

FROM THE EDITOR

The Value of Decision Science for Clinical Ethics

Raymond De Vries, PhD

Bioethics prides itself on its interdisciplinarity. It is a field that invites members of different disciplines to join in the conversation, to bring insights generated by their approach to knowledge to the moral problems of medicine and the life sciences. At first glance, the breadth of bioethical interdisciplinarity—encompassing philosophy, medicine, literature, nursing, social work, religion, social science, and law—is impressive. But, on further reflection, that interdisciplinarity is curiously limited. *Curious* because, despite the disciplinary diversity of bioethics, other disciplines that could improve the quality of bioethics in its clinical and research manifestations have not been invited to the party.

Decision science is one of those fields. And it is a curious omission. Consider this definition from the Center for Health Decision Science at Harvard University: “Decision science is uniquely concerned with making optimal choices based on available information. Decision science seeks to make plain the scientific issues and value judgments underlying these decisions, and to identify tradeoffs that might accompany any particular action or inaction.”¹ In their contribution to this theme issue, Brian Zikmund-Fisher and Michele Gornick offer a slightly different description: “Decision science encourages thoughtful definition of options, clarification of information needs, and acknowledgement of the heterogeneity of people’s experiences and underlying values.”² Reading these 2 definitions, we are forced to ask: Why are we in bioethics not working side by side with decision scientists? Much of our work involves helping people—be they patients, research subjects, caregivers, or researchers—make “optimal choices based on available information” by taking into account their values, experiences, and the trade-offs involved in choosing one option over another.

The University of Michigan Center for Bioethics and Social Sciences in Medicine (CBSSM), of which I am associate director, is fortunate to number decision scientists among its core faculty. I would like to say that their presence is the result of our vision, wisdom, and careful planning, but, in fact—just like the field of bioethics itself—the composition of our center is a consequence of circumstance and happy accident. The field of bioethics arose from the work of a collection of theologians and philosophers who turned their attention to medicine and medical science at a time—the 1960s and 1970s—when the authority of society’s institutions was being questioned and when medical technologies were challenging established boundaries of life, redefining when life begins and ends.^{3,4} It could have been otherwise: the content and concerns of bioethics would look much different had the field emerged in a different historical and social context.⁵ At the CBSSM, it happened that the

people drawn to bioethics included those with expertise in decision science,^{6,7,8} allowing us to combine the concerns of both areas of inquiry. Those who identified with bioethics saw the value in decision science, and those in decision science recognized the importance of bioethics for their work. That history is reflected in the articles collected here.

As you will see, central to the work of both bioethics and decision science is attentiveness to the way values inform choice. Because *value* has multiple, related meanings, when we speak of values, we need to tread carefully. In the context of health care, value often refers to matters economic: the worth of something expressed in monetary value. Indeed, when I first heard of efforts to encourage value-based health care, I thought, *Wow, health care is finally realizing that people's values need to be considered in how care is delivered!* After all, I do work in bioethics, and I assumed that the values in value-based health care referred to those things we find important in life. But I quickly learned that I had the wrong definition of the word. The *NEJM Catalyst* defines value-based health care as “a healthcare delivery model in which providers, including hospitals and physicians, are paid based on patient health outcomes.... Value-based care differs from a fee-for-service or capitated approach, in which providers are paid based on the amount of healthcare services they deliver.”⁹

You, the reader, should keep the differing meanings of value in mind as you consider the theme issue authors' arguments: think about how those 2 meanings are intertwined. Economic value, for example, can be, and often is, something that is “important in life”—a factor to be considered when weighing an ethical question. But the value placed on *costs* is just one among several cultural values—a fact that is confirmed by the uneasiness we would feel if ethicists relied solely on an economic analysis when deciding on the most moral approach to delivering care. True to the goal of decision science—which, in Zikmund-Fisher and Gornick's words, is “to produce choices that are values-congruent”²—the articles included here focus, for the most part, on value as described in the second, important-in-life meaning of the word. Those that do consider costs call attention to the need to weigh the value of economic value.

Concern with the link between value(s) and culture is particularly relevant because this collection is the result of a collaboration between the CBSSM and the Metamedica Department of the Vrije Universiteit Amsterdam led by Guy Widdershoven. This kind of cross-cultural work happens too seldom in the field of bioethics, and its value (yes!) is apparent in the contrast between the differing models of ethical deliberation described by ethicists from the Netherlands and the United States. In explaining the process of *moral case deliberation*,¹⁰ contributors from the Netherlands call attention to the way facts are produced by values and underscore the need to consider both professional and patient values. Their approach to ethical deliberation—which explicitly solicits and applies the values of all parties involved in an ethical dilemma—could prompt American bioethicists to reassess the top-down model of clinical ethics consultation widely used in the United States.¹¹

Using decision science to approach ethical decisions highlights the different ways that values shape the content, process, and outcomes of ethical deliberation. Zikmund-Fisher and Gornick set the stage for the collection in their essay, “What Clinical Ethics Can Learn From Decision Science.” They remind us that those making (or helping others to make) decisions in the context of clinical ethics should consider not only the information that stakeholders must know to make an informed decision but also the “[predictable biases](#)” that influence people’s perceptions and how the task of decision making in conditions of uncertainty is “simultaneously analytical and emotion driven.” Responding to a case in which parents are conflicted about [end-of-life care options](#) for their child, Katherine J. Feder and Janice I. Firn offer an example of how the goal of decision science—to make values-congruent choices—can be realized in practice. They point out the importance of encouraging reflective—instead of reactive—thinking and the need to emphasize that there is no “right” decision, even when ethicists are asked to explain the “right thing to do.”

