

Do No Harm: Ethical Considerations in Continuing Life-Sustaining Treatment when Treating Outside the Standard of Care

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This is a case of a 50 year-old man with sickle cell anemia and schizophrenia who presented with vaso-occlusive pain crisis. His course was complicated by lethargy, confusion, and worsening abdominal pain and he was diagnosed with a bowel perforation. At the time of admission, he had decision-making capacity and elected full code status; however, he was found to lack decisional capacity at the time of diagnosis of bowel perforation. No surrogate decision-maker had been named, so this role fell to his mother, legal next of kin. The patient's mother, in consultation with his brother, decided against surgical management of the bowel perforation and opted for maximal medical therapy, a decision partially based on the fact that the patient had declined surgery for suspected bowel perforation one year prior. The patient received treatment with antibiotics and IV fluids, and his course was further complicated by bacteremia as well as acute renal and hepatic failure. He continued to lack capacity to make his own medical decisions. He frequently pulled at IV lines, requested to eat on his own, and asked to go home. The patient's family continued to elect maximal medical treatment, basing their decision in part on the patient's decision to elect full code status on admission. An ethics consult was obtained regarding treatment over objection in the setting of therapy outside the standard of care for a bowel perforation with an ambiguous endpoint. A time-limited trial of therapy was proposed. This was viewed as a useful approach to consistently re-evaluate the patient's clinical status with hopes of restoring the patient's decision-making ability. The patient was started on total parenteral nutrition and his bowel perforation worsened. He had significant pain requiring IV opioids. After a discussion with his mother, the patient was transitioned to DNR/DNI. He eventually developed respiratory failure and worsening encephalopathy and was transferred to the ICU for trial of BiPAP. He later developed anuric renal failure and BiPAP was stopped due to worsening abdominal distension. After discussion with the ICU team and palliative care, the patient was transitioned to a comfort measures approach, and he passed away less than 24 hours later. This case illustrates the ethical dilemma surrounding the medical team's obligation to provide life-sustaining treatment outside the standard of care as well as the moral distress which accompanies treatment over objection in patients who lack decision-making capacity. This case also demonstrates the potential of a time-limited trial of therapy as an ethical approach to avoid a prolonged course of ineffective treatment.