Death Is Certain. Strategy Isn’t.

Assessing RWJF’s End-of-Life Grantmaking

Field Building in End of Life

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A Story about Strategy

An Assessment of 20 Years of Grantmaking

This report is an assessment of The Robert Wood Johnson Foundation’s work to improve end-of-life care in America.

It’s also a story about strategy.

The Foundation’s investments in end-of-life work tell us much about the role a foundation plays in shaping and executing strategic direction, how a foundation can both facilitate and impede progress in a field, and how a foundation can take substantial steps to build that field by:

- Identifying and framing an issue that captures public and professional emotion and attention
- Coalescing ideas, knowledge, and professionals into a burgeoning field
- Helping key leaders grapple with strategic choices
- Focusing or dispersing resources
- Ensuring that advances can be sustained

Readers of this assessment will certainly learn about the Foundation’s work and accomplishments in end-of-life care. They will also learn about foundation strategy—its promise and its weaknesses.

For many in philanthropy, the word “strategy” has come to imply a de rigueur set of formal steps: research, analysis and development of “theories of change” or “logic models,” and identification and tracking of outputs and outcomes. This study does not focus on such a process. As evaluators, we do not place great value in formal planning processes that attempt to deconstruct a vision or goal into a series of mechanical steps. Research has shown repeatedly that five-year plans and logic models are of little consequence to bottom-line impact. Research also offers plenty of examples of organizations breaking through to innovation with structures that look chaotic to the outside observer but, to internal participants, offer the freedom to foster achievement.

This assessment shows how such breakthroughs can emerge within a field and how a foundation can contribute to them. It also shows how a foundation can hinder progress or foster indecision or dispersal of energy and resources.
Without question, strategy to overcome some of our country’s most intractable social problems is phenomenally difficult to construct and just as difficult to execute and sustain. As much as uncertainty befuddles markets and industry, when crafting ways to intervene in issues such as how people die, far greater challenges arise. For a foundation strategy to have an impact on a significant social problem, numerous issues must be addressed. To name three:

- **Setting a goal that can be achieved** and identifying where this goal is shared with others. Who or what target to change? Who are the natural partners? How to intervene? Where to intervene? What it will cost? How much change is likely to occur given what is known about the problem and solutions? And how much change is needed to make a significant difference?

- **Executing strategy.** Who can do the work? How to know that progress is being made? How to resolve conflicts among partners? When to stick with a strategy and when to alter direction and how to know one from the other? What if the basic assumptions are wrong? What if the problem is far more complex than you thought? How mistakes and successes can inform current and future work?

- **Sustaining effects over time.** For whatever strategy is chosen, how to ensure durability, if warranted, and/ or proper adaptation? How to defend against unintended dissipation of effects post funding? And is sustainability even possible or desirable?

These questions can be vexing to many foundations. Yet it pays to wrestle with them. They can serve as a bare-bones test of whether a strategy is in place. When answered explicitly and openly, they can pave the way for productive focusing, efficient resource allocation and greater realism, both within foundations and organizations in the fields they fund. But these questions are not answered easily or at one point in time. And— most difficult to stomach for many in the foundation world—they are rarely, if ever, answered with certainty.

We are mindful that there is no one right way to construct a strategy. The most productive approaches seem to land somewhere between the extremes of complete uncertainty and complete certainty, between those program officers who throw up their hands and say the world is too complex a place for planning to succeed and those who act as if change can fairly easily be planned via tightly locked “if/then” statements and logic models. The truth is that the level of planning certainty depends on the nature of the problem and its circumstances. But the bigger point is that foundation management has an important role in pushing for clarity in strategy even as it acknowledges uncertainty, identifies where learning is needed, and explicitly makes calculated guesses as new patterns emerge.
Despite the uncertainty, each foundation must find its own way to making grants. Not unlike death, payout is inevitable. Grants must be made. Clarity and alignment matter because –like it or not—strategy will be inferred by the field as grants are made. As one grantee put it, “Strategy is what you do, not what you say.”
Study Overview

Rationale and Method

The Foundation commissioned Patrizi Associates to conduct a strategic assessment of its investments in “improving the end of life.” The purpose of this assessment was to create an overall learning opportunity for Foundation staff and others interested in how foundations construct and execute grantmaking strategies. We sought to document strategy and field-level effects related to the portfolio as a whole, effects not always noticeable when individual programs were evaluated. We also wanted to create an opportunity for the Foundation to hear directly from leaders in the end-of-life field.

Study methods

This report was researched and developed through a process of analyzing a set of critical questions about the Foundation’s end-of-life strategy using a variety of sources, as follows:

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<th>QUESTIONS</th>
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<tr>
<td>Was the strategy creation process sound?</td>
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<td>Was an appropriate strategy well chosen and was it well developed?</td>
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<td>Was the strategy executed well, and was learning leveraged throughout the process?</td>
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<td>What outcomes can be associated with the effort?</td>
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<th>SOURCES</th>
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<tr>
<td>Multiple staff interviews</td>
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<td>Reviewed 337 grants and complete files of 150</td>
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<td>Interviewed 10 current and former RWJF staff</td>
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<td>Interviewed 63 external: 31 grantees, 32 non grantees</td>
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<td>Reviewed seminal documents on grantee and national organization websites and in professional journals and reports</td>
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<td>Analyzed data by portfolio</td>
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<th>PROCESS</th>
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<tr>
<td>Perspectives collected from interviews</td>
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<td>Strategy inferences drawn</td>
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<tr>
<td>Financial and output data analyzed</td>
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<tr>
<td>Hypotheses, conclusions, reality testing with staff and external experts</td>
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<tr>
<td>Learning opportunities identified</td>
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Foundation staff, past as well as present, spent extensive time with us discussing their motivations, intentions, perceptions, knowledge of the field and what they hoped to
achieve. None of those interviewed from the Foundation skimped on the time needed to address our questions. In Appendix 1, we include a list of our interviewees. A full list of references is at the end of this report. (Appendix 7)

Three caveats

There are three important caveats to consider.

First, this is a retrospective study of a body of work completed over two years ago and reaching back to 1986, when the idea to invest in these issues first surfaced at the Foundation. This means that some of the most important decisions that ultimately shaped the strategic direction of the grantmaking were made more than 20 years ago. Of those involved, only two are currently on the Foundation’s staff, and all were challenged by our questions to reconstruct events from long ago. In considering how we would present this history, we tended to put more weight on impressions that could be corroborated by others or by documents. We also took care to see impressions as just that—impressionistic views on the climate and culture of decisions at the Foundation from years before.

Second, we are acutely aware of the changes in how foundations now approach strategy development and execution compared to then. We frequently found ourselves applying standards in this review that, with few exceptions, were not commonly appreciated in the field of philanthropy at the time. In some respects, our assessment is based on what now is considered to be “gold standard” criteria for strategy construction. We repeatedly took this into account and urge our readers to do so as well.

Third, this report was written with limited access to a major body of work related to Last Acts and its associated programming. We did not interview grantees from Last Acts, however, we did review Foundation documents and Last Acts was often raised in our interviews with leaders in the field.
From Confidence to Strategic Uncertainty

Evolution of the Strategy

The Prologue: SUPPORT

From 1988 through 1994, The Robert Wood Johnson Foundation funded a landmark study of how Americans die, known as SUPPORT—Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. SUPPORT gave credence to a growing, but until then unconfirmed and unexamined, understanding of the shabby state of end-of-life care in this country.

For many in the health care field, the Foundation’s investment in SUPPORT made the case that inadequacies of care at the end of life were profound, and that something should be done about it. The Foundation’s investment in SUPPORT and its dissemination was considerable—$31 million dollars over nearly ten years. The returns were vast, although in unexpected ways.

SUPPORT emerged from a 1986 meeting of researchers convened by the Foundation to address concerns about decisions physicians were making regarding their patients at the end of life. Participants came away from the meeting with the sense “that elderly, fatally ill persons were likely to be vigorously treated in intensive care units, at great financial cost and suffering, even if their families objected.” At the end of the meeting, the Foundation asked a group of researchers to “learn about what could be done to understand and improve the care of critically ill persons in hospitals” (Lynn 1997).

SUPPORT “sought first to understand the experience of those critically ill and dying in hospitals and then to test an intervention to address some of the significant shortfalls witnessed.” Phase 1 was a descriptive, observational study of 4,301 patients hospitalized with life-threatening medical conditions who were expected to die within six months. During this first phase, the researchers produced what for many was shocking information:

“Physicians did not know what patients wanted with regard to resuscitation, even though these patients were at high risk of cardiac arrest. Orders against resuscitation were written in the last few days of life. Most patients who died in the hospital spent most of their last days on ventilators in intensive care. We had not expected to find the high levels of pain that were being reported, especially in non-cancer illnesses. Except for the comatose, more than half of the patients with any of the nine diseases were reported (by the family member of the patient) to have substantial pain” (Lynn 1997).
At the end of Phase 1, researchers concluded that physicians were unable to predict either severe disability or death and that they had an inadequate understanding of their patients’ wishes. Lewis Sandy, MD, who was to join the Foundation some time later as Executive Vice President, understood the rationale for a second phase of SUPPORT as addressing two key issues: the need for better “prognosticating about death” and the need for decisions more in concert with the patient’s wishes and trajectory.

“We needed to learn why patients were not getting the right care. In SUPPORT, we hypothesized that there was not good detailed information on the nature of the projection of the disease, that we were bad at both prognosticating about the likely path of what would happen to those who were dying and that we had no mechanism to elicit information from the patient… We went after better and more detailed information that would allow us to know the likely trajectory of what would happen. We thought we would get the information and that should work to influence medical decisions.”

The research team moved to a change strategy within six months of the end of the first phase. “Convinced by the expert consensus that targeted interventions would work,” the research team “designed a second phase aimed at fixing these problems” (Schroeder, 1999). Phase 2 instituted a controlled clinical trial involving an experimental group of 2,652 seriously ill patients and a comparison group of similar size. Three interventions were offered:

- Validated prognostic models were developed for each patient so that physicians could estimate the likelihood of severe disability or death.
- Specially trained nurses talked with patients and their families to understand their wishes and to relay them to physicians and nurses involved.
- Detailed written instructions about patients and families’ wishes regarding treatment were given to physicians.

SUPPORT’s Phase 2, implemented over three years, was expected to change the landscape of care in America. The Foundation was fully prepared for a large media push to publicize the positive results of SUPPORT.

It was not to be.

In 1994, researchers presented the totally unexpected and unequivocal finding of “no effects” to a stunned Foundation staff. In hindsight, many say that the SUPPORT strategy was overly “rational,” and “underestimated the depth and complexity of the problem.”
Failure becomes a case for change

But the disappointing findings did not mark the end of the story. Steve Schroeder, then President of the Foundation, saw an opportunity to transform this great disappointment into a case for fundamental change. “I felt this was a chance to show that this was not a simple problem and that much needed to be done,” he says. “This was a huge problem and we needed to put together a movement.” Instead of the planned campaign to promote the success of SUPPORT, Schroeder and his communications staff focused the campaign on how entrenched this problem was and the need to address it. The findings from SUPPORT made front-page news across the country.

Many say that the Foundation’s work to communicate the findings from SUPPORT was the real home run in the effort. The information from SUPPORT—and its credibility—galvanized professional awareness and action, unlike anything else, around how Americans die.

Kathleen Foley, MD, Director of the Project on Death in America (PDIA), funded by the Open Society Institute, called publication of the SUPPORT study the “tipping point in the history of these movements and in public and professional discussions about end-of-life care, which validated widespread concerns among the public and health care professionals about the barriers and challenges to providing humane, compassionate care.” (Foley 2005) In fact, Foley credits the first SUPPORT study as part of the rationale for the Open Society Institute’s investment in PDIA.

According to Foley, a consensus about care at the end of life emerged from this work: that the problem was serious and complex and “significant barriers – organizational, institutional, educational, and economic—had to be overcome before end-of-life care could be improved.”

In 1997, Joanne Lynn, MD, one of the two directors of SUPPORT, summarized what for many still holds true about end-of-life care: “Surely we can do better. Pain could be much more of a focus. Decisions could be made in advance and care plans shaped much more creatively. Clearly, long-standing habits exist for a myriad of poorly understood reasons and do not yield readily to change.” (Lynn 1997).

From SUPPORT to the End-of-Life strategy

Much debate and a number of landmark policies and decisions shaped the Foundation’s work in this area. In the early 1990s, the nation was immersed in a struggle about care at the end of life. New laws and high-profile court cases were making headlines. The 1990 Cruzan decision broke new ground by authorizing patients to reject medical treatment,
including food and water. Jack Kevorkian, or “Dr. Death” as he was known, came to public attention with his first acknowledged assisted suicide. The Patient Self-Determination Act came into law and required hospitals to inform patients of their right to make treatment choices regarding resuscitation and other life-saving technology. In 1994, Oregon residents voted to approve the “Death with Dignity Act” to legalize euthanasia. (See Appendix 2 for selected key events in the end-of-life care field.)

At the same time, health experts and the public pondered the implications of shifts in demography, epidemiology and biomedical technology. The news media carried stories about advancing life expectancy and the rise of chronic illnesses, such as heart disease, cancer or stroke, as the leading causes of death. Biomedical technology was advancing and high-tech care had become commonplace at the end of life, yet health-care costs were mounting and were a source of real national concern. When should high-tech care be used? What were the moral and economic principles that should guide our choices?

Medicare provided benefits for hospice care, yet relatively few people took advantage of it. Only a small proportion of Americans had prepared advance directives to guide their care. The SUPPORT study showed that many Americans were still dying in pain, but SUPPORT’s intervention—which up to that point was the end-of-life care field’s best bet at a solution—had failed to fix the problem.

In this context, The Robert Wood Johnson Foundation entered the end-of-life care field, anew.
After SUPPORT ended in 1994, the Foundation was uncertain about how to move forward and began what one Foundation executive, called “a collective head scratch.” Unsure about what would work and wanting to address “a broad array of factors leading to social change,” staff sought to “activate an impassioned consumer movement” that would motivate the public as well as professionals and help transform the culture of institutions charged with delivering care to the critically ill (Weisfeld et al 2000). The position of the Foundation was probably best articulated by Schroeder’s expression of the felt need for a “broad movement with simultaneous work on multiple fronts.”

Over the next year, a staff team was formed to address issues related to what came to be known at the Foundation as “End Of Life” or “EOL.” Although never articulated this way, two major streams of work emerged: one focused on communicating and activating the public and another dedicated to transforming care. The communications team was already in gear from its work on SUPPORT. The plans to transform care, however, did not formally emerge until after an Institute of Medicine report, *Approaching Death: Improving Care at the End of Life*, was issued in 1997, but significant staff reconnaissance took place for two years prior. Staff met with end-of-life care experts and members of interested organizations, such as the American Medical
Association and the American Nurses Association and representatives from the hospice movement. It was not until sometime in 1997\(^1\) that the Foundation formalized its objectives for moving forward.

