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# Forty Years of Work on End-of-Life Care — From Patients' Rights to Systemic Reform

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More than 2.5 million people die in the United States each year, most of them from progressive health conditions. Facing death is a profound challenge for patients, their relatives and friends, their caregivers, and health care institutions. Nearly 40 years of intensive work to improve care at the end of life has shown that aligning care with patients' needs and preferences in order to ease the dying process is surprisingly difficult — although there has been some incremental progress. Early optimism that the establishment of patients' legal and ethical rights to make decisions about their own care would lead to more appropriate end-of-life treatment faded in the face of sobering data showing that declaring these rights was not enough to alter treatment patterns and that systemic issues loomed large. This history has demonstrated the need to attack the problem at all levels, from individual rights, to family and caregiving relationships, to institutional and health systems reform.

## SECURING RIGHTS (1976–1994)

In 1976, New Jersey's highest court decided the groundbreaking case of Karen Ann Quinlan, whose father sought permission to discontinue mechanical ventilation when she was in a persistent vegetative state. The court found that although "the doctors say that removing Karen from the respirator will conflict with their professional judgment," Karen had a "right of choice" that could be exercised by her father as surrogate decision maker. Many cases followed in which courts recognized the constitutional and common-law rights of patients to refuse life-sustaining treatment and the authority of surrogate decision makers for patients who lacked decision-making capacity.[1,2] Courts also began to address decisions to forgo life-sustaining treatment in newborns.

In those early days of efforts to curb overtreatment at the end of life and to improve the dying process, establishing the ethical and legal right to refuse life-sustaining treatment was a priority. More challenging was establishing surrogates' authority to refuse care on behalf of incompetent patients, articulating standards for surrogate decision making, and reaching general agreement on limits to surrogate authority. Cases involving patients who were never competent to make decisions about care and involving the cessation of artificial nutrition and hydration were notoriously difficult, as was decision making for incompetent patients without surrogates.

As more cases reached the courts and public attention intensified, experts began analyzing the issues and generating recommendations. In 1983, the President's Commission on Bioethics issued a report advocating the right of patients to decide about their health care, while addressing moral and legal limits.[3] In 1987, the Hastings Center published comprehensive ethics guidelines regarding end-of-life care.[4] These guidelines focused on recognizing a patient's right to refuse unwanted life-sustaining treatment and on articulating a three-tier standard for surrogate decision making that prioritized following the patient's wishes when known but otherwise relied on the surrogate to decide on the basis of the patient's values or, absent information on those values, in accordance with the patient's best interests. The guidelines also recommended processes for designating surrogates for patients with no family or friends to serve in that role and proposed using time-limited trials of treatment to inform decisions. The document addressed the need to improve pain relief, recommended rejecting requests for treatment that could not accomplish its physiological objective, differentiated treatment refusal from physician-assisted suicide and euthanasia, and considered obstacles to individual rights.

In the 1990 case of Nancy Cruzan — a Missouri woman in a persistent vegetative state, whose parents wanted artificial nutrition and hydration stopped — the U.S. Supreme Court finally recognized a patient's right to refuse life-sustaining treatment, although the Court noted that states could restrict the authority of surrogates to make decisions for patients lacking decisional capacity. In her concurrence, Justice Sandra Day O'Connor cited the Hastings Center guidelines and suggested that a surrogate's authority would be better protected if the surrogate were appointed by the patient in an advance directive. The *Cruzan* opinion and the passage of the federal Patient Self-Determination Act in 1990 spurred efforts to promote advance directives.[5]

## FACING CLINICAL REALITIES (1995–2009)

The establishment of patients' rights and the option to use advance directives proved necessary but far from sufficient to align treatment with patients' preferences. In 1995, investigators in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) — a multimillion-dollar effort by the Robert Wood Johnson Foundation to improve end-of-life care — began publishing findings showing that documented treatment preferences, even when championed by a nurse advocate, failed to change clinical practice.[6] As one commentator wrote, "Improving the quality of care generally requires changes in the organization and culture of the hospital and the active support of hospital leaders."[7]

Further studies attempted to identify potential routes to progress, including improved access to palliative care. Although Congress had added a hospice benefit to the Medicare program in 1982 — to provide palliative and comfort care for patients nearing the end of their lives — barriers to hospice access remained, including the requirement that death be expected within 6 months and that curative treatment efforts be abandoned. Throughout the 1990s, professional societies including the American College of Physicians,[8] American Medical Association,[9] and American Nurses Association[10] issued papers and policies aimed at identifying obstacles to good care at the end of life and improving clinical practice. Nonprofit organizations mounted efforts such as the Project on Death in America, which funded research on impediments to compassionate end-of-life care.[11] In 1997, the Institute of Medicine (IOM) published *Approaching Death: Improving Care at the End of Life,* which analyzed research, educational, clinical, and policy challenges and emphasized the need for tools to measure quality and outcomes of end-of-life care.[12]

