



Robert Wood Johnson Foundation

RWJF Retrospective Series

Improving Care at the End of Life

How the Robert Wood Johnson Foundation and Its Grantees Built the Field

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Preface

Between 1991 and 2005, the Robert Wood Johnson Foundation (RWJF) invested over \$170 million to improve care at the end of life. It is important for us at the Foundation and for the field of end-of-life care to understand the impact of this body of work and to monitor the state of the field into the future. To this end, Patricia Patrizi and colleagues have conducted an independent retrospective analysis of these investments. The analysis documents impact and also provides lessons about Foundation strategy.

Impact. As a physician, I have witnessed care for dying patients improve dramatically, and believe Patrizi's conclusion that RWJF played a major role in helping that to happen. My professional career has paralleled the evolution of the field of end-of-life care and the movement for better palliative and hospice care. As a geriatrician, changes in end-of-life care directly affected the care of my patients and I have seen a sea change in attitudes and practice.

Three observations from three different periods in my professional life may help illustrate the point.

- In the late 1970s and early 1980s when I was a doctor in training, hospice and palliative care didn't exist. More often than not, a dying patient was viewed as a practitioner's and the health care "system's" failure—a failure of technology and know-how to cure disease or at least to extend life. Too often, I observed two equally inadequate responses to this perceived failure—apply more technology more intensively or withdraw completely—physically and emotionally. Performing heroic measures—surgery, chemotherapy, artificial life support—even when there was no hope for cure or significantly prolonging life—was the prevailing standard of care. Rarely did I see my teachers and colleagues admit that the patient was dying, but when we did the response was always the same. We moved the patient to a private room, turned off the lights, closed the door and stopped including the patient in our rounds.
- In the early 1990s, I found myself in the middle of an ugly conflict over how best to meet the needs of a dying patient. The patient had pancreatic cancer and was so riddled with the malignancy that his skin was bright yellow and he couldn't even sit up in bed. He had been clear that he wanted to die without pain and heroic measures. Controlling his pain proved difficult because members of the care team disagreed intensely about the choice and dose of medication that could be given safely. The fighting on the team became so bitter that one

person filed a complaint to hospital administration about the actions of another team member. What we needed was a palliative care specialist or service to advise us. What we ended up with was a legal battle. A few years later, a palliative care service and fellowship patterned after the pioneering, RWJF-supported work of Christine Cassel and Diane Meier, was established at University of Pennsylvania-affiliated hospitals.

I am currently a trustee of a community hospital similar to thousands of hospitals in America. I was pleased to learn that the hospital, which had a hospice service for years, was adding palliative care service. The multidisciplinary service was established in 2007 in response to patient requests and a recognition that such care is essential to delivering the standard of care patients, families and health care professionals expect, as is the case in thousands of community hospitals in America. In fact, the palliative care specialist who heads the service was trained at one of the sites that RWJF supported. What RWJF started is now common practice. This retrospective report illustrates an important fact of philanthropic life: a strategy for dealing with difficult health and social problems is seldom planned perfectly from inception. Instead, the strategy often emerges over time and organically, as investments gain traction in some areas but not others. Patrizi et al. describes how the RWJF end-of-life strategy emerged, and how the different parts of the strategy had impact or fell short.

Evaluating the impact of the entire body of end-of-life work, as if it were designed as a strategy from the beginning (which it wasn't), is essential to glean lessons applicable to current and future efforts. Here are the lessons I took away from Patrizi's analysis:

- *Have a strategy and objective that integrate a body of work.* Articulating the objective and strategy for meeting the objective is now routine at RWJF. We have moved beyond requiring this simply of individual programs and have evolved to understanding that program objectives within the same field or addressing the same issue must be coordinated and connected.
- *Tie the strategy to changing policies and incentives.* The failed attempt to get every physician to learn about palliative care taught us that voluntary actions and persuasion are less effective than fostering systemic changes in curricula and certification exams. This lesson is transferable to our work in creating healthy schools, higher-functioning public health systems and indeed all of our targeted work.
- *Communications and evaluation must work synergistically with the demonstrations and other programming.* By not having stronger linkages we probably missed an opportunity to have a greater impact, have it more quickly or perhaps both. Structurally we are now organized into program teams with strong communication and evaluation expertise on each team. In general, managing and integrating the people and programs within a strategy has to be an active, ongoing process.

- *Plan how RWJF can leverage other forces for change and collaborate formally and informally with others working on the problem.* RWJF's work on end-of-life care preceded and complemented that of the Open Society Foundation. In virtually every area, we now collaborate with other funders and change agents and are formalizing these relationships. Increasingly we look for opportunities to leverage trends and actions by both business and the public sector.
- *Exit with care—know and factor in what other funders and partners are planning.* That we dialed down our funding of end-of-life care at the same time Open Society did, was a mistake. We mitigated, in part, that mistake through a challenge grant to continue to foster hospice and palliative care that eased the transition, but we must always be cognizant of our role relative to other key players in a field.

