

REUNITING HUMAN RIGHTS AND BIOETHICS TO ADDRESS MEDICAL FUTILITY AND END-OF-LIFE TREATMENT

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International human rights and bioethics share a common historical beginning and a common ideological basis. Both human rights and bioethics trace their ancestry to the Nuremberg trials of Nazi war criminals following World War II. And both bioethics and human rights stem from the same fundamental axiom: all human beings are born free and equal and possess “dignity and worth.”

But, as George Annas and others have recently observed, human rights and bioethics have since grown apart. For decades, each has developed independently from the other. In this paper, I draw human rights and bioethics back together. I do that through the lens of one of the most important issues in bioethics and an increasingly pressing issue in human rights: medical futility. Can governments allow (or even encourage) health care providers to withdraw life-sustaining medical treatment (LSMT) from patients who want it continued? Can they deny these patients a so-called “right to life”?

Bioethics and human rights should be reunited and harmonized to more effectively address medical futility and other major health issues. Bioethics has, for too long, focused on a too-narrow range of high-technology issues affecting few people. Human rights’ focus on globalization and public health can be used to beneficially reorient bioethics to address broader issues. As international human rights law has expanded over the past few years, governments should review domestic health law against these standards. And human rights law can similarly benefit. Since it has limited experience with medical issues, human rights law can gain a rich vocabulary and conceptual toolkit from bioethics.

Rights to health are vaguely addressed in Article 25 of the 1948 Universal Declaration of Human Rights and the 1966 International Convention on Economic, Social and Cultural Rights. But while end-of-life issues have been thoroughly examined in the bioethics world, they have just recently started coming onto the human rights agenda. For example, only among its latest initiatives has the World Health Organization Department of Ethics, Trade, Human Rights, and Health Law begun addressing equity in access and barriers to appropriate pain control and end-of-life care.

In an attempt to rationally allocate scarce health care resources, many European countries, the United States, and Australia routinely unilaterally withhold or withdraw life-sustaining medical treatment from patients against the objections of family members and surrogate decision makers. Domestic law in these countries clothes health care providers with the color of state law to refuse requested LSMT, protecting providers from civil, criminal, and disciplinary sanctions that might otherwise apply.

Aware of this background, Mr. Leslie Burke naturally feared that his UK providers might, contrary to his preferences and instructions, withdraw his LSMT when his progressively degenerative neurological disease reached a certain dismal point. Unable to secure a guarantee from domestic courts, Burke brought his case before the European Court on Human Rights. In late 2006, that court upheld UK law, finding that Burke was not subject to any “real and imminent threat.”

The ECHR decision seems correct in that the UK Guidance specifically prohibits treating a disabled patient’s life as less worthwhile. But on closer inspection, it becomes obvious that, as Burke himself recognized, this clause actually provides little protection. It is trumped by another provision of the Guidance that permits providers to unilaterally withdraw treatment when they determine that is in the patient’s best interests. As “best interests” is not and probably cannot be defined, the Guidance preserves a central role for provider discretion. In the end, providers may very well judge Burke’s quality of life through negative stereotypical assumptions.

Some might take the *Burke* decision as a signal that human rights law has a limited role to play in growing debate over medical futility. But such an assessment is too hasty. Among his other claims under the European Convention, Burke sued under Article 14 which prohibits disability discrimination. While the ECHR decided that states enjoy a “margin of appreciation in assessing whether and to what extent differences in otherwise similar situations justify a different treatment,” it did not examine the extent of those margins. Nor did the court consider obligations under the new, broader health rights for the disabled guaranteed under Article 25 of the new Convention on the Rights of Persons with Disabilities.

States’ attempts to rationally allocate increasingly expensive end-of-life and other health care resources will inevitably implicate the *new* Disability Convention just U.S. rationing efforts have impinged the Americans with Disabilities Act. Perhaps health care providers should be able to unilaterally refuse LSMT in some circumstances. But the ECHR was wrong to categorically defer to clinical judgment. That judgment must be constrained by either substantive standards or procedural requirements.