Between 1996 and 2005, the Foundation invested $169,893,678 overall in the End-of-Life area, focusing on three major objectives:

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<tr>
<th>Objective</th>
<th>Total grant amount</th>
<th>Percentage of portfolio</th>
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<tr>
<td><strong>Objective 1:</strong> To improve the knowledge and capacity of health care professionals and others to care for the dying</td>
<td>$25,662,305</td>
<td>15.1%</td>
</tr>
<tr>
<td><strong>Objective 2:</strong> To improve the institutional environment in health care institutions and in public policies and regulatory apparatus to enable better care of the dying</td>
<td>$64,425,644</td>
<td>37.9%</td>
</tr>
<tr>
<td><strong>Objective 3:</strong> To engage the public and professionals in efforts to improve end-of-life care</td>
<td>$79,008,196</td>
<td>46.5%</td>
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<tr>
<td>Other</td>
<td>$797,533</td>
<td>.5%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$169,893,678</strong></td>
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The Power of Inside Knowledge

Assessment of Objective 1 Achievement

The Foundation invested $25.7 million toward the Objective 1: “to improve the knowledge and capacity of health care professionals and others to care for the dying.” This work constituted 15 percent of the overall End-of-Life portfolio.

While the Foundation recognized that the range of practitioners who provide care at the end of life—including those in social work, pharmacy, and mental health—all needed more and better knowledge about the end of life, objective 1 work “started from [the Foundation’s] traditional strength—working primarily with doctors and nurses” (Weisfeld et al 2000).

Although the objective broadly targets “health care professionals and others,” most of the resources -- 66 percent -- were invested in physicians and reforming medical education.

Staff believed that to change care in meaningful ways they needed to change physicians, and how they are educated, as the primary priority. Referring to hospice and palliative
care-related education, two of the field’s early leaders wrote, “These programs won’t produce real change unless they also address the hidden curriculum of medical schools—the values, attitudes and beliefs that constitute the basic culture of medicine” (Sullivan and Block 2003). With this in mind, Foundation staff sought to focus its attention on medicine.

To our knowledge, there were no overall internal strategy documents pertaining to Objective 1, although an article in Health Affairs provided a good outline of the overall goals with key lines of work and examples (Weisfeld 2000). The central analytic and programmatic source document behind the objective’s work, partially supported by RWJF in 1996, was produced by the Institute of Medicine (IOM), “Approaching Death: Improving Care at the End of Life.” This study came to frame the clinical and related system issues for the field. The report, written principally by clinicians, gives its best guidance around shortfalls in clinical practice and the institutional structures surrounding that care. It was, however, limited in offering the perspective of economists and others who might have lent a view on larger system change issues.

Less formal but even more influential in shaping the medical education reform approach under this objective was the relationship that developed between Kathleen Foley, MD, and Rosemary Gibson, one of the lead program officers at the Foundation. Foley, a neurologist specializing in pain at Memorial Sloan Kettering Cancer Center, was also the director of Project on Death in America (PDIA). Her perspective on how medicine is structured and influenced shaped much of RWJF’s work. PDIA’s most significant investment, The Faculty Scholars Program, was to become the most important source of leadership for RWJF’s emerging program (See Appendix 5: PDIA Scholars’ Roles in RWJF Programs).

The Foundation in the end focused on three core areas:

A. Training all practicing physicians to deliver better of end-of-life care

B. Reforming medical education

C. Reforming nursing education

Woven throughout each of these areas was an investment in building the body of knowledge on end-of-life care.
A tale of two theories

The vast majority of the work under Objective 1 focused on system change, applying what can be considered “push strategies”—regulatory and licensing changes to activate whole-system reform. This was clearly the case for the strategies constructed to reform medical and nursing education.

For the work of training all physicians, a more direct approach was used: marketing to physicians who would then market to other physicians. The idea was to transmit knowledge from person to person, relying on an ever growing pyramid of successive retraining.

The two approaches—systems reform and direct physician marketing—fared quite differently.

The core theory of change underlying medical and nursing education reform centered on stimulating demand for palliative care knowledge by changing the licensing tests administered to nurses as well as to physicians at three different times in their educational career. This approach, along with the writing, speaking and efforts of a cadre of strong and outspoken physicians produced change within the existing system of medical education. The same approach was adopted with some modifications by nursing as well. The investments yielded many impressive achievements in both medical and nursing education.

As systematic and well-reasoned as the approach to change medical education was, the line of work to “train all practicing physicians” was as unrealistic as its goal. Education in Palliative and End-of-Life Care (EPEC) was funded to conduct an “educational campaign for all practicing physicians in palliative care and advance care planning” (Gibson undated document). The intent behind the grant was that all U.S. physicians (emphasis added) should be trained either by the program or by trainers trained by the program. EPEC was seen as a way to interest physicians in end-of-life care and provide a gateway to further development. As we will see, the training work would not have the effect that the systems change approach did.

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1 In marketing, a push strategy is one where a brand pushes a consumer to buy something by affecting the distributor. In public policy, push is used to refer to strategies that are more coercive, while pull refers to more invitational approaches.
**Area A: Training Practicing Physicians**

The first major initiative under Objective 1 was undertaken by Education in Palliative and End-of-Life Care (EPEC), a program designed and run by the American Medical Association. EPEC had two major lines of work:

1. Develop a curriculum
2. Use the curriculum to train all practicing physicians. Here EPEC used a “train-the-trainer” model, forming a pyramid structure to reach its target of all practicing physicians. It trained physicians and hoped that others in the training would decide to lead more training sessions.

By all accounts, the program succeeded in developing a core curriculum for palliative care. EPEC’s greatest success as reported by many of those involved was the substantive material produced, EPEC created a coherent, comprehensive curriculum that would prepare a practicing physician to deal with the issues faced when caring for patients at the end of life.

The EPEC approach produced a number of important accomplishments but had three major flaws.

First, EPEC over-estimated its capacity to train all physicians. Sutton Group, which did an evaluation of EPEC in 2000, found that EPEC was most likely to reach health care providers already interested in palliative care, rather than those resisting or disinterested. The targeting of “all physicians” did little to help the program segment its strategies to meet differences among its target audiences.

Observers believe that the Foundation and the grantee were unrealistic in their assessment that all doctors could be persuaded to change. EPEC did not effectively differentiate among those physicians likely to become advocates, those likely to remain resistant, and those who would acknowledge the needs of the dying but would not want to change their own practice to meet those needs. In all likelihood, affecting each of these groups would have called for different change strategies (if in fact change could have been achieved with all segments).
Second, EPEC did not take into account the time physicians have to devote to training. Even if doctors were interested in learning about end-of-life care, many could not devote the time to attend the full nine-module EPEC curriculum. As a result, the training inevitably was watered down from the nine-modules in the design to one session that mainly described the problem.

In 2003, EPEC reported that it had trained 1,500 of these source trainers and extrapolated that these trainers, in turn, had trained 300,000. This extrapolation has not been actually validated. These numbers appear to include training delivered largely to allied health professionals rather than to the doctors themselves. About half of the trainers surveyed in 2000 indicated that less than one-third of those they trained were physicians.

Third, some also questioned the efficacy of the program design itself as the training was based on presentations and lacked hands-on experience. As two different interviewees commented:

“I’m not sure about the long-term impact of EPEC. The curriculum is a good resource for people, but is the model effective?”

“EPEC is not as effective as it could be…It is successful in raising awareness but not as a learning mechanism. EPEC is a lecture-based program. More interactive works the best. Effective educational practice has not been integrated into EPEC.”

On the upside, the EPEC curriculum has been adopted by other organizations better positioned to reach and train physicians. EPEC has been replicated and modified for many specialty groups, including emergency medicine and geriatrics. And the program was modified by oncologists who created EPEC-O, funded by the National Cancer Institute and the Lance Armstrong Foundation in partnership with the American Society for Clinical Oncology and Oncology Nursing Society. The American Osteopathic Association used the EPEC curriculum to train 45 faculty in 17 of the 19 osteopathic medical schools. In July, 2003, the American Osteopathic Association elevated end-of-life care to a standing committee, and in February, 2007, the American Osteopathic Association Board approved a resolution to institute the equivalent of a subspecialty for their system.

From a strategic perspective, it is well credited that EPEC laid the footprint for the knowledge required by practicing physicians. As the program adjusted to address some of the shortfalls evidenced by its train-the-trainer approach it engaged multiple professional organizations, which by offering EPEC as part of their Continuing Medical Education Curricula, endorsed and validated the need for the body of knowledge. On the flip side of the coin, the program lost credibility as it failed to reach a goal, which was never achievable in the first place. It is not at all unusual for a foundation to face the claims of an enthusiastic and prominent grantee that it can undertake an
unreachable goal; a foundation, however, is in the position to reframe goals in a manner that can support ambition and help redirect the organization toward more productive efforts.

**Area B: Reforming Medical Education**

RWJF’s approach to reform medical education was jointly constructed by Rosemary Gibson of the Foundation, Kathleen Foley, MD of PDIA, Susan Block, MD of Harvard Medical School and a number of other key leaders in the field. It was based on the following theory:

- Institutions need external motivation to change
- Changes in the medical licensing exam would provide an incentive to teach to the test
- Changes in the exam would require new knowledge
- New knowledge would require researchers to produce it, a curriculum to organize it and faculty trained to teach it

For this “push” of the medical education system to work fully, students would need clinical sites where they can observe and practice, and these sites -- namely, hospitals -- would need incentives to use the skills and knowledge available to them. Changes in The Joint Commission standards offered some of these incentives as did the Center to Advance Palliative Care, which used a pull strategy by making the business case for palliative care units within hospitals and by providing technical assistance to interested providers.

Key to all of this work was a small 1998 grant that the Foundation awarded to the National Board of Medical Examiners to strengthen end-of-life content in medical licensing exams. Students and later physicians take these exams at the end of the second year of medical school on basic sciences, at the end of the fourth year on clinical sciences and finally after one or more post-graduate years in preparation for acquiring a medical license.

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1 $98,000 was awarded
In line with the plan to build incentives, the Foundation also made a series of targeted grants that would help meet the demand for knowledge created by these tests. For example:

- UCSF: Stephen Mc Phee, MD, reviewed end-of-life content in top selling medical textbooks and worked with publishers, editors and authors to make improvements. A 2001 follow-up survey showed that 40 percent of publishers and editors reported new content in existing chapters, and an additional 24 percent planned to make improvements.

- Medical College of Wisconsin: This national project helped internal medicine residency programs meet what were then new requirements from the American Board of Internal Medicine that they include end-of-life care training into the curriculum for medical residents. As of the end of 2006, 347 programs had completed the national residency end-of-life education project, which ultimately grew to include family practice, neurology and surgery. With RWJF support, the program is now developing course material for medical schools, as well.

- Medical College of Wisconsin: A national End-of-Life/Palliative Care Education Resource Center was established. EPERC, as it is called, maintains a web site containing peer-reviewed educational materials, recommended books and articles, training opportunities, funding sources, conferences and links to other resources, and an electronic newsletter. By mid-2004, the web site had 12,000 registered users from 104 countries and was getting more than 300,000 hits per month.

The Foundation also made several grants to influence whole systems of care. The most successful and important was a grant of $943,480 made to the Veterans Administration in 1998. To Foundation staff, the VA represented a system serving a large number of elderly and one that could have a relatively quick impact on its faculty and its residents. Overall, the VA offers approximately 15 percent of the fellowship slots in palliative care in the United States so the reach of this investment was potentially significant.
It takes more than one foundation to build a field: an example

A key decision faced in Objective 1 work was whether palliative care needed to become a subspecialty. It provides an excellent illustration of how two foundations, Open Society Institute’s Project on Death in America and the Robert Wood Johnson Foundation, worked in genuine partnership building on complementary roles.

PDIA and RWJF were not fully on the same page regarding the need for specialists in palliative care. RWJF took an “agnostic” stance on the issue. Not wanting “to add to medical divisiveness and fragmentation,” the Foundation chose to abstain from taking a position, to “let physicians do this themselves,” and to respond to requests from the field.

PDIA, on the other hand, wholly endorsed the creation of a subspecialty that could assume status and position within medicine. PDIA’s Kathleen Foley, MD believed in the importance of following an “elite strategy.” As she saw it, “The only way to address the issue was to create a subspecialty informed by a clear and well-respected base of knowledge. These specialists would be charged to create curriculum and teach. But to be taken seriously, they would need the same credentials and quality of knowledge that their colleagues commanded; from this would follow the demand for and earned respect.” Another source interviewed validated this opinion, saying, “It became clear that physicians in the field felt they wouldn’t be taken seriously until there was recognition of hospice and palliative care as a specialty or sub-specialty.”

RWJF straddled this issue by supporting The American Board of Hospice and Palliative Medicine (ABHPM) to develop and standardize the accreditation process for fellowship training programs in hospice and palliative medicine, improve the certification exam for physicians in the field and adopt a plan for a recertification test.

The Project on Death in America also provided support during this period for ABHPM to take a leadership role in formalizing recognition of hospice and palliative medicine. With combined support from RWJF and PDIA, ABHPM helped hospice and palliative medicine achieve recognition as a medical subspecialty in near record time. In 2006, the American Board of Medical Specialties agreed to recognize hospice and palliative medicine as a legitimate subspecialty, and the Accreditation Council for Graduate Medical Education voted to accredit fellowship training programs.

The work on different aspects of the specialization effort is an example of the strength of the RWJF—PDIA partnership and how it worked to great effects. As one grantee said, two major funders allowed for two different roles for the use of the money. “The Soros money (PDIA) let us focus on building our capacity to advocate for the field; the Johnson money supported the development of standards, and built the knowledge base.” PDIA staff saw RWJF as a “strong partner in that it could offer support for the substantive work” and “we were happy to fund the networking and convenings.”
Results for medical education reform

By finding key leverage points in the system, the Foundation was able to invest relatively small amounts of money that resulted in significant effects on medical education reform. For example:

- Questions were successfully included in the licensing exams, a development that many credit as creating the momentum for other changes.

- By 2003, the VA issued formal standards for palliative care and mandated that all units have palliative care services. In August 2006, the VA directed its medical program to ensure that it met the proposed accreditation standards and “to support palliative care programs in general and palliative medicine training programs in particular.” The current head of the VA’s Hospice and Palliative Care Program was a RWJF-funded faculty fellow.