In the face of difficulty in improving end-of-life care and ensuring access to good pain relief and other palliative measures, the movement to legalize physician aid to terminally ill patients who wished to end their lives gathered steam. In a 1994 ballot measure, reconfirmed in 1997, Oregon became the first state to vote for legalization of physician-assisted suicide and enacted the Death with Dignity Act. The statute survived federal litigation over the authority of the U.S. attorney general to limit the practice (*Gonzales v. Oregon*, 2006). In 1997, the Supreme Court rejected arguments that state bans on physician-assisted suicide violated patients' constitutional rights, and the Court recognized states' authority to prohibit or legalize the practice within their borders (*Vacco v. Quill*, 1997; *Washington v. Glucksberg*, 1997). Washington State followed Oregon and has now been joined by Vermont; the Montana Supreme Court and a lower court in New Mexico have also issued rulings allowing the practice.

As work progressed to change the clinical realities of end-of-life care, focus turned to the barriers facing subpopulations, such as terminally ill children. In the 2002 publication *When Children Die,* the IOM described problems in pediatric care, including that of parents being forced to choose between life-prolonging treatment and hospice care for their children.[13] The IOM then detailed research gaps in *Describing Death in America*, which urged the use of Medicare records as an important data set.[14]

Meanwhile, there was growing controversy over decisions to end life-sustaining treatment in cases of long-term disability. People with disabilities raised concerns that such decisions were sometimes based on inappropriate assumptions about quality of life. Neurologic disabilities raised additional concerns, as research distinguished the minimally conscious state, in which patients retain some potential for cognitive recovery, from the permanent vegetative state (*Wendland v. Wendland*, 2001).[15] In 2005, the case of Terri Schiavo — a Florida woman whose parents rejected the medical conclusion that she was in a vegetative state with no potential for recovery and objected to her husband's decision as surrogate to terminate tube feeding — triggered national controversy, revealing that decades of progress on surrogate decision making could not avert conflict over the termination of artificial nutrition and hydration in an incompetent patient who was in a permanent vegetative state when family members disagreed with one another.

The politics of end-of-life care became even more divisive in 2009, when opponents of the Affordable Care Act (ACA) spread the false assertion that a proposed ACA provision meant to authorize the reimbursement of physicians for voluntary counseling about end-of-life planning would create "death panels." The provision was removed under political pressure, and a similar Medicare-reform proposal was subsequently withdrawn. Thus, a period that began with a sobering realization that the validation of rights was not enough to change clinical realities was marked by important research and innovation — yet growing controversy.

## REFORMING END-OF-LIFE CARE SYSTEMS (2010–)

In 2010, Congress passed the ACA, the largest attempt at reform of health care finance and systems in decades. With advances in systemic reform, efforts to improve end-of-life care have become increasingly focused on health care institutions, systems, and finance. In 2014, the IOM released a new report, *Dying in America*.[16] The report and related commentary analyzed research showing that current financial incentives do not support ready access to the care patients want and need near the end of life.[17] The integration of palliative care with treatment remains incomplete, despite ample evidence of benefit.[18] Although hospice use has increased, Medicare data reveal patterns of treatment escalation before hospice enrollment.[19] Medicare data also reveal regional variation in transfers from nursing homes to hospitals, which are associated with medically inappropriate feeding-tube insertion.[20] The aging of the baby boomers will mean a sharp increase in the number of U.S. patients with Alzheimer's disease, which will place new pressures on families and care systems.[21] As ACA implementation drives system changes, renewed efforts to improve end-of-life care at the system level are emerging, including funding for concurrent hospice and curative care efforts for seriously ill children and renewed efforts to fund conversations between physicians and patients for end-of-life care planning.

