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# The ethics of ICDs: History and future directions

**I**N 1975, JULIA AND JOSEPH QUINLAN approached the administrator of St. Clare's Hospital in Denville, New Jersey, and requested that the mechanical ventilator on which their adopted daughter, Karen, was dependent be turned off. Karen Ann Quinlan, 21 years old, was in a permanent vegetative state after a severe anoxic event, and her parents had been informed by the hospital's medical staff that she would never regain consciousness.

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To the Quinlans' request to withdraw the ventilator, the hospital administrator replied, "You have to understand our position, Mrs. Quinlan. In this hospital we don't kill people."<sup>1</sup>

The administrator's response was consistent with prevailing ethical and legal perspectives, analyses, and directives at that time related to discontinuation of life-sustaining treatment. In the mid-1970s, the American Medical Association's position was that it was permissible to not put a patient on a ventilator (ie, a physician could withhold a life-sustaining treatment), but once a patient was on a ventilator, it was not permissible to take the patient off if the intention was to allow death to occur.<sup>1</sup> However, the New Jersey Supreme Court ultimately found this distinction between withholding and withdrawing unconvincing, and ruled unanimously that Karen Quinlan's ventilator could be turned off.<sup>2</sup>

\*Dr. Kodish has disclosed consulting for Biogen.

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## ■ THE HASTINGS CENTER REPORT: STOPPING IS THE SAME AS NOT STARTING

During the subsequent decade, further ethical analysis and additional legal cases resulted in new insights and more nuanced thinking about forgoing life-sustaining treatment.

These developments were summarized in a 1987 report by the Hastings Center,<sup>3</sup> a leading bioethics research and policy institute. The report provided normative guidance for the termination of life-sustaining treatment and for the care of dying patients. It acknowledged that deciding not to start a life-sustaining treatment can emotionally and psychologically affect healthcare professionals differently than deciding to stop such a treatment. However, the report also asserted that there is no morally important difference between withholding and withdrawing such treatments.

Reflecting a partnership model between patients and professionals for healthcare decision-making, and affirming the ethical significance of both a burden-benefit analysis and patient autonomy, the report stated that when a patient or surrogate in collaboration with a responsible healthcare professional decides that a treatment under way and the life it supports have become more burdensome than beneficial to the patient, that is sufficient reason to stop. There is no ethical requirement that treatment, once initiated, must continue against the patient's wishes or when the surrogate determines that it is more burdensome than beneficial from the patient's perspective. In fact, imposing treatment in such circumstances violates the patient's right to self-determination.<sup>3</sup>

The report noted further that, because of frequent uncertainty about the efficacy of pro-

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posed treatments, it is preferable to initiate time-limited trials of treatments and then later stop them if they prove ineffective or become overly burdensome from a patient's perspective.

**■ ICDs ARE LIKE OTHER LIFE-SUSTAINING THERAPIES**

In this issue of *Cleveland Clinic Journal of Medicine*, Baibars et al<sup>4</sup> address the question of how implantable cardioverter-defibrillators (ICDs) should be managed at the end of life. The historical events and developments recounted above regarding withdrawing life-sustaining technologies are an appropriate context for ethically assessing the management of ICDs for dying patients.

Obviously, ICDs are not ventilators, but like ventilators, they are life-sustaining therapy, as are dialysis machines, blood transfusions, medically supplied nutrition and hydration, ventricular assist devices, and other implantable electronic cardiac devices such as pacemakers. Each of these life-sustaining therapies, depending on a patient's clinical condition, underlying illness, and comorbidities, can become a death-prolonging technology.

An ethical framework and analysis about whether to continue any life-sustaining therapy, including an ICD, must include an assessment of the benefit-to-burden ratio from the patient's perspective. Does the therapy enhance or maintain a quality of life acceptable to the patient? Or has it become overly burdensome and does it maintain a quality of life the patient finds (or would find) unacceptable? If the latter is true, and especially in the context of an underlying terminal condition, then shifting the goals of care to focus on comfort is always appropriate and ethically justified. Treatments—including ICDs—that

do not contribute to patient comfort should be withdrawn.

**■ TOWARD COMPETENCY IN ETHICAL MANAGEMENT**

Baibars et al note that much more needs to be done to enhance competencies, increase proficiencies, and mitigate the moral distress of healthcare professionals caring for dying patients with ICDs and other devices. To help clinicians achieve a personal and professional "comfort zone" for ethically managing patients with ICDs, we recommend that healthcare institutions, medical schools, and nursing schools take the following steps:

**Develop comprehensive end-of-life policies, procedures, and protocols** that incorporate specific guidance for managing cardiac devices and that have been endorsed by a hospital ethics committee. Such guidance can be informative and educational and can ensure that decisions and resulting actions (including stopping cardiac devices) are ethically supportable.

**Provide more palliative care training** in medical and nursing schools, residency programs, and continuing education activities so that front-line clinicians can deliver "basic," "primary" palliative care not requiring specialty palliative medicine. This training, called for in the Institute of Medicine's 2014 report, *Dying in America*,<sup>5</sup> should include explicit ethics discussions about managing cardiac devices at the end of life.

**Provide ongoing training in communication skills** needed for all patient-professional encounters. Effectively engaging patients in goals-of-care discussions, especially patients with life-limiting illnesses such as heart failure, cannot be achieved without these skills. ■

**ICDs are not ventilators, but like ventilators, they are a life-sustaining therapy**

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