Strategy emerges, and it is not perfect. A greater sense of urgency, more resources or clearer, bolder objectives might have accelerated progress in the end-of-life field. Just as strategy is often emergent and not fully planned, social change takes time. The changes in the field of end-of-life care occurred over 20 years, and signify that RWJF is committed to sticking with challenging, long-term problems over the long haul.

Risa Lavizzo-Mourey, M.D., M.B.A.

President and Chief Executive Officer

Section 1

Introduction

“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.”

In 2006 the Robert Wood Johnson Foundation (RWJF) commissioned an assessment of its work to improve end-of-life care in America. This was no simple task as the Foundation made 337 grants and invested nearly \$170 million between 1996 and 2005. The grants were made within the context of three objectives established in 1997:

- To improve the knowledge and capacity of health care professionals and others to care for the dying
- To improve the institutional environment in health care institutions and in public policies and regulatory apparatus to enable better care of the dying
- To engage the public and professions in efforts to improve end-of-life care (RWJF, 2003)

Our retrospective evaluation, which took place over the course of two years, adopted a novel approach. Instead of a grant-by-grant analysis, we asked questions about the “how” and “why” of the grantmaking as a whole; our goal was to understand the emergence of the strategy that ultimately guided the Foundation’s work.

This paper, based on that assessment, brings a specific lens to the presentation of the work—that is, how can a funder understand what it takes “to build a field”?

We were prompted to take this approach because of what we learned in the evaluation—that the Foundation is widely, and consistently, credited with “building the field” of end-of-life care or, as it evolved, palliative care. Early on, *New York Times* reporter Judith Miller recognized the Robert Wood Johnson Foundation (RWJF) and the Open Society Institute (two partner foundations in this work) as important in building the interest and will to create an academic field (Miller, 1997). During our interviews, others supported this conclusion:

- “Over the 10 years of RWJF grantmaking, they have created a groundswell.”
- “There is a generational difference in end-of-life 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.”

It is understandable that most of the field building conversation focuses on the conventional “building blocks” of a field, including its people, organizations and base of knowledge. ... Yet we know that creating a vibrant field requires more than just developing basic building blocks. One needs to understand the dynamics and forces that influence development and sustain it over time.

In fact, the achievements are remarkable. In what may be the shortest time in the history of such things, the American Board of Medical Specialties (ABMS) approved hospice and palliative medicine¹ as a medical subspecialty in 2006. In 2008 the Centers for Medicare & Medicaid Services (CMS) followed suit by recognizing the specialty, a precursor to approving payment for service. A growing cadre of professionals has been certified in the practice of hospice and palliative medicine. ABMS reported that 1,271 physicians received subspecialty certification from one of the 10 cosponsoring boards following the first exam in 2008 (American Academy of Hospice and Palliative Medicine website). And there has been an increasing presence of palliative care content in the curriculum and teaching in medical schools, residencies and nursing programs throughout the nation (Penrod and Morrison, 2004).

The impact is being felt in the actual practice of medicine. In 2008 nearly one-third of hospitals (1,300 or 31%) nationally reported having palliative care programs—and 58 percent of hospitals with 50 or more beds, and 81 percent of hospitals with 300 or more beds offer palliative care (Center to Advance Palliative Care, 2010). All Department of Veterans Affairs (VA) (formerly called Veterans Administration) hospitals have a palliative care team (Edes, Shreve and Casarett, 2007). Similarly, the number of hospice programs has grown from 3,300 in 2003 to approximately 5,000 hospice programs today (National Hospice and Palliative Care Organization, 2003 and 2010). And early studies indicate improved clinical, satisfaction and utilization outcomes related to palliative care services (Meier, 2006).

The substantial evidence indicating the emergence of a “field” prompted us to probe the data at a deeper level. We wanted to learn whether and how the principal actors went about designing and constructing a field that many now consider “built.”

What brought about such significant change in such a short time period? How did a new field emerge and get such strong traction, when so many others still flounder after many attempts?

Much of the literature in the arena of field building describes elements or components of “fields,” such as the existence of a knowledge base, key organizations, standards and quality. Comparatively little is written about the nature of the compelling forces that can drive or hamper the development of a field, although discussion is emerging particularly in light of technology, infrastructure and networks needed to foster field development.

It is understandable that most of the field building conversation focuses on the conventional “building blocks” of a field, including its people, organizations and base of knowledge. These are concrete areas amenable to organized involvement and investment.

Yet we know that creating a vibrant field requires more than just developing basic building blocks. One needs to understand the dynamics and forces that influence development and sustain it over time. We posit that it is the less tangible forces that ultimately determine success.

This paper describes what we learned about RWJF’s role in building the end-of-life care field, illustrated through the story of the Foundation’s investments, relationships, decisions and approach. We point out how through deep relationships with actors in the field, the Foundation not only helped to put building blocks in place, but also activated many of the essential dynamics that allow a field to come together and grow strong.

The story starts with the end of the Foundation’s first major initiative in end of life— SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments). SUPPORT was first funded in 1986 and continued through 1994. While the project predated the scope of our assignment, we quickly learned that its effects set the stage for the future of what was to become the field.

