LEARNING TO LEARN

Robert Wood Johnson Foundation

TIME MAGAZINE'S BRIGHT RED, YELLOW AND BLUE COVER was all about the BIG BANG and the very beginnings of life on Earth.

Tucked deep inside the December 4, 1995, issue, however, was a very different and distressing story about the tortured endings of life, in needless pain and suffering, for millions of Americans.

The article was based on the just-concluded and largest clinical investigation on dying ever conducted in America. The study was conceived, organized and funded by the Robert Wood Johnson Foundation (RWJF). It still stands as one of the largest research projects we've undertaken, and perhaps the most influential. Its dramatic findings set off a cascade of changes in how Americans and their physicians deal with dying and death.

Importantly, for our ongoing practice of philanthropy, the experience taught us lasting lessons about our own preconceptions of success and failure, what they teach us and what we do with what we learn. How we got there is one of the best stories we've ever told, one about ultimate success cloaked in immediate failure, unintended consequences, unexpected lessons, and the organization of a whole new field called "end-of-life" care.

A series of wrenching personal experiences with aging and dying family members deeply affected some of the Foundation's leaders amid the rise of national "right-to-die" and physician-assisted-suicide movements in the early 1980s.

The leaders were encountering firsthand one of the dark secrets of American health care. As *TIME* later put it: "In hospitals across the U.S., doctors ignore, or

are unaware of, the last wishes of dying patients, needlessly prolonging their pain and suffering."

Hopelessly and terminally ill patients were likely to be treated as tenaciously as if they might still be miraculously cured, despite patients' obvious agony, regardless of ruinously high costs, and contrary to the desperate wishes of families and the patients themselves.

At the Foundation, where these disturbing facts of end-of-life care were personally pertinent, we recognized this was a teachable moment. So we did what we do so well—convened a meeting of experts to consider the issues at play.

The eventual result, after 36 months of meetings, proposals and pilots, was the huge undertaking that eventually received so much national publicity. It was given a clunky name, "the study to understand prognoses and preferences for outcomes and risks of treatment," which translated into an ideal acronym: SUPPORT.

The project took six years, and cost nearly $30 million. To put it in perspective, back then the typical RWJF-funded research project cost less than $500,000 and didn't involve patients at all.

Today SUPPORT is regarded as seismic, a truly seminal work that shattered entrenched presumptions. The shock waves have yet to subside both within and outside the Foundation.

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From the outset, we understood we needed more than mere insight into the issues. So our aim was twofold: First, assemble the most comprehensive database possible, describing very sick hospitalized patients and the care of those who die. Second, apply the results by improving end-of-life care at selected hospitals.

Part one was wildly successful. Predictably, we found large gaps between what patients wanted and what they got. Often, physicians didn't even seem to know what kind of care their patients wanted. Half of the patients spent at least half of their last 72 hours in moderate to severe pain.

"There is a tremendous mismatch between the health care many seriously ill people want and what they get," said William Knaus, SUPPORT co-director. "We don't know when or where to stop."

The conclusion seemed obvious: Better communications between physicians and patients and their families would mean better care.

Part two of the study was designed to accomplish just that. This was a big deal for us, moving immediately from evidence collection to action as part of an integrated continuum of learning. The clinical intervention over the next two years was intense.

The results were shocking: We expected success and instead found what appeared to be abject failure. Part two's interventions did nothing to improve patient care or outcomes. It seemed that medical and hospital professionals didn't even pay attention to them.

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"We were stunned," said Joanne Lynn, SUPPORT's other co-director. "Astonished" was the word used by RWJF's then-President, Steve Schroeder.

What had gone so terrifically wrong? At first we couldn't figure it out. After all, isn't research supposed to be the art of the soluble?

Our post-study debrief reaffirmed our faith in SUPPORT's leadership, methodology and credibility. We certainly didn't scrimp on resources and staying power. The analysis and interventions were spot-on with the data.

We even commissioned a rapid-response follow-up to make sure that our prestigious hospital partners were, indeed, representative of how medicine is practiced and health care delivered in the United States. They were.

