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CASE AND COMMENTARY

How Should Clinical Ethics Consultants Support Parents' Decision Making?

Katherine J. Feder, MS and Janice I. Firn, PhD, LMSW

Abstract

Clinical ethics consultants (CECs) frequently provide guidance to parents feeling grief and uncertainty. In response to a case in which a CEC works with parents making end-of-life decisions for their child, we argue that CECs should use insights from decision science to consider how emotional distress, information-processing heuristics, and person-environment relationships can influence decision making. Rather than rely on decision aids, CECs should take a personalized, values-based approach to facilitating decision making that acknowledges context and a plurality of possible "right" answers. By using this approach and insights from decision science to support parental decision making, the consultation itself becomes a decision aid, as consultants and parents engage in shared decision making through facilitated discussion and reflection.

Case

Dr AE, the clinical ethics consultant on call, receives a consultation request from parents of a previously healthy 3-year-old patient admitted to the pediatric intensive care unit. The patient suffered an anoxic brain injury after cardiac arrest during surgery. The damage to his brain is widespread. In the medical team's clinical opinion, he will have lasting neurological deficits, including, but not limited to, problems with cognition, vision, language, and motor function. His parents want to meet with someone from the ethics consultation service to discuss the ethical permissibility of withholding or withdrawing specific interventions from their child. The clinical team would support the parents' decision either to continue aggressive treatment or to transition to comfort care.

When Dr AE enters the consultation room, the parents say, "We're glad you're here. You can tell us the right thing to do."

Dr AE is uncomfortable with the parents' stated expectations about her role as an ethics consultant and about their perception of the role of her expertise in their decision-making process. Before addressing these concerns, Dr AE first seeks to learn more about what the parents view as ethical concerns regarding their son's situation.

The parents explain that they want to make sure they have done "everything" for their son, but they also express that they do not want him to live his life like a "vegetable." They love their child and want to be good parents to him, but they are struggling with how to do that because they feel both medical paths fail him in some important way that seems to compromise their goals and best wishes for him. Dr AE recognizes the parents' grief and their experience of conflict about their clinical options.

Commentary

Like many pediatric intensive care ethics consultations involving treatment and quality-of-life decisions for children, Dr AE is called upon to facilitate grieving parents' decision making when the choices with which they are confronted will result in dramatic and lasting consequences. Given the emotional valence of the consultation, Dr AE will need to draw upon decision science approaches and resources that acknowledge and subsequently mitigate the influence of distress on decision making. Various stakeholders have recommended the use of patient decision aids (PDA) to promote a shared decision making model.[1] Although such aids are useful for certain choices, such as whether or not to be screened for prostate cancer or how to choose a medication, we argue that each ethics consultation is distinct and requires the ethics consultant to learn more about the individual patient and the patient's family situation to help decision makers engage in shared decision making based on their values and self-determined best interests. While there is a dearth of PDAs for solving ethical dilemmas, their absence does not preclude the use of decision science, which, as we show, goes beyond aids to encompass the various factors that affect decision-making processes and the science of how human beings make choices.[1,2,3]

Emotions and Decision Making

Stressful situations and acute emotional states can impair our ability to process complex information and can cause communication to be less effective.[4] How we make decisions under stress, therefore, is affected by instincts, emotions, and perceptions as much as—if not more so than—by reason, calculation, and logic.[3] Even in the best of circumstances, most of us function with less-than-perfect information and cannot analyze all costs and benefits for every possible alternative; cognitive space is limited and our minds concentrate on immediate rather than future needs.[3] In addition, a given situation's relative ambiguity, predictability, uncertainty, and duration also influence how an event is evaluated and which coping mechanisms are used, potentially further impeding decision making.[5] Under stress, we can overlook salient facts, neglect to involve key stakeholders, or fail to attend sufficiently to long-term consequences.[3] *Action bias*, the desire to do something—perhaps anything—to decrease anxiety, could lead to a hasty or poorly considered decision.[2,3]

In pediatric cases, parents could be viewed as a single unit rather than as individuals. While both parents commonly want to do what is best for their child, it is important to

acknowledge that each parent might process information differently and bring unique perspectives and narratives to the decision-making process, which in turn could influence their experience of grief.[5,6,7,8]

Roles of an Ethics Consultant

Involving someone less emotionally connected to a situation who is professionally trained to facilitate ethically complex decision making can help reconcile varying perspectives, engender support, and counter a sense of isolation many feel when grieving.[3,6] Good ethics consultation processes should create a space for decision makers to pause, to assess, and to explore both short- and long-term effects of different choices.[3,5,6,9] The consultation process also allows for exploration of assumptions held by caregivers or other stakeholders.[3,6]

To facilitate decision making under the stressful circumstances in the case, Dr AE might use several techniques. One is to reframe the situation in the third person to give the parents some emotional separation from the issue.[3,6] Dr AE could also emphasize that decision making is not a static process but one that changes over time as new information, experiences, and context emerge and thus that the parents are not bound to a single course of action but can pivot in response to changing circumstances.[5] Furthermore, Dr AE could help clarify the timing of the choice to be made.