This landmark study into how Americans die gave credence to a growing, but until then unconfirmed, understanding of the shabby state of end-of-life care in this country. It began with a study that described the treatment received by 4,301 patients who were hospitalized with life-threatening medical conditions and who were expected to die within six months. The researchers produced what was, for many, 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 . . . were reported (by the patient or family member) to have substantial pain” (Lynn, 1997).

The [SUPPORT] study surfaced the fact that most Americans die in hospitals, often alone and in pain, after days or weeks of futile treatment, with little advance planning, and at high cost to the institution and the family.

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The Foundation took this information and asked the same group of researchers to design a solution to address the problems identified. The design was endorsed by many. The second phase of the work took the form of a randomized controlled clinical trial implemented over three years and involving an experimental group of 2,652 seriously ill patients plus a control group of similar size. “Convinced by expert consensus that targeted interventions would work,” the research team “designed a second phase aimed at fixing these problems” (Schroeder, 1999).

It was not to be. In 1994 researchers presented the totally unexpected and unequivocal finding of “no effects” to a stunned Foundation staff. But the disappointing findings did not mark the end of the story.

With this news, RWJ faced a dilemma. The Foundation already had geared up to launch a major media campaign publicizing the expected positive results from the study, and the medical world awaited a big announcement. Given the actual findings, the media push was no longer appropriate as planned. “As the time approached for announcing these findings, we . . . worried that people might interpret them too narrowly,” wrote RWJF’s then-president, communications officer, and two program officers in a published essay. “They might say that the results showed dysfunctions in the five medical centers studied—or in medical centers generally—not problems in our health care system as a whole” (Weisfeld, Miller, Gibson and Schroeder, 2000).

What to do with such unexpected, negative—and public—results? Steven Schroeder, then RWJF’s president, saw “an opportunity to transform this great disappointment into a case for fundamental change.” Instead of the planned campaign to promote the success story of SUPPORT, the Foundation refocused the campaign on building awareness of how entrenched problems are in care at the end of life, and the urgency to address this issue. The Foundation poured great

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sums into publicizing the SUPPORT findings—a highly unusual step at the time, when the common practice of foundations was to ignore evaluation findings or suppress negative ones.

The findings from SUPPORT made front-page news across the country. In fact, the communication of SUPPORT's "failure" was cited as creating "the tipping point in the history of this movement" and marked the beginning of a renewed commitment at the Foundation to address the needs of the dying and their families.

Many say that the Foundation's work to communicate the findings from SUPPORT was the real home run in the effort: unlike anything previously, information from SUPPORT—and its credibility—galvanized professional awareness and action around how Americans die. Kathleen Foley, M.D., Director of the Open Society Institute's Project on Death in America (PDIA), viewed publication of the SUPPORT study as "validating 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 PDIA, a nine-year multimillion-dollar investment in the field.

In 1995 the "field" of palliative care had at best nascent versions of the elements that traditionally define an academic field. At the time, undergraduate, graduate and continuing education programs in health care offered little formal training on end-of-life care, and major medical and nursing textbooks had little end-of-life care content. The research base on the needs and experiences of dying patients, best practices in clinical care, and methods to measure and assure quality were limited. Hospice programs served only a small percentage of patients who died in the United States each year.

There also was a fractious and widespread debate about end-of-life care in the news and in related policy and practice circles across the nation. 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.

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, while health care costs were mounting and were a source of real national concern.

In terms of the field's impact on patients, only a small number of hospitals offered palliative care services, and while Medicare provided benefits for hospice care, relatively few people took advantage of it. Only a small proportion of Americans had prepared advance directives to guide their care.

Section 2

Uncertainty

The Foundation entered two years of what one Foundation leader called, “a collective head scratch.” The SUPPORT study showed that many Americans were dying in pain, but SUPPORT’s intervention²—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 stark contrast to the certitude surrounding SUPPORT, the Foundation found itself with no easy answers.

However, the need to build “a broad movement with simultaneous work on multiple fronts” took hold, as did the perspective among some at the Foundation that “ground-up” solutions were needed to create the magnitude of change desired.³ Unsure of what would work, some staff believed that a “broad array of factors leading to social change” should be addressed. Staff also 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, Miller, Gibson and Schroeder, 2000).

Staff engaged in what became nearly a two-year process of reconnaissance. They went into the field and struck up relationships with professionals from diverse backgrounds. And advocates working to improve end-of-life care reached out to the Foundation. Some had learned about RWJF’s commitment to the issue through publicity about SUPPORT. Foundation staff was open to meeting with committed professionals and hearing their ideas, many of which would shape the strategy indelibly. During this time, staff met and engaged with dozens of future leaders of the Foundation’s as yet unfunded programs.

The Foundation’s early grantmaking reflected openness to hearing from the field. Three important grants were made: Last Acts,[®] *Promoting Excellence in End-of-Life Care*, and Education in Palliative and End-of-Life Care.