- In 2006, the American Board of Medical Specialties (ABMS) approved Hospice and Palliative Medicine as a subspecialty. Ten participating boards (anesthesiology, emergency medicine, family medicine, obstetrics and gynecology, internal medicine, pediatrics, physical medicine and rehabilitation, psychiatry and neurology, radiology and surgery) endorsed hospice and palliative medicine as a subspecialty of their fields (Kuehn 2007).

- In 2006, the Accreditation Council for Graduate Medical Education (ACGME) decided to begin accrediting Hospice and Palliative Medicine fellowship programs. In the past 15 years, the number of fellowship programs in palliative and hospice medicine grew from 5 to more than 50. (Kuehn 2007).

- In 2007, the American Osteopathic Association approved a Certificate of Added Qualification in Hospice and Palliative Medicine to be offered through Family Medicine, Internal Medicine, Neurology and Psychiatry and Physical Medicine and Rehabilitation. (American Osteopathic Association website)

- There are now 56 active fellowship programs in hospice and palliative care, with five more in formation, offering 140 fellowship positions, including 20 research slots (American Academy of Hospice and Palliative Medicine website).

- Between 1996 through 2006, more than 2,800 physicians obtained certification from the American Board of Hospice and Palliative Medicine.

- In 1988, the American Academy of Hospice and Palliative Medicine began with 250 founding members; it now has more than 2,600 members.
Area C: Reforming Nursing Education

The rationale and strategy for nursing paralleled the approach employed in medical education reform. As with medicine, the nursing approach was grounded in research illustrating that nurses were inadequately prepared to care for patients in pain or at the end of life. The goal was to address this deficiency by embedding end-of-life care content into nursing textbooks, teaching, licensure and certification.

Like medicine, nursing education reform efforts applied a “push strategy:” If new licensing and certification procedures required knowledge and skills in end-of-life care, then these requirements would drive demand for nursing textbooks, curricula and training programs with the necessary content.

The nursing strategy was built on a partnership between Betty Ferrell, RN, PhD, FAAN, Research Scientist at City of Hope National Medical Center, and Anne Rhome, MPH, RN, Former Deputy Director, and others at the American Academy of Colleges of Nursing (AACN). Ferrell laid the groundwork for the approach and collaborated with the team at AACN to carry it forward in a national end-of-life care education program for nurses.

In 1997, RWJF supported AACN to convene a roundtable of nurse educators, clinicians and researchers. The result was *A Peaceful Death: Recommended Competencies and Curriculum Guidelines for End-of-Life Care*. These competencies were made part of the baccalaureate essentials of nursing education. Also, they provided the framework for the End-of-Life Care Nursing Education Consortium (ELNEC) training program established three years later with RWJF support to:

- Design an evidence-based curriculum for nurses
- Use the curriculum to train undergraduate nursing faculty and continuing education providers throughout the US in end-of-life care
- Prepare trainees to integrate what they learned into the education programs of their home institutions

Investments in improving nursing came about through dogged advocacy by a handful of nursing leaders who “knew what needed to be done.” It was a well-designed strategy that was effectively executed, with documented effects. Reflecting on the work, Foundation staff say “they knew nursing would get it right and do it meticulously.”

Area C Overview

- Phasing of licensing and certification requirements to build demand for new curricula, expertise and training programs
- $6.4 million, 3.8% of the total portfolio
partnership with AACN was the instrument. As a membership organization of more than 800 schools of nursing, it could engage nursing colleges effectively and bring credibility to the ELNEC training. In turn, the City of Hope team provided the research and content expertise in designing the end-of-life curriculum and led the effort to create a pediatric version of end-of-life training.

**Results for nursing education reform**

Many accomplishments emerged, including:

- Palliative care competencies added to the essentials of baccalaureate nursing education.
- In response to a RWJF-funded assessment showing that only 2 percent of the major nursing textbooks addressed end-of-life issues, 40 percent of authors and publishers had made changes or were in the process of doing so.
- By 2000, the National Council of State Boards of Nursing had adopted a revised test plan that includes improved end-of-life content in the exam for registered nurses.
- One year after their efforts, 10 of 48 boards reported changes to nursing school curricula for pain and end-of-life care. An additional 24 boards anticipated making changes in the future.
- The Hospice and Palliative Nurses Association (formerly Hospice Nurses Association) started in 1987 and now has over 9,200 members (www.hpna.org)
- ELNEC developed a well-received curriculum, and nursing schools overall have added 10 hours of end-of-life content to it. ELNEC was highly attentive to evaluation, tracking real numbers and real progress. Within one year of ELNEC training, 500 nurse faculty had trained 19,000 students. As of 2004, 1400 nurse educators were trained, representing one-third of nursing schools in all 50 states.
- ELNEC continues to try to meet the need even though RWJF funding ended in 2004. At 11 national conferences this year, ELNEC offered its core curriculum as well as specialty courses in end-of-life care for graduate nursing, critical care, geriatrics, oncology and pediatrics. Nevertheless, faculty from two-thirds of the nation’s nursing schools remains untrained in end-of-life care.
Last words on both medical and nursing education strategies

Each strategy was deliberate, built on evidence, led by high-profile and well-regarded physicians and nurses, and embedded in elite organizations in medicine and nursing. Each was clear, focused and well-financed. The work had low costs and high returns in terms of what was accomplished.

Both medical and nursing education took a strong systemic approach to change by:

- Taking lessons from history in planning the change effort
- Having clear objectives and outcomes, which were followed closely by those with most at stake in the enterprise
- Being subtle and fast and maintaining strong, high quality partnerships
- Executing close to the ground, relying on field-based leadership and increasing the chances that change would be institutionalized by using existing actors, levers and organizations
- Ensuring that information flowed consistently from field leaders to the Foundation

The end-of-life field has grown and developed with the Foundation’s support. While progress was made, the need for professionals trained in end-of-life and palliative care still far outruns the supply, particularly in view of the aging of the population and increases in chronic and life threatening conditions.
Moving Palliative Care Upstream

Assessment of Objective 2 Achievement

Objective 2—to improve the institutional environment in health care institutions and in public policies and regulatory apparatus—yielded some of the most significant work in the entire end-of-life care portfolio. In Health Affairs’ “Grant Watch (2000),” Foundation staff described their purposes under this objective in the following terms:

“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 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.” (Weisfeld et. al. 2000)

Breakdown of Objective 2 Grantmaking

<table>
<thead>
<tr>
<th>Component</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Promoting Excellence</td>
<td>$19,844,909 (31% of portfolio)</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>$29,083,604 (45%)</td>
</tr>
<tr>
<td>State Policy Reform</td>
<td>$4,338,187 (7%)</td>
</tr>
<tr>
<td>Institutional Quality</td>
<td>$7,320,172 (11%)</td>
</tr>
<tr>
<td>Other</td>
<td>$3,838,772 (6%)</td>
</tr>
<tr>
<td>Total</td>
<td>$64,425,644</td>
</tr>
</tbody>
</table>
While the objective remained broadly cast, over time the investments under Objective 2 focused on four major areas. These were:

A. *Promoting Excellence in End-of-Life Care.* The Foundation’s first national program under this objective, Promoting Excellence was an early (1997) effort to support the design and delivery of palliative care systems in many different settings, serving a broad range of population groups.

B. *Palliative Care in Hospitals.* The Foundation’s most significant investment under this objective, totaling $29 million, promoted hospital-based palliative care programs, largely but not exclusively through grants to the Center to Advance Palliative Care (CAPC). CAPC was instituted in 2000 as a national resource center to impart skills, build leadership and create the momentum to grow hospital-based palliative care programs throughout the nation.

C. *State Policy Reform.* Through grants to the University of Wisconsin, this work aimed to improve regulated prescription and practice policies related to pain and how they affect physician pain management. To some extent, the work also was advanced through the national program, Community-State Partnerships to Improve End-of-Life Care (CSP), discussed in detail under Objective 3. The chart at the beginning of this section does not include the investment in CSP, as its coalitions focused on numerous activities beyond state-policy change, making it difficult to apportion an amount specifically to this section. CSP received a total of $15.8 million; part of that amount could reasonably be allocated to Objective 2.

D. *Institutional Quality.* Finally, the Foundation made 15 grants amounting to $5.6 million to support the development and use of quality measurement and improvement tools across clinical settings as well as to support public policy work.
Searching for a strategy

Area A: Promoting Excellence in End-of-Life Care

The aims of Objective 2 work did not sharpen until late in 1999, after the Foundation had made more than 50 grants and invested almost $23 million in a broad range of institutional settings with different foci. One of the first grants the Foundation supported, Promoting Excellence in End-of-Life Care, which many interviewed found to have had far flung goals and questioned what would come from a program that was as heterogeneous as this one, in terms of diseases, populations, and settings.

Promoting Excellence was launched one year after the grant to the Institute of Medicine was made and two years after SUPPORT findings were released. In response to SUPPORT, staff recognized that “something needed to be done but that there was no scaleable response quite in sight as yet.”

The program was shaped in many ways by its proximity to the release of the SUPPORT findings. The SUPPORT program was originally framed with what could be called an overdose of confidence, both in the assumption that problems were well understood and that solutions were fairly clear. After the SUPPORT evaluation indicated otherwise, Promoting Excellence was cast as a search for “models that work.”

It very well may be that such a broad strategic approach was justified in light of the need to learn more about what might work, but the Foundation did not have clear learning objectives. While substantial experience emerged from the program, the yield for the Foundation might have been limited by lack of clear intention about what it wanted to learn, the huge variation among the projects, and the relatively weak use of evaluation.

Ira Byock, MD, Director of the Promoting Excellence National Program Office, ¹ is described as a “passionate advocate” and “visionary.” His book, Dying Well, influenced Rosemary Gibson. “He was well respected, was doing the work and had a vision.” As

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¹ Byock directed the work initially out of The Missoula Demonstration Project, started in 1996, to study the experience of dying and the quality of life’s end in one community and to serve as an example of what could be accomplished in any community.
an emergency medicine physician, he understood the importance of translating the need for and practice of palliative care to physicians who were most on the line to save or extend life.

By supporting projects reflecting a range of diseases, settings, patients and provider characteristics, Promoting Excellence reached out to many different population groups, thereby addressing the heterogeneity of those dying. Program leadership aimed to demonstrate that palliative care services could be delivered in many different settings and to people with vastly different conditions. The program portfolio was highly varied, serving special populations including children, prisoners, Native Americans, the seriously mentally ill, urban African Americans and others. It also focused on special conditions and diseases including Alzheimer’s, HIV/AIDS, and advanced renal, liver, lung, heart and kidney disease. The projects were located in difficult settings, including cancer centers, nursing homes, prisons, mental institutions and group homes, as well as hard-to-serve rural and urban communities.

While all but two of the 26 projects continue in some form to this day, little patient outcome data were collected or assessed. The projects, however, produced volumes of articles addressing operational and clinical care issues.

Late in its evolution, Promoting Excellence took steps toward greater focus. Building on the efforts of the Critical Care Peer Workgroup (discussed below), in 2003 Promoting Excellence awarded grants to four health care institutions to develop innovative ways to integrate palliative care services into critical care settings. This second phase of grants had better-defined aims, as well as an agenda for common data collection and outcomes-related research.

An unanticipated success

After receiving 678 letters of intent responding to the initial call for proposals, Promoting Excellence saw an opportunity to work with medical specialties and their leaders. These “thought leaders” were convened in eight “Peer Workgroups” that focused primarily on specific diseases or conditions—thereby building a network of more than 200 mainstream specialists interested in palliative care. Meeting for two years, each team assessed the challenges in their field and made recommendations for improvement. Each group was charged to develop a vision for its field and given support to communicate with that field effectively. These workgroups formulated, developed and inserted appropriate knowledge about palliative care into their fields from the perspective of practitioners of mainstream care, most notably surgeons and critical care specialists.

The Peer Workgroups emerged as an unanticipated success in developing palliative care strongholds within specialty areas—generally not the most fertile ground for palliative
The workgroups energized key leaders in prominent specialty areas to successfully take on the palliative care agenda. As one observer said, “The impact of the work groups was breathtaking. The surgery and critical care groups were incredible at digging in. They looked at the quality domains that were at the core of the discipline of palliative care and said, ‘We have to integrate this.’”

The Promoting Excellence national program office translated the initial broad goals of the program into a focus on demonstrating “the larger do-ability” of the premise that palliative care could be acceptable to a broad range of clinicians and populations and successfully administered earlier in the illness than most had previously assumed possible. Byock, reflecting back on the start of the grants, said, “Nine years ago, there were serious questions about whether it was even possible to provide palliative care at the same time clinicians are actively treating cancer or heart problems. The Promoting Excellence projects definitively demonstrated that you can provide concurrent palliative care without requiring patients to give up active, disease modifying treatment. The grantees’ programs showed that concurrent care is feasible and well-accepted in a variety of settings and patient populations. Clinicians, patients, families and local health systems all loved it.”

In many ways, Promoting Excellence served as a testing ground where officers and the field could learn about what was needed by those facing a life-threatening illness. While SUPPORT was designed to test a single solution, Promoting Excellence explored many solutions, in many settings. At the same time, the program was costly, and some may argue that these results could have been achieved with less funding.

Coming to strategic focus

Area B: Promoting Palliative Care in Hospitals

The first grant to the Center to Advance Palliative Care (CAPC) was made in 1999 and in many ways, was an extension of the medical education reform work supported under Objective 1. At the outset, hospital palliative care centers were envisioned as providing clinical sites for teaching residents. While viewed modestly in the beginning, this line of grantmaking evolved to become a significant part of the portfolio and the main way to promote and anchor palliative care in hospitals. CAPC is the current lynchpin in the education and care delivery system developed by the Foundation in concert with PDIA and other leaders in the field.

Area B Overview

- Increase number of hospitals that provide quality Palliative Care
- Target -- 20% of all US hospitals by 2005
- $29 million invested, 17% of total portfolio
- Primary support to Center to Advance Palliative Care
- Later support of Palliative Care Leadership Centers to extend dissemination potential
The grant to CAPC provides the on-the-ground connection between the work supported under Objectives 1 and 2, if we consider the following:

- Palliative care centers have an essential role as training sites.
- Research conducted within palliative care centers translates into knowledge and practices used in training physicians.
- Employment opportunities are developed for fellows or others with training in palliative care.
- Centers are located in the heart of the health care system and help build the demand for palliative care expertise within it.