It became apparent the problem was not in SUPPORT's approach but in the system's rejection of scrutiny and change. Old practices were deeply entrenched and institutionally resistant to even the most benign intrusion.

SUPPORT was a blow to the conventional view of improving end-of-life care.

Physicians were not adequately prepared to accept death as part of life. Payment systems were geared to cover high-tech lifesaving efforts but not comfort-producing palliative care. Families and patients were woefully uninformed.

The blinding complexity of the issue made it easy to avoid open discussion of such a personally unsettling subject, even among supposedly sophisticated and hardened medical experts.

We proved the negative. Now the big question remained—where's the positive? Our answer: Let's learn from this. And once we know for sure what we know, let's act on it.

This wasn't the end, but just the beginning of our work in end-of-life issues.

That brings us, as they say, to the rest of the story.

We laid out a four-pronged strategy that, looking back, was high-risk and unabashedly ambitious. And it proved to be up to the task of bringing about a sea change in end-of-life care.

Here is what we set out to do:

1. To improve the knowledge and capacity of health care professionals and others to care for the dying.
2. To improve the institutional environment in health care institutions and to improve public policies and the regulatory apparatus to enable better care of the dying.
3. To engage the public and professionals in efforts to improve end-of-life care.

As we moved forward with grantmaking in the later 1990s, we were encouraged by the welcoming response to the principles of palliative care. It helped that SUPPORT's findings and our next steps were quickly accepted by professional and lay audiences.

The environment was primed for change, and our new national end-of-life programs became brand names in the field. We started the *Center for Palliative Care* at Harvard Medical School, the *Center to Advance Palliative Care* at Mount Sinai Medical Center in New York City, and the *Practical Ethics Center* at the University of Montana.

Promoting Excellence in End-of-Life Care, run by the center at the University of Montana, led to the re-engineering of palliative care in clinical settings across the country. Priorities were special populations, including children; Native Americans; the seriously mentally ill; urban African Americans; Alzheimer's and AIDS patients; and high-challenge clinical settings, such as cancer centers, nursing homes and underserved rural communities. Our public education program, with more than 900 partners, reached 20 million people through outreach surrounding a four-part PBS series with Bill Moyers called "Dying in America." Millions more watched end-of-life plot lines, generated by the RWJF Writer's Project, unfold in prime-time television dramas like "ER," "Gideon's Crossing" and "NYPD Blue."

Community-State Partnerships to Improve End-of-Life Care led to policy and clinical initiatives in 21 states.

By 2003, we'd invested nearly $150 million to improve care at the end of life. This time, success was clearly evident as systems and culture changes came online.

In 2000 through 2005, the number of hospitals with palliative-care centers grew by 96 percent, from 632 to 1,240, in part because we were able to demonstrate to hospitals that providing palliative care is cost-effective, even a profit center. The powerful Joint Commission on Accreditation of Healthcare Organizations, with RWJF funding, developed mandatory standards for assessing and treating pain. Membership in the American Academy of Hospice and Palliative Medicine increased tenfold.

The American Board of Medical Specialties formally recognized the field of palliative and hospice care as a subspecialty in 2006. Now, multiple specialty groups—anesthesiology, emergency medicine, family medicine, obstetrics and gynecology, internal medicine, pediatrics, physical medicine and rehabilitation, psychiatry and neurology, radiology, nursing, and surgery—endorse hospice and palliative medicine as a subspecialty in their fields.

Meanwhile, the Accreditation Council for Graduate Medical Education, starting in 2008, will accredit fellowship programs in hospice care and palliative medicine.

The story's not over. Our original end-of-life strategies continue to inform and alter attitudes and change systems. Everyone is affected. It is almost certain that just about each individual who reads this piece at one time or another will personally experience the effects of what we've done.

More than any effort we've undertaken, our long, hard campaign to transform end-of-life care changed forever our Foundation's capacity to convert the classic cycle of risk-failure-success into a far-reaching learning experience.

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