Last Acts began in 1995, initially as part of the RWJF program, *Targeted End-of-Life Projects Initiative*, the first and ultimately one of the largest programs to emerge from the Foundation’s investments in the end-of-life care area. It was rooted in the belief that a “broad movement” was needed to affect change. At this early stage, Last Acts sought to create and maintain a climate of interest and support for improvement in end-of-life care. Its efforts reflected the perspective that

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there were no clear answers to the problem and that the Foundation “needed to listen more to communities.”⁴ Last Acts was able to capitalize on the growing interest in end-of-life care issues and became an important source of information, as well as an organizing entity for local advocates. Last Acts evolved over time (and is discussed later in Section 5).

Promoting Excellence in End-of-Life Care was launched in 1996, one year after SUPPORT findings were released. With the passage of time, staff recognized that “something needed to be done but there was no scalable response quite in sight as yet.”⁵ In many ways, *Promoting Excellence* was a direct reaction to what many saw as the over-confidence built into the assumptions behind SUPPORT—that the problem was 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.” Ira Byock, M.D., Director of the *Promoting Excellence* national program office,⁶ was an emergency medicine physician often described as a “passionate advocate” and “visionary.” He understood the importance of translating the practice of palliative care to physicians most on the line to decide about saving or extending life.

Promoting Excellence tested an emerging idea in the field—that care and cure could co-exist. *Promoting Excellence* was founded on the principle that patients should not have to choose between palliative care and life-prolonging treatment (RWJF, 2009). With this emphasis, the program responded to a major source of resistance to palliative care from medicine and from the dying.

This program was able to make the case for “the larger do-ability” of palliative care—one that could be acceptable to a broad range of clinicians and people, and successfully administered earlier in an illness than most had previously assumed possible. Reflecting back on the start of the grants, Byock 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 projects demonstrated that you can provide concurrent palliative care without requiring patients to give up active, disease modifying treatment.”

Education in Palliative and End-of-Life Care (EPEC), developed by the American Medical Association, was a program to change how practicing physicians approached the delivery of care at the end of life. The Foundation funded EPEC in 1997 to: 1) develop a curriculum to train practicing physicians, and 2) implement a large-scale “train the trainer” model that theoretically would reach all practicing physicians in the United States by relying on an ever-growing pyramid of successive training.

Not surprisingly, EPEC was challenged in achieving its goal to reach all practicing physicians. Nevertheless, it has been credited with significant achievements—most notably, creating a coherent, comprehensive curriculum that would prepare a practicing physician with the skills to provide good care to patients at the end of life. EPEC’s core curriculum for palliative care has been adapted and adopted by many others. The substance of the material also has served to inform education standards developed subsequently, and has populated much of the substance in educational programs for the VA health system, osteopaths and specialty areas. In essence, EPEC outlined the knowledge required by an emerging field.

At the end of the reconnaissance period, the Institute of Medicine of the National Academies (IOM) published *Approaching Death: Improving Care at the End of Life* (Field and Cassel, 1997). This document analyzed and presented recommendations on each aspect of care at the end of life, and it offered a call to action to the medical community. The report greatly informed those in the field, as well as the formulation and execution of RWJF's strategy. Ultimately, the Foundation selected three main objectives that addressed many elements in the report:

1. To improve the knowledge and capacity of health care professionals and others to care for the dying
2. To improve the institutional environment in health care institutions and in public policies and regulatory apparatus to enable better care of the dying
3. To engage the public and professions in efforts to improve end-of-life care (RWJF, 2003)

Approaching Death: Improving Care at the End of Life became the touchstone for much of the work later supported by the Foundation. The study came to frame the clinical and related system issues for the field, and laid the footprint for a more evolved field. However, the IOM report did not specify strategies to create the change envisioned.

Section 3

Emergent Strategy

This next period at the Foundation was marked by significant and highly formative learning that yielded a growing appreciation of the many building blocks necessary for change. It also supported a growing understanding of *how* and under what circumstances change would occur. Importantly, a deeper and shared understanding of some of the underlying dynamics of the field emerged.

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Elements of a Knowledge Field

- Shared identity and sense of mission among the members
- Leaders
- Systems for training, education
- Credentialing
- Locations to practice
- Knowledge base
- Quality standards
- Public policy support and funding

During this time, Foundation staff, working in close partnership with the PDIA, as well as other field leaders, began to articulate their perspective on how change occurs in medicine. Their concepts accounted for the culture of medicine, the nature of medical schools, how care is reimbursed, who teaches, who/what determines what is learned and how all are reinforced. At the core of the work was an assessment of the dynamics that drive the system influencing or governing medical education. They concluded that medicine responds primarily to these three things: legitimacy, peer relationships and money.

- **Legitimacy.** For a medical field to gain legitimacy it should be built into prestigious organizations that are early adopters, as well as backed by highly respected professionals with top-ranked academic backgrounds, and who publish in peer-reviewed journals. Also, a medical field needs a set of clinical approaches based on empirical research. Standards and certification are important as well. The field needs the ability to assure the quality of its practitioners and their emerging practices.

- **Peer relationships.** Physicians listen best to other physicians, particularly those within the same specialty. The IOM report resonated because it was drafted largely by clinicians, and it tackled the broad landscape of changes needed to create widespread impact. Its call to action was heard because the experts involved were powerful enough to affect change.
- **Money.** Clinical practices need to be reimbursable, or at least cost-effective enough, to induce institutions to adopt them.