**Why hospitals?**

An important question to address in this assessment was: Why hospitals? They are complex institutions, under financial duress and not likely candidates to come around to thinking differently about palliative care. Why not consider nursing homes, since they serve predominantly the very old? Why not address the severe shortages in community-based care? Or why not deal with what many considered the root of the problem—the inadequacies in the role of primary care for those in need of palliative care services?

The logic offered by Foundation staff and confirmed by many observers was that the hospital-based strategy made sense for the following reasons:

- Hospitals are the site where most people die.
- The costs associated with the end of life are huge, and most of these costs are associated with hospitals.
- Hospitals have some incentives to address these issues in that they need to find ways to cut costs, and single outlier patients with palliative care needs can absorb enormous resources.
- Physicians are often ill-equipped to deal with the nature and depth of demand placed upon them by patients and families, and a solution that ameliorates this burden, without pointing the finger at “inadequacies,” has appeal.
Staff also recognized that significant strategic barriers would make it difficult for the
Foundation (or at least a Foundation officer) to make large scale investments in other
settings. These included:

- The primary care system in America was seen as being in “shambles,” with
doctors unable to offer the kind of care and advice needed by patients facing the
end of their lives or long-term debilitating illnesses.

- There was no viable community health system that could adequately provide
palliative care. Effective scale-up would have been difficult to achieve and
strategies to do so are not easy to imagine or execute.

- Prospective reimbursement for home health was insufficient to cover good
palliative care, and there was no good system of delivery.

- Nursing homes, a logical focus for reform, lacked the stability, level and quantity
of professional staff that would allow for building a system of palliative care.

- Hospices, while addressing care needs of the dying, did not represent the
mainstream of medicine or a major component of the health care system.

The bottom line was that investing in hospitals was “doable”— a program officer could
make grants to relatively stable organizations that had the capacity to address specific
problems. In essence, the site and the work were amenable to investments from a
foundation and had a chance to yield some success. This logic is reasonable—if not
yielding transformative changes in the health care system. Diane Meier, MD, CAPC’s
director, would be among the first to say that the hospital palliative care center cannot
transform the entire system of care for the seriously ill. Nevertheless, in the current U.S.
health care system where hospitals and medical centers dominate the marketplace, it
was seen as the most pragmatic and cost-effective means to rapidly improve existing
care, and as a base upon which other palliative care interventions could be constructed
across the continuum of care. Additionally, she and Gibson were able to make a
business case based on current reimbursement practice—not an inconsequential factor in
building a strategy.

Although Gibson expressed a deep respect for the hospice model, in her view the
hospital was “where the patients were,” who were not getting this kind of care and that
by strengthening palliative care in hospitals, referrals to hospice would likely increase.
This was an important strategic decision, and probably a good one. As a core strategy
decision, it is one where Foundation leadership should have had a role. The decision
had ramifications in the field as it set off what came to be a divide between those
espousing hospice and those advancing palliative care in more upstream settings.
Likewise, the Foundation communications staff could have helped shape communications to lessen tensions that emerged.

The role of the Center to Advance Palliative Care

Once the grant to CAPC was made, it became clear fairly quickly that an untapped market had been discovered and Foundation investments thereafter focused sharply on expanding hospital-based palliative care.

CAPC’s first grant, established a National Resource Center for Palliative Care at Mount Sinai School of Medicine in New York. The grant’s aims were to:

- Increase the number of hospitals with capability to provide quality palliative care
- Create sufficient momentum that hospital-based palliative care becomes standard practice in comprehensive patient care
- Provide leadership in the development of standards for palliative care programs.

In 2000, 632 hospitals had palliative care capability. RWJF aimed for this to increase to 20 percent of the hospitals in the U.S. The demand for CAPC’s services quickly increased beyond the capacities of the Center. In part, growth resulted from the success of other elements of the portfolio. After the airing of Bill Moyers’ program, On Our Own Terms, in which CAPC was featured, CAPC received more than 1,200 contacts from hospitals asking for information and help.

To assist CAPC respond to the growing interest on the part of hospitals, in 2003, the Foundation funded CAPC to establish Palliative Care Leadership Centers (PCLCs). Rather than having CAPC respond to each request, the intent was to train six PCLCs to help hospitals and hospices establish and sustain palliative care programs. In addition, the goals were to build a cadre of leaders in the field, strengthen exemplary programs, and develop working relationships so that CAPC and the PCLCs could aggregate their data and move quickly to support change. The PCLCs are located in different regions of the country, and include in the group: a community hospital, a cancer center, an academic medical center, a pediatrics program, and a hospice, thereby providing a range of institutional settings for learning.

CAPC also developed a strategy for dissemination, including “how to” materials and provision of technical assistance offered through CAPC consultants on a range of issues related to successfully operating palliative care centers in hospitals.

While the broad strategy was developed prior to CAPC receiving its grant, Diane Meier, MD, CAPC’s director, significantly refined and deepened it. She understood that she
had to “sell” palliative care and brought in marketing, business modeling and financial
talent to do so. She continually adjusted and refined her strategy based on what she
was learning.

Important early marketing decisions helped position CAPC not as an advocacy
organization but as one with great technical skills and a strong product to sell. Early on,
Meier worked with Sutton Group,¹ a social marketing firm, to develop a segmented
market analysis of her audience, building upon a research-based analysis of who the
audiences are, what they want and the factors that influence their choices. With Sutton,
she identified six important but very different audiences for palliative care centers and
concluded that they had very different needs. These audiences and their needs were
identified by Meier as follows:

- **Health care professionals who care for patients but are not palliative care
  specialists:** “Admitting physicians can be overwhelmed when they have just
  one really sick patient in the hospital. It’s time consuming to work with patients
  and families as they make decisions. CAPC says, ‘We’ll help you, doctor, with
  the care of your patient.’ We do endless family meetings. It’s a labor intensive
  process but it’s a necessity in hospital care.”

- **Practicing physicians who say they don’t need help managing pain:** “We hear
  all the time that physicians need help answering all the pages from nurses and
  the calls from family. We developed the “Got Pages” brochure for practicing
  physicians. The message isn’t about incompetence or death and dying.”

- **Patients and families:** “Most hospice and end-of-life websites talk about care of
  the dying and grief and bereavement, but no one defines him or herself as dying.
  They won’t come. Bob Arnold at the University of Pittsburgh learned this lesson
  from the Make A Wish Foundation. Parents would not self identify their
  children as dying. In focus groups, parents would say, ‘My child isn’t eligible.’
  Now the signs in airports say something like, “The power of a wish is to get
  better.’”

- **Hospital CEOs:** “Palliative care physicians often view CEOs as the enemy. We
  teach that “you’re on the same side of the table as the hospital CEO. If the CEO
  can’t keep the hospital doors open, your service will close. You can help your
  CEO assure high quality care, through-put and highly technical efficiency. If you
  look at payment by diagnosis for a hospital stay – if you have someone with a
  sixty-day length of stay, that’s blocking 23 admissions and that’s a huge loss to
  the hospital. It happens that palliative care improves operations.”

¹ Sutton Group had just completed a study of EPEC and applied this knowledge of physician preferences to their work
with CAPC.
- **Philanthropists:** “Some palliative care people find it distasteful to ask for money. We tell them to make the case to funders as follows: Invest in success, leadership, vision and optimism. Explain why investing in you is a good venture capital investment, and makes the foundation more successful as well.”

- **Palliative care professionals:** “We speak in a way that acknowledges the transcendent and rewarding nature of their work. We recognize their contribution and understand the difficulty of what they are doing.”

Rather than assuming the innate social good of the CAPC product, Meier came to an assessment of her market that ran against the conventional wisdom espoused by most of her colleagues, who tended to believe that all physicians should incorporate palliative care into their medical practices.

The market analysis influenced the strategy in several ways, helping CAPC to:

- Demonstrate that offering palliative care made financial sense. Financial models were built and disseminated.

- Insert palliative care specialists to help admitting physicians on these issues (in contrast to SUPPORT, which assumed that the majority of physicians could change their decision making and practices).

- Market to admitting physicians in a way to meet their needs as defined by them.

- Reframe the problem and objective from offering care toward a “good death” to providing care to those who are seriously ill in hospitals, thereby expanding both the target population and the acceptability of the services of these centers.

This work was not without challenges for Meier. Part of the creation of the strategy for CAPC involved what Meier described as “coming to terms with the limited market for good dying.” She concluded that “the notion that a very sick person is interested in a good death is wrong. We get feedback from our palliative care website saying, ’I clicked on your resources, but my dad doesn’t need hospice. He’s not dying.’ Phrases like ‘good care of the dying’ or ‘bereavement’ turn people off.”

But the payoff has been noteworthy, as CAPC is as well regarded by CEOs as it is by clinicians and advocates for care of this kind. The outcomes have been significant:

- 30% of all US hospitals, and 70% of hospitals with 250+ beds, have adopted palliative care programs.

- CAPC, the American Academy of Hospice and Palliative Care, Hospice and Palliative Nurses Association, Last Acts Partnership and National Hospice and
Palliative Care Organization developed the National Consensus Project (NCP) Guidelines for Quality Palliative Care. In turn, these guidelines became the basis for the National Quality Forum framework for palliative and hospice care. The framework is intended to guide the selection of quality measures and preferred practices in palliative and hospice care. This, too, was seen as setting the stage for direct Medicare reimbursement.

- The program trained 572 hospital teams. 88% of them started palliative care programs within two years.
- CAPC collaborated with The Joint Commission on pain management standards.

While CAPC has a great deal of operational data and can make a strong financial case to support its approach, it has not initiated an evaluation of its effects on patient outcomes. This is a concern, as the program has been in operation now for over seven years. The program is, however, launching an evaluation of cancer patients treated by palliative care centers, with funding from the National Cancer Institute.

Keeping a foothold: When good work just emerges

Area C: State Policy Reform

What emerged as a successful although not central area of effort to change state policy addressing pain management came out of the work of two colleagues at the University of Wisconsin: David Joranson, MSW, director of the Pain and Policy Studies Group, and June Dahl, Professor of Pharmacology in the medical school. Both had been long-time grantees of RWJF and received RWJF support for their pain management work prior to RWJF’s formally developing its end-of-life portfolio.

Long an advocate of sound pain policies, Joranson helped establish the first state Cancer Pain Initiative in Wisconsin, which has been emulated by 46 other states. Joranson had received several grants from RWJF going back to the mid-1980s. His work produced one of the most effective devices in the portfolio to create state change.
From 2000 through 2007, the state pain policy progress report cards grading states on the quality of the pain policies and regulations were an important catalyst toward changing state policies and regulations. From 2000 to 2003, 16 states increased their report card grade. From 2003 to 2006, 19 states improved at least one grade level. The vast majority of states now have a grade above C, and no state’s grade has decreased since 2000. The report cards are now supported by the American Cancer Society, the Susan G. Komen Foundation for the Cure and the Lance Armstrong Foundation.

As early as 1992, Dahl received RWJF support to develop a network of State Pain Initiatives working to overcome barriers to pain relief through education, advocacy and institutional improvements. In 1996, a national organization, the Alliance of State Pain Initiatives, was established. Later grants supported expansion of the pain management work to hospitals, long-term care facilities and home health agencies.

With Joranson, Dahl worked with the federal Drug Enforcement Agency to develop a statement calling for a balance between addressing abuse and diversion of prescription pain medicines on the one hand and maintaining access for patients on the other. As a result of this collaboration, the DEA issued a joint statement in 2001 with a coalition of health care and pain prevention organizations that called for a more balanced opioid medication policy. Unfortunately, the dialogue between the DEA and pain community came to a halt a few years after this statement, as the DEA appeared to pull back from its earlier commitment (Duensing, 2006).

The other major effort to change state policy was through the Community-State Partnerships to Improve Care at the End of Life, which funded coalitions in 23 states, in part, to advocate for policy change. Several of the Community-State Partnerships, particularly those that included the state pain initiatives as coalition partners, worked closely with Dahl and Joranson to promote the pain report card and advocate for state policy change.

In addition to working on pain policies, a number of partnerships addressed state policies in related areas such as those related to advance directives, Medicaid reimbursement and nursing-home quality. Interviewees and Foundation staff generally recognized five partnerships as achieving significant accomplishments in changing state policies, including updating advance directives and removing conflicting provisions from legislation and regulations. However, many other coalitions faced difficulties and did not make much headway. A larger discussion of the CSP program is included in Objective 3 as many of the partnerships focused on “engaging the public.”
**Area D: Improving Institutional Quality**

The Foundation invested $5.6 million, or 3.4 percent of the entire end-of-life care portfolio, in grants designed to enhance quality measurement across clinical care settings. The grants had three general aims: to address quality needs in hospices and nursing homes, to advance quality standards developed for palliative care in hospitals, and to monitor state and national trends in care at the end of life. Projects in this part of the portfolio produced data, benchmarks and standards useful to service providers, health care administrators, policymakers and payers. As with investments in support of policy changes to pain management, grants made to promote quality were not central to the concerns of staff. They, however, recognized these efforts as having potential to address many segments of the field that did not otherwise fit into the grantmaking.

The Foundation made two major investments in institutional quality.

The first was in the work of Joan Teno, MD, Associate Director of Brown University Medical School’s Center for Gerontology and Health Care Research. A highly respected expert in quality measurement, Dr. Teno received 7 grants totaling $3.5 million from 1997 through 2006. Joan Teno’s work was to create and test new instruments to measure the care that institutions provide at the end of life, and create a web interface where health care providers can download instruments, submit data, and get results back evaluating their quality of care.

In 2004, the National Hospice and Palliative Care Organization (NHPCO), which represents 80 percent of hospices nationwide, took over and adapted the family interview component of Teno’s toolkit. The group now analyzes the data for its members.

In addition, Teno received a grant to disseminate national, state and local indicators of change in end-of-life care. The resulting Facts on Dying website contains a variety of policy-relevant information, including trends in site of death, family perceptions of end-of-life care as well as other important indicators, such as the presence of pain, advance directives, do-not-resuscitate orders and feeding tubes for nursing home residents and...
the severely cognitively impaired. The data are useful for advocates as well as national
and state policymakers.

The second major investment was to the University of Wisconsin’s June Dahl, to
improve the quality of pain care and create standards for its management. During a
meeting in 1996, Dahl and others acknowledged that education alone does not change
practice and that it would be necessary to mandate change by making pain management
a priority in the nation’s health care facilities. Dahl worked with The Joint Commission
to integrate pain assessment and management into the standards used to accredit health
care facilities across the U.S. The standards primarily affect hospitals but increasingly
long-term care and home health programs are seeking Joint Commission accreditation.

According to numerous interviewees, the work on improving institutional quality has
significantly advanced the field. Said one, “There has been tremendous uptake [in
quality]. I can honestly say that Teno has redefined how we think about quality related
to palliative care and has been instrumental in thinking about quality from the patient
and family’s perspective.”