Economic value—in the form of supply, demand, and affordability—is central to the case study of Sara Silbert, Gregory A. Yanik, and Andrew G Shuman and that of Eric Kersjes and Lauren B. Smith. Silbert and colleagues discuss the dilemma created when a highly expensive “living drug”—chimeric antigen receptor T (CAR-T) cell therapy—shows promise in treating refractory B-cell malignancies. They consider not only how health care organizations should respond but also whether the [cost of the therapy](#) should be discussed with patients. Similarly, Kersjes and Smith consider the (sometimes) [scarce resource of blood products](#) and how they should be used in end-of-life care—in this case, for a pediatric patient. In both case commentaries, we see the tension created when it is necessary to balance the value of a (costly or scarce) resource for a particular patient with the needs of other patients. The easy way out of this dilemma is what Zussman calls “Hippocratic individualism”¹²—deciding that it is ethical to care for the patient in front of you, ignoring the cost of that decision for others. The authors of these commentaries disagree with that approach and ask us to expand our ethical horizons.

Several articles examine how social values find their way into clinical care and ethics, especially the contribution of Nealie Ngo and of Chithra R. Perumalswami, Brycin D. Hanslits, and Susan D. Goold. In both we see how the way bodies are valued (or devalued) influences care. Perumalswami and colleagues examine the [treatment of patients with obesity](#) by hospice and palliative care practitioners and how stigma and the additional costs associated with the care of these patients compound moral dilemmas in decision making. Ngo uses advertisements, magazines, body satisfaction surveys, and her own struggles with body image to challenge us to consider the ways in which [social valuation of ideal body types](#) can empower and disempower us.

The articles from our colleagues at the Vrije Universiteit focus on the interplay between facts and values. Giulia Inguaggiato, Suzanne Metselaar, Bert Molewijk, and Guy Widdershoven remind us that clinical ethical decision making involves not only the values of patients but also the values brought to the conversation by physicians and nurses. They apply [moral case](#)

[deliberation](#), a method of clinical ethics support, to a case dilemma of how to treat a neonate's pain to illustrate how values influence the interpretation of the facts that are called upon to make morally informed and shared decisions. Natalie Evans, Suzanne Metselaar, Carla van El, Nina Hallowell, and Widdershoven pick up on this theme, warning about the consequences of nondirective counseling and the [use of decision aids](#) in the context of genetic risk. In particular, they argue that decision aids can remove decisions from the source of a patient's values, including family and culture, with no consideration of how the values of the physician and the health system are embedded in these instruments. Their conclusions highlight how clinical culture affects the framing of ethical issues, mirroring research that shows the negative effects on satisfaction and coping of a strong emphasis on respecting the autonomy of patients or parents in medical decision making.^{13,14}

Among the many things that may prevent decisions from reflecting the values of those who are *making* those decisions are social and legal barriers. Alexander J. Hjelmaas and Christian J. Vercler present a [case of opioid prescribing](#) that illustrates this problem and examine how the demands of a busy practice, the constraints of law, and the limits of trust conspire to compromise the patient-physician relationship. They advocate for shared decision making as a solution but admit that adding another task to the work of clinicians—one that is not required or billable—would likely fall by the wayside. In their discussion of the use and interpretation of [expanded carrier screening](#), Amanda Fakhri and Kayte Spector-Bagdady share a similar skepticism about implementing shared decision making. The source of their skepticism is too few genetic counselors, the tension between recommendations made by professional organizations and the more-is-better approach marketed by expanded carrier screening manufacturers, and the challenges facing clinicians who wish to keep up with the ever-evolving range of genetic products. Nevertheless, they insist that this knowledge of these products is essential for helping patients balance the risks and benefits of the individual tests included in the expanded carrier screening panel.

Finally, 2 contributions visually explore dimensions of decision making. In her graphic memoir, Phoebe Cohen shows that taking care of an [incarcerated patient giving birth](#) presents episodes of disagreement—and thus numerous decision points about how to respond to those episodes—among members of a paramedic and emergency response team. And Jessica S. Yang's mixed-media digital illustration of a patient-clinician encounter calls attention to the importance of how clinicians [frame information](#) in their communications with vulnerable patients.

Given the complex decisions confronting patients, health care practitioners, payers, and health policymakers—and given uncertainty about the best choice among care options—it is time to welcome the discipline of decision science to the cross-disciplinarity of bioethics. These articles, examining how patients' and clinicians' personal values color their perceptions of "objective" clinical and economic value, illustrate what we would gain by using the insights of decision science to approach ethically complex cases in health care settings.

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Raymond De Vries, PhD is the associate director of the Center for Bioethics and Social Sciences in Medicine at the University of Michigan Medical School in Ann Arbor and a visiting professor at the CAPHRI School for Public Health and Primary Care at Maastricht University in the Netherlands. A medical sociologist, he is involved in research on the regulation of science, international research ethics, the difficulties of informed consent, and bioethics and the problem of suffering, among other topics.

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