In line with this analysis, staff from RWJF and PDIA developed what they called an “elite strategy.” The approach would focus, at least in part, on galvanizing high profile and well-regarded physicians and nurses who were working in elite organizations in medicine and nursing.

With this overarching framing of the field, the Foundation began to concentrate on reforming medical education. Although the objective was stated broadly as improving the practice of *all* health professionals, the actual work was targeted to reforming how medical students were trained and the faculty who taught them.

Stimulating demand for palliative care knowledge formed the core theory of change underlying the work in medical education reform. The strategy was to institute a series of incentives that would create pressure for change within the medical education enterprise. With some modification, the same approach was adopted for nursing as well.

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The strategy was based on the following set of ideas:

- To change, institutions need external motivation.
- Changing the medical licensing exam so that it covers palliative care would require physicians to be trained in this area.
- Teachers would teach to the test and require material to do so.
- Textbooks would need to include palliative care content.
- Palliative care content would pull demand for new knowledge.
- New knowledge would require researchers to produce it, as well as a curriculum to organize it and faculty trained to teach the information.
- Faculty (specialists in palliative care) would need to meet the same exacting standards that shape highly competitive medical specialties and lead to promotion and tenure. Accordingly, the field would need fellowships and research opportunities for new entrants.
- Sites would be needed where clinical practice could be demonstrated and taught.

With this model in mind, RWJF made grants that would build on the strengths of existing organizations, and expand the number and types of leaders invested in the success of the strategy. No element of the strategy stood fully apart from the rest. All were linked by a built dynamic that would create a need for the adjacent element in the strategy. No single component, such as support to change the licensing exam, was considered in the absence of how it would affect the rest of the system. If palliative care was added to the licensing test, then new textbooks would be needed that cover this content area and so on.

In 1998 a small grant to the National Board of Medical Examiners to strengthen end-of-life content in medical licensing exams turned out to be a critical lever, which set numerous changes in motion. The exams are administered to physicians at three different times in their educational career. Students take the exam on basic sciences at the end of the second year of medical school, on clinical sciences at the end of the fourth year, and finally, after one or more post-graduate years in preparation for acquiring a medical license.

Another small grant to Stephen McPhee, M.D., at the University of California, San Francisco, had a similar effect on stimulating demand for knowledge about palliative care practices. McPhee 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 having added new content, and an additional 24 percent planned to make improvements.

Ultimately this “push” of the medical education system did, in fact, set in place the hoped-for incentives. There was a need for knowledge about what good palliative care and palliative practices are; clinical sites for students to observe and practice; and faculty to study and teach palliative care. RWJF funded a multitude of projects to help meet and shape these needs.

- 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 (RWJF, 2006).
- Medical College of Wisconsin: A national End-of-Life/Palliative Education Resource Center was established. EPERC, as it is called, maintains a website containing peer-reviewed educational materials, recommended books and articles, training opportunities, funding sources, conferences and links to other resources, and an electronic newsletter (EPERC website).
- Massachusetts General Hospital: This project, in collaboration with the Dana Farber Cancer Institute, established the Harvard Medical School Center for Palliative Care, a national resource for faculty development in palliative care. Established in 2000, the center prepares health care providers and educators to develop educational initiatives and programs in palliative care at their own institutions. As of 2007, the center had trained approximately 500 U.S. health care providers in palliative care (RWJF, 2008).

Developing and supporting palliative care as a subspecialty created significant debate in the field. Some believed that a medical subspecialty should be created that would have status and position within medicine. Kathleen Foley, M.D., director of PDIA, explained the rationale for a subspecialty in the following way:

“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.”

Another of the experts validated this opinion: “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 subspecialty.”

Ten specialty groups—
anesthesiology, emergency
medicine, family medicine,
obstetrics and gynecology,
internal medicine,
pediatrics, physical
medicine and rehabilitation,
psychiatry and neurology,
radiology and surgery—
currently endorse hospice
and palliative medicine as a
subspecialty of their fields.
With this endorsement,
physicians now have the
opportunity to pursue
post-graduate subspecialty
training in palliative care.

Not wanting “to add to medical divisiveness and fragmentation,” RWJF chose to abstain from taking a position. Instead, the Foundation wanted to “let physicians do this themselves” and to respond to requests from the field. The Foundation straddled the issue by supporting efforts by 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
- Adopt a plan for a recertification test.

In a related effort, RWJF supported the Accreditation Council for Graduate Medical Education (ACGME) to develop standards for post-residency fellowship programs in hospice and palliative care and then accredit programs as they came on line.

PDIA, on the other hand, 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.

The work on separate aspects of the specialization effort illustrates the strong partnership between RWJF and PDIA and how it worked to great effects. As one grantee noted, 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 [RWJF] 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.”

As an outgrowth of this work, in 2006, the ABMS granted subspecialty status to hospice and palliative care and ACGME voted to accredit fellowship training programs. Currently, ACGME accredits 73 fellowship programs.