Final thoughts on Objective 2

As CAPC emerged as the centerpiece of the work under Objective 2, it is possible to see
the direct links to the earlier work to reform medical education. In many ways CAPC
continued the “elite strategy” described by Kathleen Foley, MD when she noted that
influencing medicine meant speaking to powerful institutions in terms that they
understood and from vantage points they appreciated. The focus on hospitals gave the
work the institutional anchor it needed as well as a base for clinical training and
research. It maintained and strengthened what was then an area of distinctive
competence gained by the Foundation through its investment in and name recognition
related to SUPPORT: knowledge of how hospitals treat those who are seriously ill and
dying.

The other work, such as that in pain and quality, were good investments not just for
their accomplishments but also for their relevance to the range of institutions not
supported by the Foundation to any great extent—hospices, nursing homes and
community health providers.

While the Foundation made important investments in the area of pain, it is
disappointing that, although much was accomplished with relatively little money, the
strategy was not driven home sufficiently to ensure enduring results.

Much excellent work was aimed both at addressing the under-treatment of pain and
striding a better balance between regulators’ concerns about diversion and abuse of
controlled substances and physicians’ ability to prescribe medication for pain
management without fear of undue scrutiny. But with the recent prosecution of some
physicians for their prescribing practices, and the lack of clarity about the moral
rectitude of administering medication to those in pain, there seems to be significant risk
that ground will be lost.

The investments in improving quality of palliative care were on the whole important in
solidifying the substance and practice of palliative care. The work cut across many of
the divides in the field serving hospice as well as hospital, community as well as
institutional care. The quality initiatives addressed the needs of organizations such as
nursing homes and hospices, which, although not central to the portfolio, allowed these
organizations to benefit from the Foundation’s investment in end-of-life care.
The Importance of Purposeful Action

Assessment of Objective 3 Achievement

Work to advance Objective 3—engage the public and professionals in efforts to improve end-of-life care—employed communication strategies, often in conjunction with coalitions at the national, state and local levels, to reach out and engage the public and professionals. There were two major programs supported under this objective: Last Acts and Community State Partnerships.

From the outset, communications played a central role in the end-of-life portfolio. As RWJF’s president said, “I felt this was a chance to show that this was not a simple problem and that much needed to be done... this was a huge problem and we needed to put together a movement.”

As the Foundation’s communication staff were prepared to launch a campaign to promote what they assumed would be the positive

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1 There is an important caveat to apply to this part of the assessment. At the request of the Foundation, our review was not to include the major effort supported under Objective 3: Last Acts and its related programs. Although we conducted an interview and a short follow-up call with the program officer in charge of this work, we did not have the ongoing dialogue with this person that we had with the other lead staff persons working on end-of-life objectives. Many of those interviewed, however, talked extensively about Last Acts. We captured these comments but did not follow up with related questioning. In light of these constraints, we focus our attention on the broader strategic issues surrounding the goals, objectives, and tactics employed as part of Objective 3.
outcomes from the SUPPORT study, this work changed direction but stayed in full gear. The resulting Foundation-coordinated press campaign helped to get SUPPORT findings covered in a front-page story in the Boston Globe and on the ABC nightly news with Peter Jennings.

This work was important and motivated many actors in the health care system. Many of those interviewed credit the Foundation for playing a critical role in identifying an emerging issue and galvanizing advocates to address it.

A Coalition Approach

The two major programs under this objective, Last Acts and Community State Partnerships, both had coalitions and communication activities central to their work. This is perhaps not surprising. Foundation leadership at the time, publicly discussed the need to create a “movement” by activating people, both within and outside of the medical community. The Foundation had a history of using coalitions as a way of engaging organizations to reach a broad range of constituencies and it was therefore a natural for staff to use them here.

Area A: Last Acts

In 1995, the Foundation started and administered Last Acts, its first program after the release of SUPPORT findings, and before it formally developed the end-of-life care portfolio’s three objectives. Last Acts was “a coalition of professional and consumer organizations dedicated to making the public more aware of end-of-life issues and finding better ways to care for the dying” (Community-State Partnerships Grant Results Report). Its charge was to “work through [national] organizations and the media” to promote end-of-life issues. Specific activities included producing a web-site, quarterly print newsletter, a weekly e-mail newsletter, a bi-monthly partner memo, and various media relations activities to promote end-of-life issues geared to public as well as policymaker audiences.

In 2000, Partnership for Caring was awarded a grant to serve as the Last Acts program office, as responsibility was transferred from the Foundation to an external grantee. As part of a strategic planning process, the new program office identified four goals and 40 objectives for the program. The four goals were:

1. To create and maintain a climate of interest and support for improvements in end-of-life care and caring while raising expectations and demand for good care.

2. To strengthen Last Acts’ infrastructure and collaboration, in order to facilitate change in end-of-life policy and practice.
3. To promote specific improvements in medical care and spiritual and psycho-social caring near the end of life.

4. To create and operate a management structure that supports and facilitates all Last Acts strengths, growth and activity.

Area B: Community State Partnerships

The other major program, Community State Partnerships to Improve End-of-Life Care (CSP), also supported and built coalitions. Funded in 1997, the program was, in part, a response to requests from several organizations to address state policies, which determine in part how end-of-life care is provided, affecting such issues as:

- Hospice and palliative care insurance benefits
- Standards and regulations for nursing homes and other health care facilities
- Regulations around pain medications
- Medical and nursing school curriculum.

Through CSP, RWJF funded 23 grantees that were each given a $75,000 planning grant and received, on average, $440,000 for implementation. RWJF required grantees to secure matching grants equal to one-third of the RWJF grant. Statewide project staffs and partners were to gather information from community members about their needs and problems in obtaining end-of-life care. Sites held focus groups and town meetings and formed local coalitions and partnerships. The sites would use the findings to help educate policymakers, Medicaid directors and legislators about end-of-life issues.

In addition to the two large programs, the Foundation also invested in several other efforts to motivate and/or educate the public directly. The most prominent of these was support of On Our Own Terms, a four-part public television series by journalist Bill Moyers. At the time of its airing, this important series was viewed by more Americans than any other program in public television history.

Other grants included:

CSP Coalition Strategies

1. Curriculum change for healthcare professional training
2. Continuing education for practicing healthcare professionals
3. Changes in policies and procedures at healthcare facilities
4. Increasing consumer knowledge awareness and advocacy
5. Engaging clergy and faith communities in end-of-life care delivery
6. Broad-based public policy reform
7. Development of new reimbursement models
• *Finding Our Way: Living with Dying in America*, a 15 article series that appeared in major newspapers across the nation

• *Wit*, a major motion picture about a doctor diagnosed with cancer and grappling with the indignities of the disease and the health care system

• A documentary on Dame Cicely Saunders, founder of the hospice movement

To increase the impact of the Moyers’ series, the Foundation supported outreach to help organize and activate local coalitions to take actions in their communities to improve care at the end of life. CSP became a key force in developing these local coalitions. “About two-thirds of the more than 300 community coalitions developed for the Moyers special were spawned by CSP projects” according to the CSP Grant Results Report.

Finally, the Foundation made grants to organizations to promote improvements to and the use of advance directives.¹

### Strategic Considerations

Despite instances of excellence, particularly in bringing attention to end-of-life care and creating a supportive environment for professionals to focus on the issue, this line of work evoked the greatest degree of criticism from those interviewed. Many of the comments highlighted concerns that the work was unfocused and lacked direction.

Still, there were notable successes, including:

• Five of the 23 CSP coalitions achieved significant progress, mostly in the area of state-policy change addressing issues of policy related to pain management, advance directives and reimbursement (see discussion on Objective 2).

• Individuals seem to pay more attention to planning for their end-of-life care: *Five Wishes*, an advance directive, is legally binding in 40 states and has distributed over 9 million copies.

• This portfolio also created many tools and resources for advocates use in addressing end-of-life issues. Many interviewees spoke of the importance of these resources and materials, such as the report *Means to a Better End* (2002), which came out of this work.

• Most importantly, perhaps, the communication work resulted in significant media coverage and brought the issue squarely to the attention of the medical profession.

¹ An advance directive tells your doctor what kind of care you would like to have if you become unable to make medical decisions.
community and likely influenced how they viewed the issue. Although the
general public did not recall much of the Moyers’ series, key professionals within
the field likely did. The week after the airing of the series, CAPC received over
1,200 calls from hospitals around the country. We also heard that the coalitions
helped professionals on the ground feel part of something larger than
themselves.

The question remains, however, whether more traction could have been achieved if the
work had been more purposefully driven. Our interviews and review of written
evaluations and other materials revealed five key limitations to Objective 3’s approach.

1. Lack of clear goals and objectives

The aim of this part of the portfolio—to engage the public and professionals in efforts to
improve end-of-life care—was diffuse in both statement and execution. Raised as an issue
by evaluators of both programs:

“We were constantly trying to get them to clarify their objectives and be
thoughtful about whether their interventions would get them to those
objectives.”

Many of those interviewed described how this affected the work:

“CSP suffered from a lack of parameters regarding what the partnerships should
look like and accomplish. You don’t want uniformity but some standards…. CSP
involved projects of every imaginable structure and set of goals—from policy
change to community outreach to professional education. The Foundation was
trying to allow flexibility but it was too loosey goosey. Because of the differences,
it was hard for the NPO to mentor each partnership.”

“Many of the [CSP] sites didn’t have solid benchmarks, and many had unclear
goals.”

“The [consumer-focused programs] were too broad and too diluted. People
should walk away from any consumer education effort with an understanding
that they have a choice in their medical care, especially at the end of life.”

“Last Acts and related efforts were not effective because they didn’t focus
enough. Letting a thousand flowers bloom is okay to start, but then you need to
focus farther on.”

“Last Acts goals were vague. Start a national dialogue about what? To what
As described by Gibson in the CSP Grant Results Report, a key problem was “the program perhaps erred on the side of being too inclusive. The projects got everyone at the table, with the result that it became difficult to focus on two or three strategic moves. Perhaps there were too many interests, too many people in the process.”

2. A disconnect between objective 3 and the other objectives

Communication and public engagement are best understood as tools used to accomplish larger goals. Actions sought under Objective 3—whether to be taken up by professionals or a segment of the public—may have yielded more if they had been tied to the work being done under the other two objectives focused on systems change.

Unfortunately, the connections were not as strong as they should have been.

RWJF documents hypothesized about two reasons for engaging the public:

1. Need for external pressure on the medical system. The push for medical system change from within the medical establishment would go only so far; to get the medical establishment to make significant system-wide change, the public needed to demand changes and put pressure on medical leadership. This problem statement was the one most often cited in written documents.

2. Need for individuals to plan better. Individuals don't plan for end-of-life care, and they need to increase their individual planning, mainly through knowing about hospice/palliative care and asking for it when appropriate; completing advance directives and medical power of attorney; and being aware of how pain can be managed.

Although the first rationale for systems-focused change was cited more often, most of the work supported under this objective appeared focused on individual change.
Perhaps a good way to illustrate this point is by looking at the calls-to-action included in the message strategy developed for the Last Acts press conference (See box on Last Acts Campaign, March 1999) shortly before Kevorkian’s trial. Most of the calls focused on how individuals can plan better for themselves or their loved ones. The need for the public to put pressure on the medical system to change was not raised. Nor were the calls connected to the work being done as part of the other objectives.

The communications work arguably could have been better aligned with Objective 2 by focusing on increasing public demand for palliative care. A call-to-action might have been, “Make sure that your loved one is being cared for in a hospital that has a palliative care center. Visit the CAPC website to find out which hospitals in your area do.” Another important call-to-action might have drawn attention to the need for more balanced state pain policies.

A similar example of a lost opportunity for direct public action can be found in the content of the 15-part newspaper series “Finding Our Way: Living with Dying in America.” The series highlighted a broad range of stories from dealing with the loss of a child to coping with widowhood. Although well received and published in many national papers, calls-to-action were rare and, where offered, focused on individual action, rather than promoting the kind of system change envisioned by work under the other two objectives.

Similarly, while the Moyer series was watched by many, in part because of the time and effort spent

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**EXAMPLE OF MESSAGES FROM THE LAST ACTS CAMPAIGN**  
**March 1999**

**MAIN MESSAGE:** There are things you can do!

**Sub-messages**

1. Start talking about end of life care in your family. Start before someone is seriously ill. You don’t want family members to have to guess your wishes if you can’t speak for yourself. Living will and health care proxies help.

2. If you have a doctor you feel you can talk to about your wishes, do so—before you become seriously ill. Let your doctor know what is important to you about the end-of-life care you get.

3. Seriously ill patients should speak explicitly with their doctors about pain control, life support and where they want to spend their final days.

4. Don’t let someone you love be in pain. Make sure that their pain is treated.

5. Be a volunteer. Help out a local nursing home or hospice; do something for a friend or relative who is a caregiver, start a discussion group in your church or senior center.

6. Be an advocate for change. Work with any of several national organizations trying to improve care of the dying.

7. Become informed about good end of life care. To take a simple example, when people buy a new car, they talk about it with their friend, family members, and co-workers; they check consumer information; they read up, and some check the Internet. When families are faced with a serious illness, these same activities are needed. It may take some digging, but many organizations are ready, willing and able to help.

8. Be prepared to ask tough questions. Again and again.
by the coalitions, the evaluator of the program found that viewers did not remember
specific messages from the series and “recalled little beyond an emotional recollection”
of the key themes (Balch, 2002). The impact of the series on health professionals,
however, was likely greater; calls to CAPC increased dramatically. Although the
evaluator found that the series impact “did not ripple deep, long or far to the general
public or health professionals.”

3. No way for the public to voice discontent

One of the biggest disappointments expressed by those interviewed was that the work
did not allow advocates a platform to voice their discontent with the current system.
Several comments underscore this point:

“What’s missing in the field, and what I worry about daily, is still today the
virtual absence of an engaged citizen voice. The National Hospice and Palliative
Care Organization is not a consumer organization. RWJF made a good-faith
effort with the Partnership for Caring program. It had been designed to be a
consumer watchdog and activist organization, able to take strong consumer
action and able to withstand the heat. Unfortunately, the initial activist thrust of
Partnership for Caring was diluted when it was folded into Last Acts. Once that
happened, the unique intended value of Partnership for Caring was lost.”

“Absent a citizen consumer voice in the mix, I worry that all that has been done
will only move the needle so far…. We need group pressure [on the medical
system].”

“People who have had these types of experiences are mad. They want to do
something about it and don’t want others to have to deal with the same issues.
But they just don’t know how. There was so much that could have been done
here.”

