Case 68

Care at the End of Life

Robert Wood Johnson Foundation and Open Society Institute,
1989 and 1994

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Background. A century ago, most people died relatively quickly of sudden injury or disease. People usually died at home, with their families close at hand. Today, advances in medical technology and public health have greatly extended the average human lifespan, allowing more people to survive into old age. As a result, many people live for weeks, months, or years, with “chronic illness or serious disability.” Motivated by his own experience with the deaths of his parents, George Soros in 1994 directed his Open Society Institute to begin the Project on Death in America (PDIA). The project’s goal was to “transform the culture of dying” in the United States.

The Robert Wood Johnson Foundation’s interest in care at the end-of-life had begun in 1989, when it funded a five-year study for $28 million. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) examined the experiences, in U.S. hospitals, of dying people and their families. Published in 1995, the study’s results were unexpectedly bleak. SUPPORT showed that “most Americans die in hospitals, often alone and in pain, after days or weeks of futile treatment, with little advance planning, and at high cost to the institution and the family.” Rapid progress in medicine over the twentieth century had not only increased health care costs dramatically, but it had also encouraged medical practitioners to always focus on trying to prolong a patient’s life, even at the cost of the patient’s well-being, and often against the patient’s express wishes. A *Newsweek* article summed up the study’s findings, after SUPPORT was published in 1995, explaining: “The larger problem . . . is that American medicine lacks any concept of death as a part of life.”

Strategy. The Robert Wood Johnson Foundation sought to promote widespread adoption of palliative and end-of-life care by means of a three-part strategy:

1. **Professional Education:** changing medical and nursing school curricula and textbooks; offering workshops for practitioners; working to get palliative care added to licensure and certification exams; supporting journal articles (in, for example, the *Journal of the American Medical Association* and the *American Journal of Nursing*)
   - Example: RWJ has funded a program of the American Medical Association, called “Education for Physicians on End-of-Life Care,” which is designed to educate doctors on best-practices in caring for dying patients and their families.
   - Example: $1.83 million was given to the Stanford and Massachusetts General Hospitals to train their faculties in end-of-life care.

2. **Institutional Change:** increasing the capacity of hospitals to deliver palliative care; working to develop pain management standards for hospital accreditation agencies
   - Example: The “Promoting Excellence in End-of-Life Care” program funded twenty-two diverse projects aimed at changing institutions’ responses to death. Some of such programs were directed specifically at underserved populations (minorities, the mentally ill, etc.), whereas others attempted to demonstrate the efficacy of new techniques at a single institution.
Example: Last Acts, a coalition founded by the Foundation, which now comprises over 900 organizations (including the Department of Veteran’s Affairs, the AMA, etc.) has drafted a set of best practice standards, “The Precepts,” designed to guide hospitals and practitioners in the provision of care at the end of life.

3. Public Engagement: increasing public awareness of systemic factors determining patient/family experience with terminal illness and death; encouraging individual advocacy and the formation of community groups; using information and entertainment media to inform the public’s perception of the issues

Example: The Foundation spent $2.75 million to commission a four-part, six-hour documentary series by Bill Moyers. “On Our Own Terms” followed the stories of several people coping with impending death, and aired on PBS in September 2000.

Meanwhile, the Open Society Institute pursued a strategy of its own. PDIA collaborated frequently with the RWJF (such as by providing tech support and some content for the Bill Moyers documentary series). The primary focus of PDIA was on professional development: building human capital in order to help palliative and end-of-life care spread through hospitals and medical schools.

Example: The OSI Faculty Scholars Program spent $13.4 million to provide two years of funding to eighty-seven medical school faculty members for research and training in care at the end of life.

Outcomes. Since 1989, the Robert Wood Johnson Foundation has given over $148 million to programs on care at the end of life, while the Open Society Institute gave $45 million between 1994 and 2003. “Workshops conducted by the “Education for Physicians on End-of-Life Care” have been consistently oversubscribed, and the program’s training materials are widely circulated.” The “Promoting Excellence in End-of-Life Care” program received 678 responses to its Call for Proposal, of which twenty-two were funded. Each program is carefully evaluated (with RWJF assistance). Evaluation costs are funded by the Foundation (not out of the organization’s grant money), and, while it is too early to trace the lasting impacts of most of the programs, some have already served as effective demonstrations. For example, one program’s work with a native Alaskan tribe has been successful enough that it is being adopted by the Alaskan Native Tribal Health Consortium, and will soon be implemented across Alaska.” Another success—Last Acts’ “Precepts”—have been widely adopted and are “now quoted in medical literature as the most up-to-date and accepted summarization.” The critically acclaimed Bill Moyers broadcast, “On Our Own Terms,” was watched by over 20 million viewers, who were directed to additional information on the PBS website.” And within a year after the publication of an RWJF-funded article in the Journal of the American Medical Association, over one-third of all medical textbooks had added, or were in the process of writing, a new section on end-of-life-care.

The PDIA Final Report concludes that the Faculty Scholars program “had a major impact on the field.” One measure of its achievement is that the $13.4 million that the OSI spent on Faculty Scholars has been leveraged into a further $113 million in grants awarded by other funders to the eighty-seven Faculty Scholars “for research, education, and program development in hospice and palliative care.” Another is that the eighty-seven scholars have collectively published more than 2,000 books and journal articles.

Over 500 hospitals now have palliative care programs. Virtually every one of these has developed since the two foundations became involved.”

Impact. The RWJF was not the first institution to take an interest in care at the end of life. The best
hospices, for example, have, for some twenty-five years, demonstrated the benefits of palliative care at the end of life. Still, only about 20 percent of Americans receive hospice care. A range of outside factors has spurred the increased awareness of end-of-life care. They include the highly publicized actions of Dr. Jack Kevorkian, legislative debates in the '90s on euthanasia, the AIDS epidemic, and, perhaps, most significantly, the gradual aging of the massive baby boom generation, members of whom are increasingly grappling with their own, and their parents’, mortality.

Steven Schroeder credits the RWJF’s initial study with providing much of the stimulus, to both the Foundation and the larger medical community, saying, “SUPPORT’s methods were so meticulous and its investigators so credible that our nation’s medical leadership could not duck, deny, or dismiss its message: ‘Care at the end of life is lousy.’”

According to Judith Miller of the New York Times, “the sharp increase in research on death demonstrates the growing power of philanthropy almost to create an academic field.” Certainly, the Open Society Institute and the Robert Wood Johnson Foundation are not the only two foundations that have contributed to the surge in attention paid to care at the end of life. But they are widely credited with having led the charge. OSI recognized that its frequent collaborator, the RWJF, had done the most. In a letter in the PDIA’s final report, its Director, Kathleen Foley, writes that “[OSI] could never equal the Robert Wood Johnson Foundation’s impact on public education and community outreach.” But both foundations were at the vanguard of what is still a growing movement.

Notes

1016. Ibid.
1018. Ibid.
1019. The Project on Death in America ended as a result of George Soros’ decision to reorganize his philanthropic giving. The project’s final report emphasizes that the program was not discontinued either because it was failing or because it had fully succeeded, leaving nothing more to be done.
1021. Bronner, “The Foundation’s End-of-Life Programs.” The program has increased from 33 to 77 the percentage of elderly natives who die in their own villages. Previously, elders near death would be airlifted to far-away hospitals, where they would live out their final days far from all family and friends. Enabling tribesmen and women to receive palliative care at home has increased family satisfaction and reduced the cost, to the hospitals, of airlifting and admitting these patients.
1027. Schroeder, “Dying Patients and their Families.”