Paternalism in the Medically Underserved Patient: A Case Report

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Abstract

Introduction

The role of the doctor-patient relationship is a rapidly changing entity from a purely paternalistic model to one of shared decision making. Ideally the relationship should be governed by the Four Principles of Medical Ethics: autonomy, beneficence, non-maleficence, and justice. The two Principles involved in the balancing of paternalism in the delivery of healthcare are autonomy and beneficence. When there are clear limitations to a patient's autonomous decision making, such as lack of capacity, the case for paternalism is more easily justified. A stronger form of paternalism arises when the two values appear incompatible. In these instances, paternalism that overrules a patient's autonomy in the moment, must serve the purpose of promoting greater autonomy for the patient moving forward. Striking the balance between autonomy and beneficence when the two principles are at odds is part of the art of medicine.

Case Presentation

Patient is a homeless 59 year old male with past medical history significant for alcoholic cirrhosis with recurrent ascites first diagnosed in 2017, chronic alcohol, tobacco, and cocaine use disorder which he was unwilling or unable to abstain from despite its health impacts. He comes into the Emergency Department (ED) three times weekly for a paracentesis many times leaving against medical advice (AMA) prior to paracentesis. Patient has had relatively minor medical consequences of his lifestyle choices until approximately one year ago when he was hospitalized after a mild episode of hematemesis which required a blood transfusion during which time he had repeatedly refused endoscopic procedures or ways to identify any bleeding. Due to the increasingly erratic behavior, including leaving AMA from the ED three times in one day, over 150 times in the previous year, and being verbally and physically abusive to staff, a psychiatrist determined that the patient lacked capacity to make medical decisions. A court appointed guardian was obtained and the patient was treated during a three month period of involuntary commitment (IVC). Decision-making in this case was difficult in light of the patient's assertion that his independence and quality of life (QOL) were most important to him. Since each individual patient has their own beliefs about what qualifies as an acceptable QOL, and this patient's acceptable QOL included eating, drinking alcohol, and being able to receive medical care under his own terms. Understanding the value of treatment in preserving the patient's autonomy in the future held weight in making medical decisions on his behalf. Following his IVC, the patient required frequent hospitalizations. Despite having a guardian to consent to treatment, he continued to refuse medical treatment, including paracenteses. The medical team had to make the decision about how to proceed with his treatment.

Final Diagnosis

The sentinel event occurred when Patient came in with massive hematemesis requiring ICU admission and intubation. The guardian consented to emergency EGD which found Grade 3-4 esophageal varices with active bleeding which were amenable to intervention. With appropriate medical therapy, Patient was extubated and transitioned to a general medical floor where he continued to fail speech language pathology evaluations and alternative forms of feeding were explored, which patient declined despite his guardian consenting to them. A

difficult to answer question developed from treating this patient: to what extent do individuals with substance use disorders have free will and do they even have the ability to make their own complex medical decisions?

Outcome

This case illustrates an important concept in modern medicine with patients living longer and with a different QOL than in the past: at what point does a patient lose the capacity to make medical decisions for themselves? The determination of decision-making capacity possibly has different thresholds based on the gravity and complexity of the decision being made. The same patient may be deemed to have capacity to make everyday decisions while not having capacity to make medical decisions. Since this patient was well known to the service, we took what he had said in the past into account, as consistency is an integral part of capacity. He had previously indicated that he would not have liked to be on long term ventilation, have chest compressions, or to live if he was unable to eat. After given an opportunity to eat and then aspirating on his meals, he stated that he would prefer for hospice to get involved again and transition to comfort care. At this point, the benefit of treatment would have diminishing returns and we felt that this was a decision that he was capable of making with or without his guardian's approval, and aligned with his long maintained desire that QOL and independence were most important to him. As easy as it would have been to write the Patient off as having no capacity and acting paternalistically, in the end, treating physicians must have the patient's best interest at heart and allowing this patient to have his wishes heard was of utmost importance to him and he was ultimately satisfied with the outcome.

Learning Objectives

Upon completion of this lecture, learners should be better prepared to determine how to balance paternalism and autonomy in medical decision making.