“There is still a huge gap. Individuals who want and need end-of-life care and
still don’t know how to get it and be their own advocates.”

4. Promotion is just one part of advocacy

Although research was done to understand better the public’s interest and perception of
end-of-life issues, most of the analyses focused on how to promote these issues. But
promotion is just one part of advocacy, and good communication strategies do more
than just promote a topic. Effective strategies need to incorporate understanding about
how to motivate people to take actions that can lead to the change sought.
Although staff understood the challenges related to engaging and motivating the public around end-of-life issues, there seemed to be little translation of this understanding into ways to overcome barriers. While providing more information may get some attention, it is not likely to overcome the obstacles to real engagement and action.

While grantees in other parts of the portfolio made substantial headway in addressing these issues, those lessons were not incorporated into the work done under this objective. For example, CAPC achieved significant advances in this regard by moving away from talking about dying and “end-of-life” to “getting the care you need.”

5. Too little guidance from the Foundation

Many of those interviewed who received grants under this objective wanted clearer direction and focus from the Foundation concerning priorities. Instead, the Foundation delegated agenda setting to each coalition.

Perhaps because of a lack of certainty about what the Foundation should do after SUPPORT, the approach taken was to let each coalition decide what would work in their communities. This could be a sound approach, yet without guidance from the foundation about what it sought to learn about, coalitions tended to work on many things at once, resources were therefore diffused and many were without the capacity to tackle the most difficult issues.

Overall Objective 3 Conclusions

The use of coalitions was one of the two central strategies employed under this objective, yet their suitability for the work was never examined. Perhaps because the Foundation found themselves without a strategy after the failure of SUPPORT or because the RWJF used coalitions repeatedly to address many and varied issues, or because the officer in charge of this work believed that only communities themselves could decide what they needed—or all three—coalitions were chosen to address a vast array of issues in their communities. Underneath all of this, however, was still the belief that the coalitions had the potential to apply enough pressure on the systems that regulated or delivered care to create change.

With few exceptions, what evolved was a potpourri of activities. Some coalitions in fact did undertake the difficult work of policy change but these were the exceptions. And the hoped for relentless force for systems change did not emerge.

Undoubtedly, the Foundation’s national program office offered assistance to help coalitions understand their capacities and build capacity where there was little. But no office could support the vast array of activities undertaken by the coalitions. Further, resources were diffused in a corresponding manner.
The questions that make sense then to consider are: when can coalitions best address a problem, how can they be supported to focus their attentions on what they can achieve and how can they be supported to do well what they can.
Building the End-of-Life Field

Conclusion

What did the Foundation accomplish?

SUPPORT remains the single most important source of knowledge in the area. No study before or since has looked so closely and systematically at how people die in America. Its approach was rigorous and its researchers beyond reproach; the study’s credibility was never an issue. The Foundation is to be credited for seeing this as an important moment to make a clarion call to action. It succeeded in mobilizing parts of the medical community and, more importantly, in moving the issue from the fringe to the center of the health care debate.

Buoyed by this new environment, a group of leaders in the field used Foundation support to accomplish significant advances, including:

1. Creating demand for enhanced knowledge and skills in end-of-life care by identifying and pushing key levers within the medical and nursing education systems. By engaging and convincing the National Board of Medical Examiners and National Council of State Boards of Nursing to include questions on palliative care in their licensing exams for physicians and nurses, grantees were able to set off the creation of a series of incentives which went far to align the rest of the system.

2. Enabling The Joint Commission\(^1\) to develop a new standard for assessment and treatment of pain.

3. Creating a supply of knowledge to meet new demand by supporting research, publishing, curricula development and approaches to training faculty

4. Creating an institutional driver, the Center to Advance Palliative Care at Mount Sinai School of Medicine in New York, to meet increased demand for knowledge of palliative care within the hospital setting, and doing it in a way that was acceptable to hospital CEOs, admitting physicians and specialists alike.

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\(^1\) Throughout this document, we refer to The Joint Commission, which had been called the Joint Commission on Accreditation of Health Care Organizations (JCAHO) during the period from 1987 through 2006.
5. Supporting some of the core infrastructure needs of an emerging field by
developing standards of care and the capacity to assess and monitor those
standards across institutional settings.

6. Bringing attention to the quality of pain treatment in states with regulatory
policies that inhibit physicians in caring properly for patients in pain.

7. Fostering, in partnership with the Project on Death in America, the advancement
of careers and emerging leadership in a relatively undeveloped field.

8. Creating an enormous base of knowledge in a relatively short period of time,
particularly in areas of clinical care and organization and delivery of services.

By helping create demand for knowledge and building the capacity to produce that
knowledge, the Foundation created a linked system of supply and demand that nearly
all interviewed say “put the field on the map.”

- “Over the ten years of RWJF grantmaking, they have created a groundswell.”
- “There is a generational difference in EOL care today. RWJF has significantly
  influenced the shift.”
- “Few foundations can say they built a field of medicine, but RWJF can... The
  effect is that they built a very important field of medicine that hadn’t existed
  before.”

But what exactly is “field building,” anyhow? Many speak the phrase. Few have
formally defined it. Yet most have a sense of what it is (and what it isn’t), a sense we
might unpack as follows:

A field has an identity with discernable edges; those in it know they are in it. It is
populated by individuals with different roles. There are leaders and followers,
knowledge producers and knowledge appliers. Professional fields have trained
practitioners, researchers and educators as well as institutions where training, research
and education occur.

A field has a body of knowledge and practice which, as it matures, becomes more
organized. It develops and applies standards. Quality and its absence become more
recognizable. A field needs places where the work happens and places where people,
knowledge and practice intersect. A field has the means to foster collaboration and
focused action. A field often has strong emotional overtones leading practitioners to
become advocates who work to sustain its identity. A field grows.
Perhaps most significant, a field is more than individual organizations focused on the same issue; its strength comes from the connections holding organizations together. These connections can take the form of shared ideas, identity, purpose, language and incentives.

**The Foundation’s impact on the field**

How then did these and other investments translate into building the field?

Specifically, the Foundation had an impact on the field through the following seven key efforts:

1. **Fortifying the identity of palliative care as a legitimate arena of medical and nursing practice.** The Foundation helped turn an area from what many medical professionals saw as a small, fringe group of social workers and a few isolated doctors into a credible field within medicine. Foundation staff made three key strategic decisions:

   - To work within the accepted culture of medicine, they forwarded what one field leader called an “elite strategy,” i.e., funding the best to do the best based on research of high quality
   - To broaden palliative care beyond the hospice movement, they moved it into the medical mainstream
   - To reframe palliative care as care for the living as well as the dying, they thereby aligned it better with the training and instincts of physicians.

2. **Building the base of knowledge as well as providing funding to organize and communicate it to others in the field.** There have been many instances of foundations attempting to expand the knowledge base in a field and even more instances of research just sitting on a shelf. That was not the case here. RWJF-funded projects yielded literally hundreds of articles on clinical and organizational approaches, produced by a variety of sources and appearing in journals such as *JAMA, Journal of the American Geriatrics Society, Critical Medicine, Journal of Palliative Medicine, Innovations in End-of-Life Care*, and many others. The SUPPORT project alone produced 181 published papers. Research was a particularly important component, as having a deep knowledge base signaled to the medical profession that palliative care is a substantive field. (See Appendix 4: Building Knowledge)

The research focused on several key areas in the development of field:
• **Practice and organizational models:** The Journal of the American Medical Association series, “Perspectives on Care at the Close of Life” (which ran from 2000 through 2007), shared case studies and clinical approaches, while Promoting Excellence disseminated numerous articles on the delivery of palliative services. CAPC has broadly distributed “how to” manuals on most aspects of running hospital-based palliative care and related issues.

• **Curricula:** EPEC, the Medical College of Wisconsin and Harvard Medical School developed curricula for practicing physicians as well as those at various stages of training.

• **Institutional standards:** The Joint Commission, the National Consensus Project for Quality Palliative Care and the National Quality Forum set standards for good practice, and researchers developed assessment instruments to measure changes in policy and institutional practice.

3. **Fostering the development of a highly influential network of leaders emerging from the Project on Death in America’s Faculty Scholars Program.** Of the 87 faculty scholars supported by PDIA, 20 went on to assume major roles in Robert Wood Johnson Foundation programs. According to Foley, the Faculty Scholars Program identified and supported “outstanding clinical and academic leaders in medicine who could change medicine from the inside.” Simply put, RWJF and PDIA had one of the best-executed partnerships in philanthropy. PDIA identified the leaders, and RWJF put them to work (See Appendix 5: PDIA Scholars’ Roles in RWJF Programs)

4. **Supporting the creation of an agenda for the field.** Many credit the Foundation for providing opportunities for key leaders to come together and craft strategies, reframe problems as resolvable concerns, and generally advance an agenda forged with field leaders. In addition, the Foundation supported agenda-setting documents, such as the Institute of Medicine reports that framed issues and provided a basis for discussion and negotiation among key actors and potential grantees.

5. **Building the institutional base of practice for palliative care in a medical setting,** primarily through the Center to Advance Palliative Care. CAPC’s activities simultaneously helped to increase the availability of palliative care for patients and families across the US, and reinforce the clinical base for training.

6. **Developing core clinical and institutional practice standards,** which also provides a strong basis for advocacy when standards are not being met.
7. **Motivating medicine to act** by making the case to physicians both that their decisions have severe consequences for how their patients die and that there are reasonable potential alternatives.

To a good extent there is a direct line from the Foundations’ application of these practices to tangible evidence indicating that the field has grown substantially. Consider the following:

- The number of hospitals with palliative care programs increased 96% from 632 to 1240 between 2000 and 2005 (Kuehn 2007). As of the beginning of 2007, 30% of all U.S. hospitals, and 70% of hospitals with 250 or more beds, have adopted palliative care programs (Center to Advance Palliative Care). Almost all hospitals within the Veterans Health Administration have a palliative care program (National Palliative Care Research Center website).

- The field of palliative and hospice care was formally recognized as a subspecialty by the American Board of Medical Specialties in 2006, and 10 specialty boards have accepted it as a subspecialty (Kuehn 2007).

- There are now 56 active fellowship programs in hospice and palliative care, with five more in formation, offering a total of 140 fellowship positions, including 20 research slots (American Academy of Hospice and Palliative Medicine website).

- The Accreditation Council for Graduate Medical Education (ACGME) made the decision in 2006 to accredit hospice and palliative medicine fellowship programs. Starting in 2008, physicians can become board-certified in hospice and palliative care, and fellowship programs can pursue ACGME accreditation (Kuehn 2007).

- Between 1996 through 2006, more than 2,800 physicians obtained certification from the American Board of Hospice and Palliative Medicine (ABHPM website).

- The American Academy of Hospice and Palliative Medicine began in 1988 with 250 founding members, and has grown to include 2,600 members (AAHPM website, Kuehn 2007).

- Early studies, some produced by RWJF grantees, indicate improved clinical, satisfaction and utilization outcomes related to palliative care services (Meier 2006).
• There is also evidence that palliative care programs based in both hospital and community settings have led to increases in hospice referral rates and hospice length of stay (Meier 2006).

• Between 1990 and 2000, US census data show a 17% decrease in the number of individuals who died in a hospital (Kuehn 2007). More than 75% of adult deaths occur in institutional settings—more than 50% in hospitals and 25% in nursing homes. Meanwhile, 85% of pediatric deaths occur in hospitals. These trends run counter to the end of life preferences of Americans, more than 90% of whom say they would prefer to die at home (Meier 2006).

A critical moment

According to many interviewed, the end-of-life field is at a turning point, likely to falter if the second wave of leadership goes unsupported. “This is only a beginning,” said one leader. “All we’ll have done is to establish a nascent field.”

A soon-to-be-released article illustrates the point that there are few sources of funding to attract and develop young and mid-career faculty (Gelfman and Morrison, in press). Between 2003 and 2005, 25% of published research was conducted without extramural funding, and 50% of the studies were supported by foundations, including RWJF. As the level of investment from foundations for End of Life is quite low, we can extrapolate that the overall amount of support available for research in the field is negligible.

In other words, it is not at all clear whether a next tier of professional leaders will be able to establish themselves as academic and clinical leaders in this field. The ripple effects of this problem may threaten all aspects of accomplishments to date, as hospital-based palliative care jobs go unfilled for lack of qualified faculty.

The field faces two sustainability challenges in particular:

First, after PDIA and RWJF ceased their support toward end-of-life issues, no foundation has replaced them either in terms of providing philanthropic leadership or substantial dollars. Based on a review of grants listed in the Foundation Center database for 2004 and 2005, it is clear that the vast majority of grants in those years were very small—under $25,000. Appendix 7 shows the 15 foundations making the largest grants in 2004 and 2005. RWJF’s investments clearly dwarf those of other funders. The Emily Davie and Joseph S. Kornfeld Foundation has made a substantial commitment in the field, but even their investment supporting faculty scholars, $3,025,000 over seven years, pales in comparison to the investments of RWJF and PDIA.

Second, government has offered little support to build either careers or the base of knowledge in the field. Between 2001 and 2005, the National Institutes of Health made
only 418 total grants for Palliative Care Research (Gelfman and Morrison, in press). During this same time period, only 0.1% of total NIH funding supported Palliative Care.

What is the role of a foundation in strategy development?

The Foundation clearly had the wherewithal and fortitude to pursue an important issue at a moment when it occupied the attention of the public in dramatic ways. Yet it was more than just good timing. Foundation staff played a critical role in making these advances possible, and they did so with more than just the provision of funds.

The Foundation officer most responsible for much of the portfolio played a pivotal and strategic role. Leaders in the field recognize that her contributions go well beyond those of the typical program officer. Most of those interviewed credit her with working closely with key actors in the field to shape a vision and then help translate that vision into strategy. This work was neither what is known in foundation parlance as “proactive” or “reactive” grantmaking. She didn’t create strategy from whole cloth. Nor did she simply respond to what came to her. She was in the mix, and helped to create the mix. In essence, she facilitated the shaping and framing of an agenda for action based on the best kind of insider knowledge of how a system works. This role is important, and it was done well.

The resulting strategy, therefore, was informed and subtle enough to identify real and powerful incentives and leverage points that could magnify small actions into far larger-than-expected effects. The intelligence of this work came from a deep understanding of the ways that relationships and dynamics affect how a system responds to demands for change.

