

## Special Section: The Power of Choice: Autonomy, Informed Consent, and the Right to Refuse

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### *From the Editors*

There is power in the choices we make in that our choices exercise and express our values. Choices, as compared with preferences, which may be spontaneous, are acts of deliberate volition—ways of casting our lot between alternatives. For this Special Section, “The Power of Choice: Autonomy, Informed Consent, and the Right to Refuse” we’ve chosen a frontispiece showing a balance with one pan offset by a weight in the shape of a human head. It graphically depicts that what is really in the balance in health decisions is the reflection of who we are.

In making healthcare decisions for themselves or their families, people are often faced with choices between different ways of living—or dying—and it is not always evident as to which options will most closely express their interests and fundamental values. They turn to health professionals for help and in providing the informational foundation on which they can stand when choosing the best means of achieving what matters to them.

Cultural differences should alert us to potential problems in recognizing and respecting diverse values. In their paper, “Questioning Our Principles: Anthropological Contributions to Ethical Dilemmas in Clinical Practice,” Carolyn Sargent and Carolyn Smith-Morris question the applicability of a formal principles-based approach to decision-making and argue that anthropology

and other social science perspectives would more effectively situate ethical issues in biomedical, familial, and cultural contexts and thus generate a more informed and collaborate negotiation of critical life issues.

Choosing for others, especially infants, poses special problems. As the efficacy of genetic testing technologies improve and more is learned about genetic disease, the number of screening tests performed in newborn infants is set to increase, and Ainsley Newson asks “Should Parental Refusals of Newborn Screening Be Respected?” Despite the fact that sometimes screening can give rise to beneficial outcomes, there are occasions when screening is declined by parents, leaving healthcare professionals to face an ethically and legally contentious dilemma. Taking PKU screening as an example, the author analyzes the competing principles at play in refusals of newborn screening.

The burdens of choosing should not go unrecognized or unappreciated. Continuing the issue of newborns, John Paris, Neil Graham, Michael Schreiber, and Michele Goodwin pose the question, “Has the Emphasis on Autonomy Gone Too Far? Insights from Dostoevsky on Parental Decisionmaking in the NICU.” They propose that Dostoevsky’s understanding of human nature, as expressed in *The Brothers Karamazov*, is fundamentally at odds with the emphasis in contemporary American bioethics on

rationality, autonomy, and individual self-determination. They also propose that taking into account Dostoevsky's insights in this regard might prove of benefit especially in the physician's approach to parents of infants. Specifically, a parental decision to terminate treatment on a child cannot be equated with a health professional's rational calculus of balancing burdens and benefits or a logical conclusion of legal precedents. Because of the angst, ambiguity, and doubt involved, these dilemmas for parents cannot be viewed as an opportunity to exercise personal values and individual choice. Such situations call for a reconsideration of our approach to termination of treatment, one in which physicians emphasize that further aggressive measures are not warranted and that the goal has shifted to providing what Paul Ramsey called "comfort and company."

José Miola, in "The Need for Informed Consent: Lessons from the Ancient Greeks," responds to what he sees as a dangerous trend that proposes informed consent should not be necessary in all cases. He states that this position is not only undesirable but untenable and warns that any attempt to limit the requirement for informed consent should be strongly resisted. Suggesting we have much to learn about the importance of informed consent from the ancient Greeks, he sets about examining what

constitutes a harm and how the dignity of patients can be protected or lost. He concludes that any approach that abandons the principle of informed consent by redirecting the physician's allegiance away from the individual and toward the benefit of a collective ceases to respect that person, undermining the ethical touchstone of medical research.

Technological possibilities push the boundaries of more familiar dilemmas of choice. Carson Strong's essay, "Gamete Retrieval after Death or Irreversible Unconsciousness: What Counts as Informed Consent?" attempts to identify circumstances in which it is ethically permissible to retrieve gametes after death or irreversible unconsciousness. The paper focuses on cases in which the intent is procreative, and although the discussion deals with sperm retrieval, the author notes that the views he defends will apply to future cases involving oocytes or ovary retrieval as well.

It is hard to overemphasize the complexities involved in seeking to respect the freedom of patients to choose for themselves when it comes to health-care and, at the same time, recognize there are limits to that freedom. What is critical to remember is that when health matters are being weighed, it's *their* interests that hang in the balance and the rest of us should keep our thumbs off the scale.



Bronze balance with one pan and a weight shaped like a bust (Imperial Period, 1st–3rd CE), Musee des Antiquities Nationales, Saint-Germain-en-Laye, France. Photo credit: Erich Lessing/Art Resources, New York. Reproduced by permission.