Improving Care At The End Of Life: What Does It Take?

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Do Not Resuscitate (DNR) order until the last moment (signifying minimal advance planning). Rarely did patients have an advance directive, and, if they did, it usually was not followed. Little attention was paid to family needs, and the cost of care was high—exhausting many families’ life savings.

For years before these results were found, a variety of medical experts had suggested that two critical factors would have to be addressed to improve the way hospitals provide end-of-life care: better prognostic tools and better communication among patients, families, and providers. Phase II of SUPPORT was designed to address both. The most sophisticated computerized prognostic tools available were deployed, and trained nurse facilitators worked with the families and the care team, communicating each other’s concerns, needs, and questions.

Nearly 5,000 patients were entered into a trial of these interventions. The results were that people still died in poorly controlled pain, hooked up to machines, with no DNR order until just hours before death; few patients had advance directives, and, if they did, the documents were not followed. Family needs were minimally addressed, and the cost of care remained high.

As the time approached for announcing these findings, we at the foundation worried that people might interpret them too narrowly. They might say that the results showed dysfunctions in the five medical centers studied—or in academic medical centers generally—not problems in our health care system as a whole. So we commissioned a survey of 500 Americans with a recent bereavement. Whether their family member had died in a teaching hospital or in a community hospital, people surveyed reported problems at rates almost identical to those that SUPPORT had found. Once the SUPPORT findings were published, the foundation received anecdotal reports that other hospitals had replicated SUPPORT’s methods in various ways, trying to prove to themselves that their institutions were actually doing a good job caring for the dying. However, in every case we have heard about, these hospitals’ data completely validated the SUPPORT findings.

Was this, in the RWJF’s opinion, a poor return on our research investment? We do not believe that it was. SUPPORT has been enormously motivating. Its methods were so meticulous and its investigators so credible that our nation’s medical leadership could not dismiss its meaning. Much of what has happened in recent years in this country to try to improve end-of-life care is a legacy of SUPPORT, one that continues to pay dividends through academic publication and the ongoing advocacy of SUPPORT’s principal investigators.

SUPPORT’s conclusions have been borne out in the work of numerous other clinical and health services researchers and in the results of focus groups and surveys. A poll conducted and released in mid-March 1999, just days before the start of Jack Kevorkian’s trial for a murder broadcast on the television program 60 Minutes, found that (1) only about half of Americans think that the health care system does a good or excellent job of involving dying patients and their families in major decisions about their care; (2) only about half believe that comfort and pain control are good or excellent; (3) fewer than 40 percent believe that the system does a good or excellent job of preserving patient dignity; and (4) only 15 percent believe that the system protects family savings from high health costs.

What follows is a description of some of the RWJF’s grants that respond to SUPPORT and to the concerns of the public. We hope that this grant making, as a body of work, will promote long-term improvements in care for dying persons and their families.

**RWJF Grant Making**

Research findings and sound counsel from experts in the field have helped our staff to shape a three-part grant-making strategy in the area of end-of-life care. This strategy is like the metaphorical three-legged stool of academic medicine—all three legs are needed for it to stand. The three parts of our strategy are (1) professional education; (2) institutional change; and (3) public engagement.
In addition, we have launched a national professional and public engagement campaign, called Last Acts, directed by Karen Orloff Kaplan, executive director of Partnership for Caring.\textsuperscript{10} Last Acts' honorary chair is former first lady Rosalynn Carter, who has a long-standing interest in caregiving. In three and a half years the Last Acts coalition has grown from 75 partner organizations in February 1997 to 510 in fall 2000. Its activities support all three parts of the RWJF's grant-making strategy, by adding a strong communications arm to many projects and interconnecting them. Last Acts also has involved leaders of several other foundations that are making substantial commitments in this field. (These foundations, which sponsor many noteworthy projects, also collaborate through Grantmakers Concerned with Care at the End of Life.)\textsuperscript{11}

To date, the foundation has invested $83,671,642 in grants in this area. This essay briefly describes a few of them.