The strategy also was very intently focused. It identified a few key leverage points, chosen because they had power to entrain other subsequent actions and effects. If achieved, supported efforts—like changes in physician licensing—would set off ripple effects throughout the system. To some extent, this “systems approach” obviated the need to worry about “institutionalizing” the Foundation’s work. As the work was being done, it was built into existing structures and positions. For the most part, new organizations were not created; rather, existing organizations were given incentives to align with the goals of the effort, thereby mitigating issues of sustainability. Grantees were often chosen because of their credibility and power to influence key decision makers.

The strategy also considered where change was most likely to occur, and weighed the potential investments based on their relative risks. Where strong players were not in place and opportunities to advance change less likely, investments were not made.
We don’t want to exaggerate the positive outcomes of the work—either how it was done or the consequences of some of the decisions made:

- It evolved and got better over time. There were some weak choices, particularly early on, but staff learned from them and applied the lessons. The objectives as cast were very broad and stayed that way. Some work never really came to fruition.
- To some extent, the best work was happenstance. But when good work was occurring, the officer recognized it and made the most out of it.
- The officer could disappoint many as she applied her high standards for identifying good work and good people and kept a relentless eye on discerning whether and what kind of change was achievable. When high-leverage projects were identified, the officer supported them well, and consequently said no or delayed response to many others.
- The strength of the work came not just from the Foundation, but from the strength of its ties to the field, an approach that is not well appreciated in philanthropy for its subtlety and lack of bravado.

**How does a foundation contribute to strategy?**

In light of the widely recognized successes attributable to this program officer, what can be learned about the role of a foundation in strategy? How can a foundation contribute to or impede success?

Five key points emerged from the assessment.

1. Foundations have an important responsibility to articulate what they want to achieve in specific enough terms so that grantees, as well as staff, can organize their actions accordingly. It’s a foundation’s responsibility to understand its fields of investment and how it can best contribute to these fields.

   In some cases, however, foundations may not be sure what their objectives should be, as was the case with end of life. Where too much uncertainty exists, a foundation needs to be clear about what it seeks to learn to focus goals and commit to achieving more clarity about its intents over time.

   Given that the Foundation found itself without a clear direction at the time, it was a thoroughly legitimate strategic stance for it to delay establishing explicit goals, objectives or approaches until it learned enough to become more specific about its intent. However, there was no system within the Foundation to reflect
on what it was learning and refine its objectives accordingly. And the goals, at
least as described in the Foundation’s written objectives, never did become more
focused than they were at the outset.

2. The way foundations organize themselves and manage their work will contribute to effectiveness.

Strategy development was delegated to the end-of-life team as a whole, with no single individual authorized to manage the strategy and resolve disagreements. The teams, a relatively new organizational structure at the Foundation, had no leader but rather a convener. It was not clear who was ultimately responsible for the decisions made within the team, nor how to resolve conflicts about those decisions.

This lack of authority, combined with such broad goals, gave program staff the leeway to pursue almost any agenda. The Foundation goals then became what each program officer made them out to be.

It became clear that there was no one “overall foundation strategy” in end of life, but rather two, each led by a different program officer within the team. Not surprisingly, grants were made based on two very different theories of change, built on dissimilar perspectives. One was based on ideas about individual change, the other on ideas about systems change. These perspectives rarely operated in concert, and, at times, were in conflict. They were never systematically explored or managed as fundamental strategic issues. Instead, they were seen as a tension between “two strong-minded individuals.”

Because of this approach, the Foundation’s de facto strategy became that of the individual program officer. Therefore, the quality of the strategy was affected most by the decisions of individuals rather than the organization as a whole. The tensions, while recognized by many in the field, were never treated as strategy differences and were not explored or managed as such. Grantees were left to interpret and adjust as needed.

3. A foundation has an important role in assuring quality across grantmaking and allocating resources with some explicit logic and standards applied.

Innovation requires a certain amount of freedom, but it also requires some direction and quality control. Foundation leadership everywhere has an important role to play in examining strategy clarity, alignment and adequacy of financing. Grantees recognized differences between the officers’ approaches and were outspoken about their confusion and concerns. Yet many interviewees
expressed frustration that they had no place to bring their concerns other than to
the program officer.

4. Foundations can use information to advance and motivate a field toward a goal.
The Foundation did not require reliable information on patient outcomes and
therefore, we still do not know whether Americans die any better than they did
prior to these reforms. And we do not know whether these achievements led to
long-term improvements in care.

5. Foundations need to consider their own role as an actor in the field. Foundation
strategy is largely thought of as an articulation of what they will support others
to do. Yet, because of their resources, influence, connections and intelligence,
foundations have their own role to play, which can add distinct value to the way
a field operates. The challenge for foundations is to discover what roles they are
able to play well.

RWJF brought unique assets and strengths and worked in partnership with the
field to create change. With its ability to convene, its credibility and its ability to
influence key organizations and individuals, RWJF played an important and
distinct role in executing this strategy.

Implications for Foundation Strategy

Seeing this as a study about strategy as much as about work done in the area of end of
life led us to consider ways a foundation might address some of the issues raised in the
report. Hindsight is 20-20, of course, but our research underscored ways that the
Foundation—or any foundation—might have improved its strategy. We offer these
ideas for consideration:

1. **The capacity of program staff to develop an intimate understanding of the
dynamics of a field is essential, but it does not obviate the need for broader**
strategy discussions within the Foundation. The Foundation has an important role
in the strategy creation and execution process. Questions regarding the overall
direction of the programming effort—including the core elements of the change
strategy, the implications for resource allocation, the role of other funders and how
strategy will be monitored and learning harvested—are of central importance to
overall strategy and Foundation effectiveness. Staff need opportunities to work
through higher-level concerns with management and to hear from colleagues in a
constructive setting.

2. **Foundations need to discover ways of engaging talented program staff around the**
quality of the decisions they make. Foundation managers across philanthropy
struggle with ways to achieve the balance of managing without micro-managing senior staff embarking on an ambitious course of action. While staff need some freedom to explore and pursue reasonable hunches built on tacit knowledge, they also need to make a solid case for their strategic decisions. Management needs to break out of the cycle where problems are identified but not addressed or where uncertainty is masked by unwarranted assurance, which require skill and involved management.

3. **The Foundation can work to develop clearer objectives that reflect the reality of the intentions behind investments.** As described in the report, all three objectives were broadly cast. As written, they often chopped up or obscured the real intention behind the work taking place. In reality, the Foundation’s funding was fairly focused, particularly in the later years; clear and focused objectives could have signaled the field about the Foundation’s real interests. Grantees crave this clarity. The Center for Effective Philanthropy has reported that grantee satisfaction is associated most with how grantees experience the clarity of a foundation’s goals and guidelines.

4. **Keep a focus on the end results desired.** For the most part, evaluation in the portfolio was weak and underused. How patient care is changing (or not changing) as a result of the different grantmaking strategies remains an open question for the field.

At one point, the Foundation considered using Joan Teno’s tracking of state and national indicators as a vehicle to gauge the achievement of its objectives in end-of-life care and to answer the overall question, “Where are we as a nation in providing quality medical care for seriously ill and dying persons and their loved ones?” This did not come about.

This is particularly surprising because of the traction gained from the release of findings from SUPPORT. The Foundation might have repeated the generalizability survey SUPPORT used to validate its findings as a way to assess whether hospital care improved over time. Such a survey might have provided information to the field about progress, as well as serving as a tool for advocacy.

It is also worth considering the types of information that could best serve as measures of strategy development. In recent years, for example the Foundation has invested in the use of the indicators (as part of its Balanced Scorecard effort); the question is whether these indicators tell you how well a strategy is evolving. The Foundation might consider a range of devices to gauge the following:

- Do we have the problem right and have we framed it in a way that it is understandable, solvable and of interest to target audiences?
• Are pursued solutions garnering interest, showing results, and are they scaleable?
• Where are obstacles emerging and what solutions are coming forward in relation to them?
• Where can we experiment with ways to learn from the field?

The intent behind raising these questions is to institute the kind of feedback loops that allow for important course corrections and spur meaningful organizational learning.

5. Insert the concept of portfolio information management into team strategy development It became clear to us over time that there were distinct lines of work (or sub-objectives) under each objective. After considerable effort we were able to construct spreadsheets that allowed us to track investments along these lines of work and to record what their intended outputs and outcomes were. It allowed us to see how much was invested toward what end and to gauge the sufficiency of funding. With a device such as this simple one, teams could track the progress of their investments toward a goal such as achieving scale or other dimensions of achievement. A tracking device like this would also shed light on the question of how much is enough of any type of grantmaking (either for an individual grantee or across many) to assure goal achievement and sustainability.

6. Assess the costs of a program relative to what it is likely to achieve. All foundations need to do a better job of asking questions about the reasonableness of an investment and whether continued investment is worth it. Below are the costs associated with major efforts funded by the Foundation (from highest to lowest):

• $54.5 million: Last Acts and related efforts
• $29 million: CAPC
• $19.8 million: Promoting Excellence
• $15.8 million: Community-State Partnerships
• $8.8 million: Medical education
• $7.3 million: Quality
• $6.5 million: EPEC
• $6.4: Nursing
• $6.3 million: Direct media outreach
• $4.3 million: State policy advocacy/pain

Key questions to ask about this work, as well as of future grantmaking, are:

• Are the purposes and goals clear enough to justify a large investment? In this portfolio, the highest investment went into the least defined of the three objectives—that of public and professional engagement.
• If we are unsure about an approach, what type of investments or assessments will help us learn more? What specific areas and questions do we need to learn more about? Defining areas for learning and specifying learning objectives help ensure that lessons will be captured and applied toward strategy development as it evolves over time.

• What justifies large expenditures? The Foundation made several large grants early on before it knew what it wanted to achieve and without clear learning objectives (e.g., Promoting Excellence). Although some significant results came out of this program, many of them came from a small investment in the working groups. A key issue here: why invest so much money without knowing what needs to be done? On the other hand, the CAPC investments started small and grew over time. When making large investments, a range of issues need to be considered such as: grantee capacity and also the capacity of the field to absorb an intervention in a sustainable way; appropriateness of the intervention; alignment with other parts of the strategy.

• How realistic are the promises being made? Inserting more realism into the grant process, even with a “back of the envelope costing out” is needed. These discussions should go beyond the amount that the Foundation has at hand. A chapter in the most recent anthology discusses the importance of what the author called a “denominator exercise.” All foundations need to do better at estimating what it will cost to accomplish their goals. It is only with this kind of realism that a foundation can make strategic decisions about its capacity to fund an array of different projects and/or the need to adjust its goals.

7. How can the Foundation experiment with ways to review, discuss, monitor and learn from strategy over time? There is no set approach as to what structures or processes will work best in any single organization but most large foundations need better ways to insert their role into the strategy process regarding resource allocation, quality, goal articulation, program cohesion and institutional role in the field. Program officers alone can’t bring this perspective to strategy.

The Foundation is not alone in this problem. While many foundations have processes to discuss and approve grants, few have adopted approaches to review strategy and even fewer have found ways to resolve problems identified in the strategy. More often than not, questions are raised that officers address only peripherally.

We appreciate, too, that not every problem has an identifiable solution, nor will every solution work. The challenge for foundations is to be both tough about what will suffice for good strategy and willing to suspend disbelief when an approach of trial and error is warranted. But strategies that fall into the latter category need to be
monitored closely for evidence of market uptake, capacity to execute and effects. Too
often, strategy problems that appear early are glossed over and overlooked, only to
rear up in more significant ways as time goes by.

It helps to have strategy prepared as a written document but not overly stylized. It is
likely that conflicts and contradictions will emerge in writing that may appear to be
the result of vague or unclear writing, but, in fact, may indicate team conflict or
assumptions that have not been confirmed. This is the opportunity to engage in real
questioning, information gathering and strategy clarification, at times with the help
of outside perspectives—all the hallmarks of organizational learning. In fields such
as those of interest to the Foundation, the key to good strategy is learning with an
eye toward identifying “good bets” and what makes them work rather than with the
hope of finding and committing to solutions with unwarranted certitude.

This way of working has implications not just for program leadership and staff but
also for evaluation. Evaluation should be able to apply its wares of research,
analysis and reflection to efforts to improve problem definition, strategy
development and execution, as well as to domains seen more traditionally as within
the purview of evaluation.

Concrete Results

The grantmaking under end of life was extraordinary in many ways, and the results are
tangible. The work helped produce a body of knowledge, leading practitioners,
standards for practice, ways to assess quality, and changes in how pain is assessed and
treated. Without a doubt, palliative care now has a meaning within medicine and its
institutions that didn’t exist before. Significant system change occurred as a direct result
of Foundation grants. And there was individual change: many more people now have
advance directives, and, in most states, they are becoming more enforceable. The
Foundation, without question, helped build a field.

This story holds broader implications for foundation strategy across the sector. The
Foundation’s investments in end of life tell us much about the role of a foundation—
what it can do, what influence it can exert, how it can shape an agenda, and how it can
both facilitate and impede a field. We suspect, but will never know for sure, that more
could have been done if the Foundation had forged a deeper alliance among the parts of
the whole.

