How decision science can help with gut-wrenching medical choices

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Stress can be an obstacle in health decision-making, especially when available options involve dramatic and lasting consequences. Case in point: when parents must make end-of-life care decisions for their child.

There is a dearth of patient decision aids for navigating such ethical dilemmas, but insights from decision science can mitigate negative influence of distress on decision making and can help patients and their loved ones manage a plurality of possible responses to tough health choices. Two ethics experts explain how.

Following are highlights from an article published in the AMA Journal of Ethics® (@JournalofEthics) by Katherine J. Feder, a third-year medical student at the University of Michigan Medical School with a master’s in bioethics, and Janice I. Firn, PhD. She is a social worker and clinical ethicist in the Center for Bioethics and Social Sciences in Medicine, as well as the Department of Learning Health Sciences at the University of Michigan Medical School.

The AMA Code of Medical Ethics also covers pediatric decision-making and withholding or withdrawing life-sustaining treatment.

Using a hypothetical case of a 3-year-old patient who suffered widespread brain damage after cardiac arrest during surgery, authors of this AMA Journal of Ethics article explored how a clinical ethics consultant can adopt a personalized, values-based approach to facilitating grieving parents’ decision-making.

How stress affects decision-making

A high-stress, high-stakes situation like this one can impair some parents’ “ability to process complex
information and can cause communication to be less effective,” the authors wrote, so it is critical for physicians and clinical ethics consultants to take this into account.

Decisions made during stressful situations are “affected by instincts, emotions, and perceptions as much as—if not more so than—by reason, calculation, and logic,” the authors added. Parents also could overlook important facts, forget to talk with key people about a decision, or fail to fully consider long-term consequences.

It’s important to help parents be aware of “action bias, the desire to do something—perhaps anything—to decrease anxiety.” The authors warned that this bias “could lead to a hasty or poorly considered decision.”

Set framework for decisions

Parents might assume—or hope—that there is a single “right” answer in their situation, rather than several ethically defensible possibilities.

“It is not unreasonable for the parents to want to be told the right thing to do in their specific situation; paternalism could offer both respite from their responsibility and a beacon of clarity amidst uncertainty, grief and devastation in their family,” the authors wrote.

In such a case, a physician should clearly articulate a normative ethical framework for decision-making.

“Articulating such a framework can sometimes help families to discern how their intuitions, values and preferences can be drawn upon to express—with as much confidence and clarity as can be achieved under conditions of stress and uncertainty—an ethically defensible decision,” they added.

However, personal and environmental factors such as religious traditions, social support and health insurance can influence parents’ decisions. To better understand and acknowledge these circumstances, a physician might take a bottom-up approach to discussing ethics—for example, by focusing on the family’s needs—rather than a top-down approach, such as principlism.

Tactics for moving forward

The authors recommended these four techniques for helping parents arrive at ethically defensible decisions in times of grief and clinical uncertainty.
Ask them how they want information to be relayed. This could give insight into the family’s circumstances and decisional needs.

Use the third person. This can give parents some emotional separation from the issues at hand.

Emphasize that decision-making is not a static process. Families should know they can pivot in response to changing information and circumstances.

Clarify the timing of the decision. Parents’ assumptions might not be accurate.

The October 2019 issue of *AMA Journal of Ethics* further explores the use of decision science in clinical ethics.