\textbf{Professional education.} Improvements are needed in the education of many professions—physicians, nurses, pharmacists, social workers, mental health workers, and the clergy. Although we recognize that shortcomings exist in all of these fields, in our grant making we have started from our traditional strength—working primarily with doctors and nurses.

Medical professionals need specific knowledge and skills in many areas: pain management and symptom control, eliciting and discussing patients' and families' wishes, addressing spiritual or existential distress, nurturing the possibility of growth at the end of life, grief and bereavement, and knowing whom to call when these issues arise. Each of us would want this kind of knowledge brought to the bedside of our own loved ones. Yet there is broad consensus that our nation's professional education system falls short.\textsuperscript{12}

RWJF-funded projects address needs at many points along the educational pipeline, including the needs of physicians in practice. Initiated at the American Medical Association and now located at Northwestern University Medical School is a bellwether train-the-trainer project for practicing physicians called Education for Physicians on End-of-Life Care (EPEC).\textsuperscript{13} EPEC training sessions have been consistently oversubscribed; its materials are in great demand; and its e-mail discussion list is a lively and candid forum to examine best practices.

Reaching back along the continuum of medical training are multiple projects to improve the questions on licensing exams, support residency and faculty training, provide online curriculum modules, and influence the content of textbooks. In March 1999 Last Acts convened a meeting of textbook publishers at which reports of research on nursing and medical textbook content were presented.\textsuperscript{14} The result was an apparent commitment by publishers and editors to expanding their books' palliative care content.

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Training doctors is just part of the story; nurses actually provide most of the professional care for dying people. In nursing homes, where a growing proportion of Americans die, nurses provide almost all of the professional services.\textsuperscript{15} The RWJF is therefore trying to replicate the success of EPEC with a high-quality palliative care training program for nurse faculty. We also have a project that encourages practicing nurses to consider pain as the fifth vital sign.

\textbf{Institutional change.} We contend that even the most highly skilled and best-intentioned professionals cannot be sent into dysfunctional or inhospitable practice environments and expected to perform to the best of their ability. In our interpretation, institutional change encompasses many features, such as having standard procedures in hospitals and nursing homes that make it easier to do what is right for the patient, not what is
convenient for the staff, having in-house legal counsel who know the law regarding refusal or withdrawal of treatment and can give sound advice, for example, about stopping a ventilator or withdrawing a feeding tube, and repairing our health care financing system so that it adequately covers counseling and is not so fragmented.

At present, various institution-based programs for end-of-life care—hospital-based palliative care, hospice, nursing homes, and home care—are not well coordinated from either a care management or a financing perspective. Institutional change will require finding and stimulating innovative programs in all of these settings, so that people can count on getting good end-of-life care, wherever they are.

The RWJF has funded several programs and projects expressly designed to improve the institutional environment. The Promoting Excellence in End-of-Life Care program, headed by Ira Byock, funded innovative projects in twenty-two institutions across the country. These projects are now under way, and results will become available over the next few years. They deal with different patient groups and operate in different care settings, but the overarching concept is to promote excellence.

A potentially far-reaching institutional change occurred in January 2000, when the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) promulgated new pain management standards. These standards were developed with the assistance of an RWJF grant and are not without controversy. In the highly regulated health care industry, some facility administrators simply oppose having more standards, even though they probably agree that managing pain is a good idea. This makes trying to influence the practice environment through standards development a potentially contentious path.

If regulation is problematic, the "carrot" approach also can be tried. To that end, the RWJF has funded the American Hospital Association's new "Circle of Life" award. Starting in 2000, $25,000 cash awards will be made to up to three institutions annually that demonstrate innovative end-of-life care programs. The goal of the program is not merely to distribute these modest awards, but to use the competition and the subsequent dissemination of information on the winning entries to inspire change in other hospitals, hospices, and nursing homes.