Still, the Robert Wood Johnson Foundation advanced a field rich with talent and ideas—
not through luck (or luck alone) but through strategy. It was not the kind of strategy
based on the inputs, outputs and outcomes derived from “logic models,” but strategy
built on close-to-the-ground reconnaissance, intimate understanding of how systems
work and develop, and, most important, a deep appreciation of and willingness to work side-by-side with talent in the field.
APPENDIX 1:
EXPERTS INTERVIEWED* 

Steven Albert, PhD, Associate Chair for Research and Science, Graduate School of Public Health, University of Pittsburgh

Katya Andresen, Vice President for Marketing, Network for Good

George Balch, PhD, Principal, Balch Associates

Scott Bane, Program Manager, Jhet Foundation

Susan Block, MD, Co-Director, Harvard Medical School Center for Palliative Care, Chief, Division of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute

Ira Byock, MD, Director, Palliative Medicine, Dartmouth-Hitchcock Medical Center

Joel Cantor, ScD, Director, Center for State Health Policy, Rutgers, The State University of New Jersey

Myra Christopher, President and Chief Executive Officer, Center for Practical Bioethics

David Clark, PhD, Director, International Observatory on End of Life Care

Karyn Collins, MPA, former Director of Communications, Promoting Excellence National Program Office, Center for Ethics, University of Montana

J. Randall Curtis, MD, MPH, Professor of Pulmonary and Critical Care Medicine, Director, Harborview/University of Washington End-of-Life Research Program

June Dahl, PhD, Professor, University of Wisconsin School of Medicine and Public Health

W.A. Drew Edmonson, JD, Oklahoma State Attorney General

Linda Emanuel, MD, PhD, Buehler Professor of Geriatric Medicine, Director, Buehler Center on Aging, Health and Society, Feinberg School of Medicine, Northwestern University

Seth Emont, PhD, Principal, White Mountain Research Associates, LLC

* Titles and affiliations as of April 2007.
Betty Ferrell, PhD, Professor, Nursing Research and Education, Research Scientist, City of Hope National Medical Center

Kathleen Foley, MD, Chair and Attending Neurologist, Pain and Palliative Care Service, The Society of Memorial Sloan-Kettering Cancer Center

Mary Ellen Foti, MD, State Medical Director, Massachusetts Department of Mental Health

Rosemary Gibson, MSc, Senior Program Officer, The Robert Wood Johnson Foundation

Elinor Ginzler, Director, Livable Communities, Office of Social Impact, American Association of Retired Persons

James Hallenbeck, MD, Assistant Professor, Stanford School of Medicine, Director, Palliative Care Service, Palo Alto Veterans Affairs Health Care System

Bernard Hammes, PhD, Director, Medical Humanities, Gundersen Lutheran Medical Foundation

Bob Hughes, PhD, Chief Learning Officer, Robert Wood Johnson Foundation

Hollye Jacobs, BSN, Project Coordinator, ELNEC Pediatric Palliative Care Training Program

Bruce Jennings, MA, Senior Consultant, The Hastings Center

David Joranson, MSSW, Director, Pain and Policy Studies Group, University of Wisconsin Comprehensive Cancer Center

Mary Jane Koren, MD, Assistant Vice President, Quality of Care for Frail Elders, The Commonwealth Fund

James Knickman, PhD, President and Chief Executive Officer, New York State Health Foundation

Michelle Larkin, MS, Senior Program Officer, The Robert Wood Johnson Foundation

Allen Lichter, MD, Executive Vice President and Chief Executive Officer, American Society of Clinical Oncology

Bobye List, Executive Director, The Emily Davie and Joseph S. Kornfeld Foundation
Dale Lupu, PhD, Chief Executive Officer, American Board of Hospice and Palliative Medicine

Joanne Lynn, MD, Medical Officer, Office of Clinical Standards and Quality, Centers for Medicare and Medicaid Services

Jay Mahoney, Principal, Summit Business Group, LLC

Sharon McGill, MPH, Director, Department of Quality and Research, American Osteopathic Association

Diane Meier, MD, Chief, Division of Geriatrics, Department of Medicine, Director, Center to Advance Palliative Care, Mount Sinai Medical Center

Melanie Merriman, PhD, President, Touchtone Consulting

Robert Milch, MD, Professor of Clinical Family Medicine and General Surgery, State University of New York - Buffalo School of Medicine, Medical Director, The Center for Hospice and Palliative Care

Dorothy Moga, MPH, Consultant, American Board of Hospice and Palliative Medicine

Sean Morrison, MD, Director, National Palliative Care Research Center, and Hermann Merkin Professor of Palliative Care, Mount Sinai School of Medicine

David Morse, Vice President, Communications, Robert Wood Johnson Foundation

Anne Mosenthal, MD, Chief, Surgical Critical Care, University of Medicine and Dentistry of New Jersey

Alvin Moss, MD, Professor of Medicine, Director, Center for Health Ethics and Law, West Virginia University

Dennis O’Leary, MD, President, The Joint Commission

Kate O’Malley, MS, Senior Program Officer, California Healthcare Foundation

Richard Payne, MD, Director, Duke Institute on Care at the End of Life, Duke Divinity School

Russell Portenoy, MD, Chairman, Department of Pain Medicine and Palliative Care, Beth Israel Medical Center
Kandyce Powell, MSN, Executive Director, Maine Hospice Council
Jaiya Rao, Medical Epidemiologist, Division of Adult and Community Health, Centers for Disease Control
Carol Raphael, MPA, Chief Executive Officer, Visiting Nurse Service of NYC
Anne Rhome, MPH, Former Deputy Executive Director, American Association of Colleges of Nursing
True Ryndes, MPH, Vice President for Public Policy and Advocacy, San Diego Hospice and Palliative Care Corporation
Charlie Sabatino, JD, Assistant Director, American Bar Association, Commission on Law and Aging
Elyse Salend, MSW, Program Officer, Archstone Foundation
Lewis Sandy, MD, Executive Vice President, Clinical Strategies and Policy, UnitedHealthcare
Steven A. Schroeder, MD, Distinguished Professor of Health and Health Care, Division of General Internal Medicine, Department of Medicine University of California San Francisco
J. Donald Schumacher, PsyD, President and Chief Executive Officer, National Hospice and Palliative Care Organization
Jack Schwartz, JD, Assistant Attorney General, Director, Health Policy, Maryland Attorney General’s Office
Thomas Smith, MD, Professor and Chairman, Hematology/Oncology and Palliative Care, Massey Cancer Center, Virginia Commonwealth University
Lynn Hill Spragens, MBA, President and Chief Executive Officer, Spragens and Associates, LLC
Mildred Z. Solomon, EdD, Vice President, Education Development Center Inc.
Sharyn Sutton, PhD, President, Sutton Group

Assessment of RWJF End-of-Life Portfolio
Patrizi Associates, October 2007

Appendices
Joan Teno, MD, Professor of Community Health and Medicine, Associate Director for Gerontology and Health Care Research, Brown University School of Medicine

Susan Tolle, MD, Director, Center for Ethics in Health Care at Oregon Health and Science University

Jim Towey, JD, President, St. Vincent College

Jeanne Twohig, MPA, Deputy Director, Duke Institute on Care at the End of Life, Duke Divinity School

Julio Urbina, Senior Program Officer, Health Care Program, The Fan Fox and Leslie R. Samuels Foundation, Inc.

Charles Von Gunten, MD, Medical Director, Center for Palliative Studies, San Diego Hospice and Palliative Care Corporation

Jamie Von Roenn, MD, Professor, Division of Hematology/Oncology, Director, Palliative Care Center, Northwestern Memorial Hospital, Professor, Northwestern University

Victoria Weisfeld, MPH, Independent Consultant

David Weissman, MD, Director, Palliative Care Center, Medical College of Wisconsin Palliative Care Center

John Wennberg, MD, Director, Peggy Y. Thomson Chair for the Evaluative Clinical Sciences, Professor, Department of Community and Family Medicine, Dartmouth Medical School

Diana J. Wilkie, PhD, Professor and Harriet Werley Endowed Chair for Nursing Research, Department of Medical-Surgical Nursing, College of Nursing, University of Illinois at Chicago

Assessment of RWJF End-of-Life Portfolio
Patrizi Associates, October 2007

Appendices
### APPENDIX 2:
SELECTED KEY EVENTS IN THE END-OF-LIFE CARE FIELD

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>1967</td>
<td>First hospice opens in Great Britain</td>
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<tr>
<td>1969</td>
<td>Kubler-Ross’s <em>On Death and Dying</em> published</td>
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<tr>
<td>1974</td>
<td>First hospice opens in US</td>
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<tr>
<td>1974</td>
<td>Royal Victoria Hospital establishes first hospital-based palliative care unit</td>
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<tr>
<td>1974</td>
<td>Karen Ann Quinlan case decided by New Jersey Supreme Court</td>
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<td>1978</td>
<td>National Hospice Organization (NHO) founded</td>
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<tr>
<td>1982</td>
<td>Medicare hospice benefit implemented</td>
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<tr>
<td>1984</td>
<td>JCAHO initiates hospice accreditation</td>
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<tr>
<td>1987</td>
<td>Great Britain recognizes palliative medicine as a distinct field of medicine</td>
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<tr>
<td>1988</td>
<td>Academy of Hospice Physicians established</td>
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<td>1990</td>
<td>Jack Kevorkian arrested in his first known assisted suicide, charges dropped</td>
</tr>
<tr>
<td>1990</td>
<td>US Supreme Court rules in Nancy Cruzan case</td>
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<tr>
<td>1990</td>
<td>World Health Organization defines goals of palliative care</td>
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<tr>
<td>1991</td>
<td>Patient Self-Determination Act enacted</td>
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<tr>
<td>1991</td>
<td><em>Final Exit</em> becomes bestseller</td>
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<tr>
<td>1993</td>
<td><em>Oxford Textbook of Palliative Care</em> first published</td>
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<tr>
<td>1994</td>
<td>Death with Dignity Act approved by Oregon voters</td>
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<tr>
<td>1995</td>
<td>Project on Death in America faculty scholars program begins</td>
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<tr>
<td>1995</td>
<td>SUPPORT project findings released</td>
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<tr>
<td>1996</td>
<td>Academy of Hospice Physicians becomes American Academy of Hospice and Palliative Medicine</td>
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<tr>
<td>1997</td>
<td>IOM publishes <em>Approaching Death: Improving Care at the End of Life</em></td>
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<tr>
<td>1997</td>
<td>Death with Dignity Act takes effect in Oregon</td>
</tr>
<tr>
<td>1997</td>
<td>US Supreme Court rules on physician-assisted suicide</td>
</tr>
<tr>
<td>1997</td>
<td>Jack Kevorkian appears on <em>Sixty Minutes</em></td>
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<tr>
<td>2000</td>
<td>NHO becomes National Hospice and Palliative Care Organization</td>
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<tr>
<td>2000</td>
<td>Bill Moyers series, <em>On Our Own Terms</em>, airs on public television</td>
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<td>2001</td>
<td>JCAHO implements pain standards</td>
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<tr>
<td>2004</td>
<td>National Institutes on Health <em>State of the Science Conference on Improving End-of-Life Care</em></td>
</tr>
<tr>
<td>2005</td>
<td>Terry Schiavo’s feeding tube is removed and she dies 13 days later</td>
</tr>
</tbody>
</table>
American Board of Medical Specialties (ABMS) recognizes hospice and palliative as subspecialty

Accreditation Council of Graduate Medical Education votes to accredit Palliative care fellowship training programs

ABMS to offer its first certification exam for hospice and palliative medicine
## Appendix 3: Timeline of Major Grants in End-of-Life Care

<table>
<thead>
<tr>
<th>Year</th>
<th>Event Description</th>
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<tbody>
<tr>
<td>1998</td>
<td>IOM Report - Study of Care at the End of Life</td>
</tr>
<tr>
<td>1999</td>
<td>RWJF End-of-Life Portfolio Appendices</td>
</tr>
<tr>
<td>2000</td>
<td>Patrizi Associates, October 2007</td>
</tr>
<tr>
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### Key

- Objective 1
- Objective 2
- Objective 3
APPENDIX 4:
Building Knowledge

We queried 15 experts on their opinions of the importance of 32 reports referred to us during our expert interviews. The purpose was to see whether RWJF was on point in providing at least partial funding for most, but not all, of the reports named in the survey. In our group, nine of the ten documents with the top scores – those regarded as “very important” or “moderately important” -- were produced with at least some funding from the Foundation. The five documents receiving the highest scores (all with RWJF support) were:

- *Approaching Death: Improving Care at the End of Life*, Institute of Medicine/National Academies of Science (1998) (mean rating: 2.82, where 3=very important, 2=moderately important, 1=not that important, DK=haven’t read it or not comfortable making a judgment)


- *CAPC Manual, Everything You Wanted to Know About Establishing a Palliative Care Program But Were Afraid to Ask*, Mount Sinai Medical Center (2001) (mean rating: 2.73)

- *Perspectives on the Close of Life Series*, Journal of the American Medical Association (2000-2007) (mean rating: 2.64)

- *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*, Institute of Medicine, Board of Health Sciences Policy (2003) (mean rating: 2.6)

These same documents figured into the RWJF strategy in some important ways. For example:

- The IOM report clearly was a defining document for the field as well as RWJF.

- The Joint Commission standards on pain were a stimulus for changes in clinical practice, as well as hospital interest in palliative care services.

- The CAPC manual is a how-to guide for the rapidly growing number of hospitals developing palliative care programs.

- The *JAMA* series was designed to increase physician knowledge and awareness of end of life concerns, and also raised the field’s credibility in medicine.
We also compared our ratings to the findings of a Meiers/Isaacs survey (2007), which asked respondents to suggest important articles/research in the field.

In both studies, it is clear that respondents placed a high value on literature produced by the SUPPORT project. Experts in our survey gave a high rating to Joanne Lynn’s JAGS (2000) article (it came in sixth in our study) while a series of SUPPORT articles received more mentions than any other in the Meiers/Isaacs data.
# APPENDIX 5:

PDIA Faculty Scholars’ Role in RWFJ Programs

<table>
<thead>
<tr>
<th>PDIA CLASS:</th>
<th>ROBERT WOOD JOHNSON FUNDED PROGRAMS</th>
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<td><strong>1995</strong></td>
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<td>Billings, J. Andrew, MD</td>
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<td>Goodlin, Sarah J. MD</td>
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<td>Meier, Diane Eve MD</td>
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<td>Morrison, R. Sean M.D</td>
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<td>Smith, Thomas, J. M.D, FACP</td>
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<td>Von Gunten, Charles F. MD</td>
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<td>Weissman, Davis E. MD</td>
<td>Residency Training End-of-Life/ Palliative Education Resource Center (EPERC) Palliative Care Leadership Center Medical Student Training</td>
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<td>Shuster, Jr., John Lee MD</td>
<td>Community/State Partnerships</td>
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<td><strong>1997</strong></td>
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<td>Curtis, J. Randall MD, MPH</td>
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<td>Mosenthal, Anne C. MD, FACS</td>
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<td>Rosenfeld, Kenneth E. MD</td>
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<tr>
<td>Bailey, F. Amos MD</td>
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<tr>
<td>Miller, Susan C. Ph.D, MBA</td>
<td>Best Practices for Nursing Home Care</td>
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<td>Rabow, Michael W. MD</td>
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2002

Assessment of RWJF End-of-Life Portfolio
Patrizi Associates, October 2007
APPENDIX 6: Top Funders in End-of-Life Giving

Top 15 FOUNDATIONS - 2004*

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<tr>
<th>Foundation</th>
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<tr>
<td>Johnson Foundation, Robert Wood</td>
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<td>Cannon Foundation, Inc.</td>
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<td>Kresge Foundation</td>
<td>1,150,000</td>
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<tr>
<td>UniHealth Foundation</td>
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<tr>
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<td>Reynolds Charitable Trust</td>
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<td>Charitable Leadership Foundation, NY</td>
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<td>Davis Foundation, Arthur Vining</td>
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<tr>
<td>Bristol-Meyers Squibb</td>
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<td>Offield Family Foundation</td>
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<td>Richardson Foundation</td>
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Top 15 FOUNDATIONS - 2005^

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* Data from the Foundation Center Database
* For each foundation we list the total of grants of $100,000 or more.
APPENDIX 7:
REFERENCE NOTES


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