Ten specialty groups—*anesthesiology, emergency medicine, family medicine, obstetrics and gynecology, internal medicine, pediatrics, physical medicine and rehabilitation, psychiatry and neurology, radiology and surgery*—currently endorse hospice and palliative medicine as a subspecialty of their fields. With this endorsement, physicians now have the opportunity to pursue post-graduate subspecialty training in palliative care. 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:

- There are now 74 active fellowship programs in hospice and palliative care, with more in formation, offering 181 fellowship positions, including 27 research slots (AAHPM website).
- Between 1996 through 2006, more than 2,100 physicians obtained certification from the American Board of Hospice and Palliative Medicine (National Hospice and Palliative Care Organization, 2006).
- In 1988 the Academy of Hospice Physicians began with 250 founding members; later renamed the American Academy of Hospice and Palliative Medicine, it now has more than 4,100 members (AAHPM website).

The rationale and strategy to support reform in 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, the 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.

In 1997 RWJF supported the American Association of Colleges for Nursing (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 Nursing Education Consortium (ELNEC) training program established three years later. With RWJF support, ELNEC designed and used an evidence-based curriculum to train undergraduate nursing faculty and continuing education providers, and encourage them to incorporate what they learned into 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 says “they knew nursing would get it right and do it meticulously.” The partnership with AACN was the essential 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.

The nurses made significant strides in building their part of the field:

- Palliative care competencies added to the essentials of baccalaureate nursing education.
- 40 percent of authors and publishers made changes to major nursing textbooks after a content audit revealed that only 2 percent had any relevant material on end of life.
- The National Council of State Boards of Nursing revised their test plan to include improved end-of-life content in the exam for registered nurses.
- The Hospice and Palliative Nurses Association (HPNA, formerly Hospice Nurses Association) started in 1987 and has nearly 10,000 members now (HPNA website).
- Within one year of ELNEC training, 500 nurse faculty had trained 19,000 students. In 2011, the VA awarded a three-year contract to use ELNEC to educate nurses on how to provide better palliative care for veterans with life-threatening illnesses.

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 Department of Veterans Affairs 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. By 2003 the VA issued formal standards for palliative care and mandated that all units have palliative care services.

A field is often defined by the nature of knowledge it embodies, and the extent and manner in which it informs practice. Perhaps no field is more defined by knowledge than medicine; its practitioners are aggressive knowledge users, and the level and quality of their knowledge governs their advancement in the field.

Beginning with SUPPORT, RWJF made significant investments in building the knowledge base in end-of-life care. SUPPORT was the first and most important study to provide insight into how people die in America and the nature of care they receive. No study before or since has looked so closely and systematically at this issue and experience. The SUPPORT project alone produced 181 published papers over many years and is considered to be the best evidence base in the field.

The Foundation gave considerable attention to ensuring that the SUPPORT project's findings would be disseminated widely. The study was reported in cover stories of weekly news magazines and many articles in noted academic journals. The researchers were featured on television and radio shows to discuss the implications of the findings.

The field itself responded quickly after the release of SUPPORT by commissioning the IOM to investigate the problem and propose solutions. RWJF was just one of several funders of the study.

Following SUPPORT, the Foundation continued to invest in academic research for several very practical reasons. The creation of demand for knowledge was central to the Foundation's theory of change. Knowledge would allow medical students to address the new questions in medical licensing exams and help to advance careers of those entering the field of palliative care. Furthermore, there was a growing and ultimately large demand for "how to" information as more physicians assumed palliative care responsibilities. RWJF research grants gave emerging leaders in palliative care the chance to publish, earn tenure and garner respect and influence in the world of academic medicine.

As the field required definition and parameters, the Foundation primarily supported applied research—work focused on "building the knowledge and capacity of health care professionals and others to care for the dying." As much of the work was geared to clinical practice, it was clear who was to use the knowledge and to what end. Many of the researchers were practitioners themselves.

Projects supported by RWJF yielded literally hundreds of articles on clinical and organizational issues. They appeared in journals such as *JAMA*; *CA: A Cancer Journal for Clinicians*; *Annals of Internal Medicine*; *Critical Care*; *Journal of the American Geriatrics Society*; *Journal of Palliative Medicine* and many others.

Promoting Excellence produced a substantial body of knowledge on how to provide palliative care to people with many different conditions and in a variety of settings. The breakthrough idea—that patients could simultaneously receive palliative and curative care—came to redefine the field and reduce the stigma associated with end-of-life care. The demonstration sites and work groups associated with the project produced dozens of books and articles on clinical topics, as well as quality measurement and research.

In the late 1990s RWJF funded a new online journal, *Innovations in End-of-Life Care*. The goal of this bimonthly peer-reviewed resource was to disseminate new practices and information as they emerged. For four years, each issue of the *Journal of Palliative Medicine*, the leading peer-reviewed journal in the field, included a section with feature articles and an editorial from *Innovations in End-of-Life Care*.

