Bioethics: Key Concepts and Research

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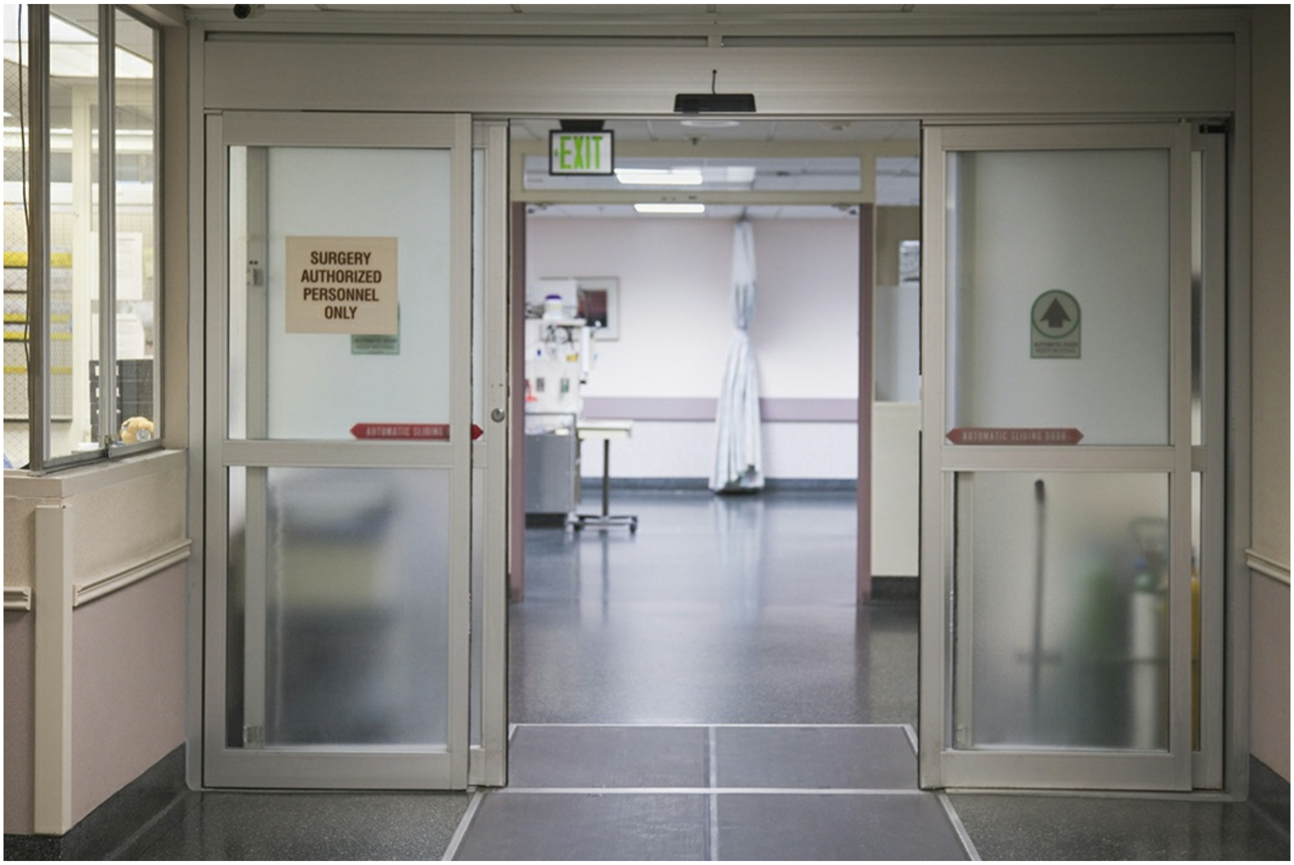

Bioethics is a field of inquiry centered around the uses and moral implications of medicine and the bio-sciences. Scholars and researchers come from a very wide variety of professional and disciplinary backgrounds, like medicine, nursing, law, theology, philosophy, history, and other humanities and science disciplines. They employ a range of methodological and theoretical approaches to investigate questions of policy, practice, and meaning in an increasingly technical and medicalized world.