As policy initiatives have become more system-focused and encompassing, so too have ethics initiatives. In 2013, the Hastings Center produced a revised, expanded edition of the 1987 guidelines, addressing not only individual rights and the clinical realities of decision making but also institutional and systemic issues such as transfers between institutions, end-of-life care in the context of large and complex health care organizations, the role of cost in decisions, and health care access for uninsured people.[22] The revised guidelines reflect the reality that patients are rarely isolated rights-bearers; family members are usually involved in end-of-life decisions and care. Both patients and family members further depend on clinicians to anchor a process of setting goals and developing treatment plans. Although respect for autonomy remains essential to end-of-life decision making, appropriately including the patient's chosen constellation of relatives and friends and helping all of them navigate care systems have emerged as integral to ethical practice. Persons living with disabilities have also provided crucial perspectives on the management of chronic conditions and treatment decision making over time.

The new guidelines and the recent IOM report similarly frame the care of dying people as "patient-centered, family-oriented,"[16] and dependent on sound systems of care and finance. The IOM report calls for a "major reorientation and restructuring of Medicare, Medicaid and other health care delivery programs" to ensure quality care that meets the needs of dying patients and their families.[16] Both documents recommend core elements of high-quality care near the end of life, including palliative care, and emphasize the need for better clinician education.

## LESSONS FROM 40 YEARS OF WORK

Establishing individuals' rights to forgo life-sustaining treatments and the authority of surrogate decision makers were signal achievements in the first phase of work on improving end-of-life care. Uncovering clinical barriers to progress in the second phase was essential. But we now know that all these efforts must be nested in systemic reform. Important strategies have emerged for continued progress on all levels.

First, clinicians can be trained to inform and support decision makers. The prospect of death inspires powerful emotions in everyone involved, creating a potential for conflict. Communication training for all professionals who care for patients facing critical treatment decisions can help support informed decision making under stressful conditions. Essential skills have been identified and tools developed for use by care teams.[23-26] Role models and access to new tools (including electronic decision-making aids and "choice architecture" techniques to structure options) can help professionals explain the options and support decision makers.[27,28] Advance care planning and the POLST (Physician Orders for Life-Sustaining Treatment) Paradigm — developed in Oregon in an effort to ensure that patients' preferences were honored in a range of care settings, including care by emergency medical services personnel — provide structured processes to help professionals and decision makers establish goals, document preferences, and create care plans.[16] Training priorities include discussing care preferences with patients with early-stage Alzheimer's disease who retain decision-making capacity and engaging in shared decision making with cognitively impaired patients and their surrogates. Pediatric specialists' experience with shared decision making in caring for the 50,000 children who die in the United States each year may offer broader lessons on effective communication with patients and families.[29]

Second, systemic improvements can be designed to assist all professions involved in caring for patients who are facing decisions about life-sustaining treatment or nearing the end of life, in all relevant clinical and residential settings. Clinicians should have access to at least generalist palliative care training[30] and be trained to collaborate across shifts, during transfers, and with family caregivers during discharge planning. Evidence-based models for safe care transitions can support better systems for end-of-life care.[31,32]

Third, productive systemic and financing reforms can be enacted. Misaligned financial incentives work against dying patients' choices, interests, and safety. Problems include referrals of dying patients to the intensive care unit or for dialysis even when such services will result in limited benefit and high burden to the patient,[19,33] the nonbeneficial use of feeding tubes in patients with end-stage Alzheimer's disease,[20] cost-shifting transfers of dying nursing home residents and hospice patients to hospitals,[34,35] and late hospice referrals for patients with cancer.[36] Abundant evidence indicates that reimbursements and organizational patterns drive these problems, and fixing them requires attention to service-utilization mandates and pressures.[37] The 2014 IOM report recommends creating financial incentives for advance care planning and shared decision making, electronic health records to support ongoing planning, and care coordination to reduce hospitalizations and emergency department visits.

End-of-life care in accountable care organizations and Medicare Advantage plans should also be rigorously evaluated. Explicit discussion of cost is essential, both in choosing care options and in addressing cost barriers to desired care. When patients lack the means to pay for needed life-sustaining treatment, professionals can advocate for them. In oncology, for example, professionals are publicly challenging ever-escalating drug prices.[38]

Facing death will never be easy, and controversial cases are inevitable. Yet too large a gulf remains between the theory and the practice of end-of-life care. More work is needed at all levels — to protect patients' rights to choose care options, to improve the quality of clinical care and clinicians' responsiveness to patients and families, and to create well-functioning health care finance and delivery systems that make high-quality care genuinely available. Federal, state, and organizational authorities can formulate explicit standards that support this progress. Health care leaders, administrators, and clinicians can also identify and confront persisting care problems within organizations and implement systems of accountability at the bedside, in the clinic, and in health care delivery and finance systems. We can apply lessons from four decades of work in order to advance toward solutions. The millions of Americans facing life-threatening conditions deserve no less.

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