Despite Dr AE's discomfort with the parents' assumption that her role is to make the decision for them ("You can tell us the right thing to do"), it is key that Dr AE establish an alliance with the parents, which could be compromised if she directly confronts their assumptions about her expertise and purpose too aggressively. Ultimately, however, Dr AE must demonstrate her role as a facilitator in the parents' decision-making process. By eliciting further information about their goals and values, answering questions as the conversation unfolds, and filling in their knowledge gaps as needed, she can clarify her role over the course of her interactions with these parents. Specifically, Dr AE's behavior and speech should enact her role as a facilitator and delimit its nature and scope; if uncertainty about her role remains as the consultation proceeds, Dr AE will hopefully have established sufficient rapport with the parents to make an explicit verbal statement about the nature and scope of her role.

Furthermore, Dr AE must make it a goal of her time with the parents to unpack what they think the "right thing to do" means. The parents' apparent assumption that the right thing to do is knowable could be based, for example, on misinformation that there is one right answer in such scenarios or that the ethics consultant is the one who knows this answer rather than being the one who could facilitate revelation of options that are ethically defensible. 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.

Dr AE should emphasize that her role is to facilitate value- and context-based discussion, not to make a decision for the parents. Accordingly, she should strive for deeper understanding of what is motivating their choices or conflict.[8] She should also articulate, in plain language, a normative ethical framework for facilitating the parents' understanding of how their personal values can be viewed as part of such a framework and thus be used to ground ethically defensible reasons for a decision affecting their child. 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.

Responding to Person-Environment Interaction

Culture, technology, social and individual values, spiritual and religious traditions, and legal and financial struggles are among the many factors that can frame and influence how families approach clinical and ethical decisions.[6] Each factor plays an important role in determining what is perceived as pertinent for well-being, how meaning is attributed to an event, what coping strategies are used, and how different possible outcomes are assessed.[6,10] In this case, the parents' lack of confidence in making a decision could be further influenced by a number of factors, including the absence of choices or of specific resources such as health insurance, social support, savings, or information.[5,6] Part of Dr AE's role is to acknowledge the diverse context-specific factors at play and their possible influence on decision making. She might consider employing a more bottom-up approach to talking about ethics—for example, by focusing on the parents' needs and the characteristics of the family—rather than employing what's often characterized as a top-down approach to ethics, such as principlism, deontology, or utilitarianism, when guiding parents through a decision-making process.[5,11,12]

In the case of this family, the clinical team would support a decision to either continue aggressive treatment or to transition to comfort care. The parents must weigh the child's quality of life under continued aggressive intervention against the irreversibility of their child's death. Their choice will be informed by both the kind of quality of life they value and have envisioned for their child and their family life at home. For example, the decision-making process for these parents could be informed by the needs and best interests of other children or elders in their household whose care could also be influenced by the consequences of this particular decision. Dr AE is obliged to offer (and possibly chart in the patient's health record, depending on the organization) recommendations intended to help a team or family make an ethically complex decision.

At present, the approach described above cannot readily incorporate PDAs. Developing effective decision aids requires understanding patients' and families' decisional needs and finding ways to create materials that can accommodate the differing informational preferences of individuals within a heterogeneous population.[2] This task is challenging enough for binary decisions ("Do I undergo BRCA testing or not?") when the patient is commonly the decision maker. It becomes even more complicated when the decision is potentially irreversible and those making it might be stakeholders other than the patient. Moreover, the use of PDAs could thwart shared decision making if they feel impersonal to decision makers and insert a dry algorithmic element into an emotionally challenging decisional process.

In any case, clinical ethics consultation and PDAs work towards the same goal: facilitating engagement in shared decision making based on patients' and family members' values.[13] It is imperative for the consultant to ask patients or families how they want information to be relayed, and it is essential to take their context into account as part of facilitating shared decision making. In taking context into account, the ethics consultation accounts for population differences in real time, functioning as a personalized decision aid.

Conclusion

In summary, clinical and ethical decision making is often influenced by emotions that affect how information is processed. To more effectively support patients and families and to facilitate decision making in line with their values, it is imperative for ethicists to create a safe space for families to transition from reactive to reflective thinking. In this case, by gauging the parents' level of understanding, eliciting their perspectives, clarifying their goals, and engaging in shared decision making, Dr AE can help the parents understand the scope of their choices and how they can draw upon their values to make a choice they can live with. Through such a shared decision-making process, Dr AE can demonstrate her role as a facilitator (rather than as a decision maker), and, by emphasizing the importance of a defensible decision over a "right" one, she can help the parents make a decision that makes sense for them. In effect, Dr AE serves as a decision aid for the family by providing techniques and resources from the broader field of decision science to fit their personal context.

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Katherine J. Feder, MS is a third-year medical student at the University of Michigan Medical School in Ann Arbor, where she is a member of the Ethics Path of Excellence co-curricular program. She received a BA in English literature from Williams College and an MS in bioethics from Columbia University. She is involved in research that examines the influence of preventive ethics at Michigan Medicine and is interested in applied ethics, especially in pediatric care.

Janice I. Firn, PhD, LMSW is a social worker and clinical ethicist in the Department of Learning Health Sciences and the Center for Bioethics and Social Sciences in Medicine at the University of Michigan Medical School in Ann Arbor. In her roles, she responds to ethics consultation requests, facilitates preventive ethics rounds, and participates in interprofessional ethics education at the undergraduate, graduate, and professional levels across the medical and academic campuses. She is also involved in a number of ethics-related research, caregiver wellness, and quality improvement and assurance initiatives.

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