The American biochemist Van Rensselaer Potter is widely credited with introducing the term “bioethics” into the academy in his 1971 book *Bioethics: Bridge to the Future*. The term “bioethics” was not immediately embraced, though. In fact, neither of the world’s first bioethics research institutes—The Hastings Center (where we work), which was founded in 1969, or The Kennedy Institute of Ethics, founded in 1971—initially used “bioethics” in their names or to describe their work.

The early U.S. national commissions that focused on bioethics issues also shied away from the term. Since the mid to late-1990s, however, the word has become more widely accepted. Bioethics centers can now be found in a growing number of medical schools around the world, many countries have national bioethics commissions, and bioethics courses and degrees are offered in colleges and universities.

This list of essential readings in bioethics is designed to introduce readers to the breadth of writing in the field. Some of the pieces address questions foundational to the field—about reproductive rights, research with human subjects, end -of-life care, and organ donation. Others, such as those about gene editing ancestry testing, consider long standing ethical issues raised by emerging technologies. This list is of course partial and, like the field thus far, has an Anglo-American focus. A relatively young field, bioethics is still expanding its methods and scope.

Theoretical Perspectives

- Albert R. Jonsen et al., "Special Supplement: The Birth of Bioethics." *The Hastings Center Report* (1993).

In 1992, 42 bioethicists who had been active in the field since its inception came together to take stock of what bioethics had accomplished and how it had changed. Warren Reich, a founder of the Kennedy Institute of Ethics, offers a history of the term "bioethics" and the ambivalence that some prominent bioethicists feel about that word.

- James F. Childress and John C. Fletcher, 'Respect for Autonomy." *The Hastings Center Report* (1994).

Following revelations of unethical research in the Tuskegee Syphilis Study, a US national commission released a major report, known as *The Belmont Report*, summarizing the ethical principles for research involving human subjects. These principles—respect for autonomy, beneficence, and justice—were further developed in Tom L. Beauchamp and James F. Childress' book *Principles of Biomedical Ethics*, which is still taught in nearly every introductory bioethics course. In this article, Childress and John Fletcher describe the ascension of one principle—respect for autonomy—which they argue deserves a central place in ethical deliberations but must also be tempered by other moral concerns, including care and compassion.

- Ann Bradshaw, "Yes! There Is an Ethics of Care: An Answer for Peter Allmark." *Journal of Medical Ethics* (1996).

Writing as a teacher of nurses, Ann Bradshaw offers historical and modern interpretations of the idea of "caring" that form the basis for an ethic of care. She understands care to not be a value-neutral project, but rather as drawing normatively and descriptively from feminist and religious thought, guided not only by altruism but also by a pursuit of justice.

- Carl E. Schneider, "Bioethics in the Language of the Law." *The Hastings Center Report* (1994).

Schneider argues that moral reasoning within bioethics is often undertaken using legal concepts and language. Law can offer bioethics a rich language and a tool for action, but the social regulatory function of the legal system can be also prove inadequate for fully evaluating moral obligations.

- Munyaradzi Felix Murove. “African Bioethics: An Explanatory Discourse.” *Journal for the Study of Religion* (2005).

All bioethics is, as this paper notes, culturally conditioned. Western frameworks, which shape much of the scholarship represented in this list, cannot fully describe the contours of ethical reasoning in other cultures. This paper develops an African bioethics that begins with an appreciation of the role of traditional healthcare practices.

Selected Issues in Bioethics

End-of-Life Care

Daniel Callahan, “Death: “The Distinguished Thing”.” *The Hastings Center Report*, 2005.

