanted to be respectful of Jacob's mother. Of course patients have the right to autonomy, but what do you do when acting upon that right causes harm to themselves, and more challenging situations, when it involves harming others.

Questions arise regarding is the medical team complacent in what they deem abuse of the child by respecting a parent's wishes? It is one scenario when a patient is refusing an intervention and can understand and accept the consequences. It's something else when a seeming lack of understanding causes undeniable harm to others. What are the limits to autonomy?