Another approach is to lead by example. Last Acts supported development of Innovations in End-of-Life Care, an international, peer-reviewed online journal and discussion forum. Its interesting and provocative issues are produced under the direction of Mildred Z. Solomon, of Education Development Center, and its content now appears in the Journal of Palliative Medicine and an annual yearbook.

Finally, in 2000 we launched an exciting new program at Mount Sinai School of Medicine in New York City, directed by Christine Cassel and Diane Meier. Called the Center to Advance Palliative Care in Hospitals and Health Systems (CAPC), the program will address the needs—and the demonstrated interest—that hospitals and health systems have in creating high-quality palliative care services. The program will convene, network, track the activities of, and provide technical assistance to hospitals and health systems around the country. The goal is to ensure that palliative care becomes standard practice in every U.S. hospital—to bring hospitals to the point where they consider having palliative care programs as essential as having, say, infection control.

**Public engagement.** We believe that unless the public starts to understand what good end-of-life care is—and to demand it—we will not succeed. For example, without this understanding it will be much more difficult to achieve needed Medicare reforms; we will not see important institutional changes; we will not generate employers' support for flexible leave and work hours for caregivers; and we will not be able to sustain professionals' long-term interest in palliative care.

Engaging the public on the issue of death is difficult. The conversation is hard to start at an individual level. Every foundation staff
member working in this area has found, however, that once the ice is broken, people have articulate, even passionate views. These personal stories motivate our staff and reinforce the need for our continued efforts. Stimulating an action-oriented conversation at the community level is also difficult. It requires getting beyond the specifics of the personal stories and generalizing to the systems problems that need to be addressed.

The RWJF has supported a variety of public engagement projects and programs. The Community-State Partnerships to Improve End-of-Life Care national program, directed by Myra Christopher, funds projects in twenty-three states to engage the public on end-of-life issues and to work on state-level policy changes. The projects are generating a wide variety of clinical, policy, and professional and public education efforts. Thousands of people are involved in the coalitions, task forces, committees, and public engagement efforts that have been stimulated by these projects.

In fall 2000 the Public Broadcasting Service (PBS) aired six hours of Bill Moyers’s programming on end-of-life issues, accompanied by an extensive national outreach campaign. By September 2000 nearly 300 communities nationwide had formed coalitions to try to address locally some of the issues raised by the program, On Our Own Terms: Moeyers on Dying. The RWJF is a cofounder of the series and the outreach campaign.

Entertainment television is a powerful component of the social milieu in which individual opinions are formed and decisions made. The Last Acts campaign includes several activities built around entertainment media, such as ER, the country’s most-watched network entertainment program, and the Pulitzer prize-winning play Wit. The RWJF has also sponsored panels at summits of producers and directors of prime-time programming and daytime television.

Lessons Learned

What follows are a number of lessons we have learned from our work to date. First, there is widespread awareness of the depth and seriousness of the problems in care of the dying. Both professionals and the public recognize this, although each group talks about it in different ways. There is enormous support for efforts to improve end-of-life care, even though changes are needed on many fronts—professional, institutional, and attitudinal, for example—and even though not all of the experts agree on what those changes should be, particularly financing and organizational changes.

Although some improvements are actually occurring in individual educational and service programs or in local communities, the process has not yet picked up enough momentum to ensure lasting, systemic, nationwide change. Because there are many possible targets of change, great creativity is possible at the local and national levels. Targets are as diverse as state medical board policies, emergency response training, clergy engagement, and application of new information technologies.

We have learned that few members of the public know what “palliative care” is, nor do many health professionals. Promoting this concept is an important part of the public education that needs to take place. The public does not know much about hospice, either, unless they have experienced it. If they have, they are usually strong advocates for it, but absent personal experience, hospice is perceived as “giving up,” and patients feel that their physician is abandoning them if he or she recommends hospice care. The notion of a “good death,” which hospice effectively provides for many persons, has salience only after a loved one has died. Most people—and families—facing a serious illness do not want a “good death”; they want a cure.