- Death, and the myriad ways that dignity may or may not attend it, is one of the enduring themes of bioethics. Daniel Callahan, widely regarded as an originator of the field (and one of the founders of The Hastings Center) asks how we ought to think about the relationship between caring for the dying and the nature of death itself by examining the historical ways that those two concepts have been both conflated and separated.

Defining Death

Seema K Shah, Robert D Truog, and Franklin G Miller, “Death and Legal Fictions.” *Journal of Medical Ethics* (2011).

- Advances in life-sustaining treatment and in transplantation medicine have challenged understandings of the definition of death. The introduction in the 1980s of the concept of “brain death” sought to resolve both legal and moral dilemmas by providing additional scientific criteria for determination of death. Shah, Truog, and Miller argue that these changes have created a legal fiction, whereby organs for transplantation are being procured from still-living donors.

Research on Human Subjects

Charles W. Lidz, and Paul S. Appelbaum. “The Therapeutic Misconception: Problems and Solutions.” *Medical Care* (2002).

- Clinical research forms the backbone of medical progress, but history is fraught with ethical lapses and oversights that have imperiled human research subjects. One enduring problem is known as the “therapeutic misconception,” in which patients confuse the goals of research and treatment. While medical care is focused on helping a specific patient and is tailored to their needs, research is designed primarily to produce generalizable knowledge, not primarily to help the research subject. This misconception can prevent research subjects from fully appreciating the risks of research or the possibility that they might receive an unproven treatment or even a placebo.

Nancy E. Kass, Ruth R. Faden, Steven N. Goodman, Peter Pronovost, Sean Tunis, And Tom L. Beauchamp, "The Research-Treatment Distinction: A Problematic Approach for Determining Which Activities Should Have Ethical Oversight." *The Hastings Center Report* (2013).

- Since the 1970s, scholars have argued for distinguishing research from treatment, so as to avoid confusion like that described by Lidz and Appelbaum above. The authors of this paper note, however, that distinguishing research from treatment too definitively occludes the fact that for some patients, participation in research is part of their treatment, especially when their illnesses are rare or lack well-established courses of therapy. Thus, adequately protecting patients requires rethinking the research-treatment distinction.

Medical Error

Nancy Berlinger, "Avoiding Cheap Grace: Medical Harm, Patient Safety, and the Culture(s) of Forgiveness." *The Hastings Center Report* (2003).

- Medical errors account for a remarkable number of injuries and deaths. After medical error, patients and families can feel pressure to forgive healthcare providers. Nancy Berlinger argues though that automatic forgiveness amounts to "cheap grace" –it is individual, rather than systemic; a forgiveness achieved without the participation of the injured party; aimed at ending uncomfortable or sad encounters rather than preventing further harm from happening. It asks those who have been harmed to merely 'do the right thing' – to forgive, rather than demand change or recompense from those who have erred.

Reproductive Technology

Eva Feder Kittay, "Planning a Trip to Italy, Arriving in Holland: The Delusion of Choice in Planning a Family." *International Journal of Feminist Approaches to Bioethics* (2010).

- New technologies, particularly reproductive ones, purport to offer an ever-expanding range of choices: about if and when to procreate, about who will be genetically related to new offspring, about what kind of health a baby will be born into. Choice is highly valued in many Western cultures, and is strongly defended in much bioethics scholarship. But, Eva Kittay cautions, "choice is not always what it seems and too often it promises what it cannot deliver."

John A. Robertson, "Procreative Liberty and the Control of Conception, Pregnancy, and Childbirth." *Virginia Law Review* (1983).

- John Robertson argues for an expansion of reproductive freedom beyond the right to access contraception and abortion to include the right to access new reproductive technologies. This additional freedom, which he calls "procreative liberty," amounts to an additional negative right –the right to be free from government interference in the use of technology to aid *reproduction*.

Judith Jarvis Thomson. "A Defense of Abortion." *Philosophy & Public Affairs* (1971).