In 2000 the Foundation sponsored the first four years of a series published in *JAMA* called “[Perspectives on Care at the Close of Life](#).” The series shared case studies and clinical approaches in one of mainstream medicine’s most widely read publications. The Foundation also supported a monthly series on palliative care in the *American Journal of Nursing*.

Most recently, the Center to Advance Palliative Care has distributed “how to” manuals on most aspects of running a palliative care program. Hospitals, hospice programs and nursing homes use the guides to develop or strengthen their palliative care services.

The interplay between research and other aspects of the field is clear. The results of RWJF-funded research infiltrated the development of educational curricula, quality standards, service design and public policy discussion in palliative care. The action elements of the Foundation’s agenda—to reform medical education, redefine palliative care by moving it upstream in patient treatment, and to create new models of care—drove the urgency of developing new knowledge. The change agenda also built the audience for research.

Section 4

Moving Palliative Care Upstream and Institutionalizing Its Practice

Even professionals with the best skills and intentions cannot perform to the best of their ability when they practice in dysfunctional or inhospitable organizations. It is organizations that connect ideas with practice.

Building the field required the construction of a viable place to practice palliative care and treat those who were dying. Even professionals with the best skills and intentions cannot perform to the best of their ability when they practice in dysfunctional or inhospitable organizations. It is organizations that connect ideas with practice.

RWJF staff focused on hospitals as the central locus for practice based on the prevailing rationale that most people die in hospitals. In addition, the hospital setting was valuable for the following reasons:

- It provided a place of practice where newly trained palliative care fellows could conduct clinical trials and train medical students.
- The costs associated with care at the end of life are huge, and most of these costs are incurred in hospitals. Under the prevailing payment mechanisms, hospital incentives to address the high cost of end-of-life care were clear. Single outlier patients with palliative care needs can absorb enormous resources for which hospitals are at financial risk and palliative care can address these cases cost effectively.
- Hospitals are a place to move palliative care “upstream” and allow physicians to offer palliative care along with curative treatment, unlike the hospice funding requirements.

And while there were certainly other places to intervene, there were significant barriers at the time. Consider the following:

- 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.
- A viable community health system did not exist to adequately provide palliative care. Effective scale-up would be difficult to achieve and strategies to do so were not easy to imagine or execute.

For RWJF, 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 patient care. In essence, the work was amenable to investments from a foundation.

- Prospective payment 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.

For RWJF, 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 patient care. In essence, the work was amenable to investments from a foundation.

The Center to Advance Palliative Care (CAPC) has been the institutional anchor of this work. Diane Meier, M.D., ran a respected palliative care center at Mt. Sinai Hospital in New York. The Foundation approached her to explore whether she would establish a program to help other hospitals adopt some of the practices she had developed at Mount Sinai. These centers were also seen as potential clinical sites for teaching and employment of palliative care fellows.

In 1999 RWJF’s first grant to Meier established CAPC as a national resource center to impart skills, build leadership and create the momentum to grow hospital-based palliative care programs throughout the nation. Specifically, the 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.

The demand for CAPC’s services quickly increased beyond the capacities of the Center. In part, demand was linked to the success of other elements of the portfolio. After the airing of a RWJF-funded PBS series, *On Our Own Terms*, which featured CAPC, the Center received more than 1,200 contacts from hospitals asking for information and assistance.

In 2003, to respond to growing interest, CAPC established six Palliative Care Leadership Centers (PCLCs) located in different regions around the country. Rather than having CAPC respond to each hospital request, CAPC would train PCLCs, which would then work with individual hospitals and hospices to develop and sustain palliative care programs.

The capacity to reframe problems can be central to the development of a field.

Early in CAPC’s development, Meier attended a meeting where Sharyn Sutton, a consultant hired by RWJF to evaluate the EPEC project, presented her findings and recommendation that palliative care proponents should consider how “the market” responded to the services offered. The message resonated with Meier who recognized that she would need to help others “sell” palliative care to hospital leaders and physicians.

Rather than assuming and promulgating the innate social good of the CAPC product, Meier delved into the perceptions of practicing physicians—those who admit dying patients to the hospital. She came to this understanding: No one wants a good death—neither patients nor the physicians treating them. Meier concluded that it was an uphill and perhaps futile battle to make all physicians willing and able to provide palliative care—even though this ran against the prevailing wisdom of the field at the time.

This understanding evolved into a substantial reframing of the problem and CAPC's evolution. It may also be one of the most significant strategy shifts in the work and instrumental to what has become CAPC's enduring success. From this work, Meier proceeded to:

- Distinguish palliative care from hospice care and “end-of-life care,” thereby expanding the target population as well as the market and acceptability of the services of palliative care centers. Meier avoided terminology common at the time—“caring for the dying,” “managing grief” and “bereavement.” Instead, the centers were “providing care to those who are seriously ill” and helping hospitals “provide quality care.”
- Promote palliative care centers as a benefit to physicians who were overwhelmed by dealing with family members, or who sought expert advice on the treatment of pain.
- Introduce marketing, business modeling and financial expertise to develop a business case that would show hospital leaders the value of having a palliative care center. Ultimately, this proved instrumental to the successful spread of palliative care centers.