We at the RWJF have been persuaded that palliative care must be moved upstream, to
earlier points in the chronic care continuum. Having such services available throughout an illness not only provides better care but also removes a powerful psychological barrier for patients, who otherwise might see palliative care as a poor second choice.

None of us—not the RWJF certainly, or physicians, or any one sector—can improve end-of-life care alone. We all need partners who will reach out to physician colleagues who should be making referrals to palliative care and hospice; partners who will work with nonphysician providers as part of palliative care teams; partners to reach out to policymakers to help them to understand financing and other policy barriers; and partners to talk candidly to the public about what kind of care they should expect to receive when they are critically ill.

**Progress And Challenges**

Consensus and consistency in the field about what palliative care includes will aid in establishing standards for assessing quality; validating the need for changes in reimbursement policy; evaluating our work; and communicating with the public. One of the first projects that Last Acts undertook was to establish some precepts for what good palliative care should be.22

These precepts have now been endorsed by 120 organizations, including the American Medical Association, the American Hospital Association, and many individual service providers. They describe palliative care as respecting patients’ goals, preferences, and choices; providing comprehensive caring, ranging from intensive medical services for symptom control to spiritual and emotional care; using the strength of interdisciplinary resources; acknowledging and addressing caregivers’ concerns, including counseling, bereavement, and financial burden; and having an advocacy agenda to promote better care.

This broad concept of palliative care is under threat from two directions. First, there is a trend among hospices to call themselves “hospice and palliative care” centers. That would be a positive trend, if it meant that they were broadening their financing base and providing palliative care further upstream. It would be bad if the hospices could not make available the intensive medical services that patients sometimes need as part of palliative care.23 Second, there is the risk that hospitals, seeing the nascent movement toward palliative care, will modestly reconfigure existing services and call them “palliative care.” Palliative care is about more than pain management, DNR orders, and changing signage. Again, such programs would fall completely short of what is needed by dying persons and their families.

New palliative care programs—in fact, all good end-of-life care programs—face numerous challenges: (1) reimbursement—enabling provision of comprehensive services in all settings and better deploying existing funding across provider types; (2) multidisciplinary teamwork—continuing collaboration and clear lines of responsibility; (3) broad participation—involving nonphysician professionals (clergy and others) and finding ways to pay for their services; (4) inclusion of families—increasing family involvement in care decisions and renegotiating who is in charge; (5) institutional will—realizing that change, even for the better, always comes at a cost, and inertia is powerful; and (6) individual resistance—helping people understand that palliative care may be something they want.

All of these are challenges worthy of creative thinkers and skilled doers, many of whom we have found among our grantees and national program directors. We only hope that they, and we, can maintain our ambitious goals without being overwhelmed by the complexity and long trajectory of social change.
NOTES
7. B.A. Tyler et al., The Quest to Die with Dignity (Atlanta: American Health Decisions, 1997). To request copies, call Beverly A. Tyler at 800-544-3751.
8. Lake Snell Perry and Associates, Omnibus Survey Results: Last Acts, survey of 1,000 Americans age eighteen or older (Washington: Lake Snell Perry, March 1999).
11. Examples are the Open Society Institute’s Project on Death in America fellowship program, which has engaged some sixty-eight young leaders nationwide; the Fan Fox and Leslie R. Samuels Foundation’s support of research on advance care planning; the Mayday Fund’s work on pain; the Fetzer Institute’s concerns for the spiritual aspects of death and dying; the Nathan Cummings Foundation’s support of the Missoula Demonstration Project; and the Archstone Foundation’s grant to Americans for Better Care of the Dying for the Medically Project.
17. Information about the RWJF’s Promoting Excellence in End-of-Life Care national program is available at <www.promotingexcellence.org>, or by calling 406-243-6601.
19. Information about the Center to Advance Palliative Care in Hospitals and Health Systems (CAPC) is available at <www.capcmss.org>, or by calling 212-241-7885.
20. Information about the Community-State Partnerships to Improve End-of-Life Care national program is available on the Web, <www.midbio.org/npo-about.htm>, or by calling 816-842-7110.