- Debates about abortion infuse many contemporary issues in bioethics. The pro-life argument against abortion is typically premised on the notion that a fetus is a person from the moment of conception. Judith Jarvis Thomson offers a defense of abortion that, contrary to the way the argument usually goes, accepts that premise, using an extended allegory to locate the moral permissibility of abortion instead in the right of the pregnant woman to decide what should happen in and to her body.

Gene Editing

Brendan P. Foht, "Gene Editing: New Technology, Old Moral Questions." *The New Atlantis* (2016).

- Gene editing technologies such as CRISPR-Cas9 are only the latest in the evolution of increasingly precise ways for humans to modify genes. These technologies raise longstanding moral and ethical questions about setting limits, heritable and non-heritable genetic changes, consent, and gratitude. This piece concludes with a pro-life perspective on therapeutic gene editing in humans.

Organ Donation

Thomas H. Murray, "Gifts of the Body and the Needs of Strangers." *The Hastings Center Report* (1987).

- Blood and organ donation raise some of the classic distribution problems in medical ethics: what would a fair matching system look like? Are personal behaviors, or factors such as immigration status, disqualifying? Should donors be compensated for their gifts? In this piece, Thomas Murray considers the context of the "gift" of bodily donations and argues for resisting commercialization.

Disability Rights

Tom Shakespeare, "Debating Disability." *Journal of Medical Ethics* (2008).

- Tom Shakespeare is well known for complicating the distinction between the "medical" and "social" models of disability. The former suggests that disabling traits produce disability, while the latter sees disability as caused by a world unwilling to accommodate people living with different sorts of bodies. Responding to criticism of his book, Disability Rights and Wrongs, Shakespeare details how the field of disability studies can overcome "crude dualism, the better to understand the complex dialectic of disability."

Enhancing Human Traits

Erik Parens, "Authenticity and Ambivalence: Toward Understanding the Enhancement Debate." *The Hastings Center Report* (2005).

- Many scholars and policymakers have attempted to draw lines between permissible and impermissible uses of biotechnologies by distinguishing between uses that amount to treatments and those that result in enhancement of human traits. Erik Parens reflects on how different notions of authenticity – whether we should primarily be grateful for what we've got or creative about improving ourselves – complicate the treatment-enhancement debates.

Genetics, Genealogy, and Race

Alondra Nelson, "Bio Science: Genetic Genealogy Testing and the Pursuit of African Ancestry." *Social Studies of Science* (2008).

- Do genetic ancestry tests 'geneticize' racial and ethnic identities? Drawing on ethnographic research conducted with American people of African descent, sociologist Alondra Nelson examines the use of genetics by African Americans who have been cut off from their ancestry due to slavery.

LGBTQ People and Medicine

Jamie Lindemann Nelson, "Medicine and Making Sense of Queer Lives." *Hastings Center Report*, (2014).

- Queer people have had a long and uneasy relationship with the medical establishment, which has by turns offered much-needed care and prejudicial or pathologizing treatment. Noting that medicine extracts a good deal of cultural legitimacy from its "touch of the transcendental," Jamie Nelson explores the ways that receiving a diagnosis associated with queer identity, such as gender dysphoria, can impact self-understanding.

Care

Solomon R. Benatar, Abdallah S. Daar, and Peter A. Singer, "Global Health Ethics: The Rationale for Mutual Caring." *International Affairs* (2003).

- In our world of staggering and increasing global inequality, bioethics offers insight into how global health needs to be improved by focusing on respect for the dignity of all people and promoting a conception of human flourishing that goes beyond individualistic economic concerns.

Zahra Meghani and Lisa Eckenwiler, "Care for the Caregivers? Transnational Justice and Undocumented Non-Citizen Care Workers." *International Journal of Feminist Approaches to Bioethics* (2009).

- Significant numbers of undocumented workers, often having migrated from the Global South to wealthier nations, are employed as domestic care workers for aging populations. This paper offers insight into some of the injustices these workers confront.

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