

Facilitating patient-centred decisions about serious illness care



Patient autonomy is the overriding ethical principle guiding medical decision making in the United States. This autonomy-driven model assumes an informed patient who fully understands the implications of available treatment choices and can identify those most aligned with their values and goals. However, there is increasing recognition that this conceptualisation of patient autonomy is intricate and fallible, owing largely to the complex interrelationships among human cognition, emotions, and behaviour, especially in the context of serious illness.

Patients with serious illness are commonly asked to provide their preferences regarding highly complex medical decisions, often decisions that may affect their own deaths. Even in a shared medical decision-making model, there is often an implicit assumption that patients are able to fully understand complex options, in the context of illness and distress, and to participate as an informed partner.

Things may become problematic when patients are naive to treatments such as endotracheal intubation, tracheostomy, and feeding tubes. In this case, patients may not possess the level of understanding necessary to make the decisions they would if they had the training of clinicians. This is not an argument for paternalistic decision making, but rather an argument for research to explore ways to support patients with serious illness, and their family members, in making decisions that are true to their individual values and goals.

What's needed is to find the best way to support patients with serious illness and their family members in patient- and family-centred decision making. Shared decision making is clearly the goal, but what does that mean in the context of serious illness? In striving for the best possible decisions for each patient, there are many complex nuances including the influence of cognitive biases, the effect of emotions on effective decision making, the ultimate role of intuitive decision making, and the emotional consequences of decision making about serious illness.

It must be noted that patients' own preferences for involvement in medical decision making can change over the course of a serious illness, especially in the context of psychological adjustment to serious illness. Further, negative mood impairs logical reasoning processes: anxiety increases risk aversion, sadness increases risk tolerance, and fear increases the perceived affect and consequences of negative outcomes.

Additionally cognitive dissonance theory suggests that people are adept at constructing narratives to rationalise decisions they made as the best of all potential alternatives. However, in the context of serious or even tragic choices regarding end-of-life care, cognitive dissonance may not help alleviate the emotional consequences including psychological distress, regret, and grief. A combination of a sense of personal responsibility with the ability to imagine better alternatives had one chosen differently may increase decisional regret and serious distress. For example, perceived personal responsibility for making tragic decisions about withdrawing life support for a terminally ill child seems to result in much greater distress and grief for parents than if the same outcome resulted from a choice made by physicians.

Emily B. Rubin, MD, JD, and colleagues report an elegant and innovative randomised clinical trial using psychological experimentation with hospitalised patients to compare intuitive vs. deliberative approaches to medical decision making. In the intuitive group, patients were subjected to a cognitive load (remembering a series of numbers) and instructed to provide their treatment preferences immediately based on instinct. In the deliberative group, patients were not subjected to a cognitive load and were instructed to think critically about their answers, take a full minute before answering, and explain why they made their decisions. Patients in both groups chose very similar treatments, reported very similar decisional certainty, and were equally likely to have their treatment choices match their stated personal values.

Rubin et al.'s experiment provides persuasive evidence that encouraging hospitalised patients to deliberate on life-sustaining treatment decisions does not change the content or improve the quality of their decisions. Their study also raises the important question of how to best facilitate informed decisions for seriously ill patients on their medical care that are in line with their individual values and goals.

Additional studies are needed that incorporate the novel use of psychological experiments to examine the effect of cognitive biases, mental stress, and emotional valence on decision making, decisional outcomes, and other patient- and family-centred outcomes. Simulating the real-life context in which difficult decisions are made, could help in creating approaches for supporting seriously ill patients and their families in the most effective, patient-centred decision making. Rather than supporting deliberation for the sake of patient autonomy, the goal should be making the best medical decisions with, or if they desire, for patients and their families based on the patient's values and goals.

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