These early decisions helped position CAPC not as an advocacy organization but as one with substantial technical skills and a strong product to sell.

In 2000, 632 hospitals had palliative care capability. RWJF and CAPC aimed to increase the percentage to 20 percent of the hospitals in the United States. Today, 31 percent (or 1,299) of hospitals responding to an American Hospital Association annual survey have reported they offer palliative care. Fifty-eight percent of all U.S. hospitals with 50+ beds, and 81 percent of hospitals with 300+ beds offer palliative care (CAPC, 2010). CAPC's PCLCs have trained almost half of the nation's hospital palliative care programs (CAPC website).

The most profound lesson from this work emerges from the thinking and system design approaches employed by CAPC leadership. Diane Meier combined objective analysis with wisdom from her own experience to construct a strategy that matched the preferences of practicing physicians and administrators in order to create a viable alternative to prevailing hospital practices. Key to Meier's success was her appreciation of what motivates the key actors who drive organizational decisions and performance, as well as the institutional logic that influences behavior and practice.

Meier's systemic analysis provided the insight that ultimately drove successful implementation and widespread adoption of the hospital-based palliative care centers across the United States.

For palliative care to become a customary way of practice—medical care standards, measures of quality and supporting policies and regulations—were needed to reinforce the adoption and sustainability of palliative care. Standards, particularly in medicine, play a powerful role in shaping the field. RWJF invested in a series of projects to help the field define and achieve consensus on the elements of quality, and to establish methods to measure whether standards are met.

Standards, particularly in medicine, play a powerful role in shaping the field. RWJF invested in a series of projects to help the field define and achieve consensus on the elements of quality, and to establish methods to measure whether standards are met.

RWJF and its grantees worked at many levels within medicine to promote standards, including the previously mentioned medical licensing exam questions. Additional examples include:

Palliative Care Standards

The National Consensus Project for Quality Palliative Care (NCP) began in 2002. The Task Force, which represented four coalition organizations, developed and disseminated two versions of the *Clinical Practice Guidelines for Quality Palliative Care* (2004 and 2009). The project worked to create standard definitions for what good palliative care is, and to get influential professional organizations to support the ideas.

The National Quality Forum used these guidelines as the foundation for their report—*A National Framework and Preferred Practices for Palliative and Hospice Care Quality*, which many consider to be the first step in receiving direct Medicare reimbursement. Experts anticipate that these practices will eventually lead to the development of formal palliative care standards, with implications for reimbursement, quality measurement, regulation and accreditation.

Quality Measurement

RWJF made several grants to Joan Teno, M.D., Associate Director of Brown University Medical School's Center for Gerontology and Health Care Research. A highly respected expert in quality measurement, she developed instruments to assess the quality of care for dying patients and their families in a variety of settings, including nursing homes, hospitals and hospices. She created a Web interface where health care providers could download instruments, submit their data and receive feedback on the quality of the services they offered. The National Hospice and Palliative Care Organization (NHPCO) adopted one of these tools, a brief version of the family interview (RWJF, 2006).

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 were useful for advocates as well as national and state policy-makers.

A Focus on Pain

Much of the work in this area had a substantive focus on pain management. The Foundation worked principally with two grantees who are colleagues at the University of Wisconsin: June Dahl, Ph.D., Professor of Pharmacology in the medical school and David Joranson, M.S.W., who was director of the Pain & Policy Studies Group. Both received RWJF support for their pain management work prior to the Foundation's formally developing its end-of-life portfolio.

As early as 1992, Dahl received RWJF support to develop a network of State Pain Initiatives, which sought to overcome barriers to pain relief through education, advocacy and institutional improvements. Dahl worked with The Joint Commission to integrate pain assessment and management into the standards used to accredit health care facilities across the United States. The standards primarily affect hospitals but more and more long-term care and home health programs are seeking Joint Commission accreditation.

Long an advocate of sound pain policies, Joranson's work focused on improving policy at the state level. He 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.

State pain policy progress report cards, funded from 2000 to 2007, gave each state a grade on the quality of their pain policies and regulations. Dahl and Joranson also worked to promote and publicize the results of the pain report cards, partnering with another RWJF program, *Community-State Partnerships to Improve End-of-Life Care* (CSP). Coalitions in 23 states worked to promote changes in their states. The report cards were an important catalyst toward changing state policies and regulations. From 2000 to 2003, 16 states increased their report card grade (Pain & Policy Studies Group, 2004). Nineteen states improved at least one grade level from 2003 to 2006 (Pain & Policy Studies Group, 2006). As of 2008, the vast majority of states had a grade above C, and no state's grade has decreased since 2000 (Pain & Policy Studies Group, 2008). The American Cancer Society, the Susan G. Komen Foundation for the Cure and the Lance Armstrong Foundation provided support for the 2008 report card.

Both Dahl and Joranson 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).

Section 5

Building Public and Professional Will

The work in this area employed communications strategies, often in conjunction with coalitions at the national, state and local levels, to reach out and engage the public and professionals in efforts to improve end-of-life care.

Communications played a central role in the end-of-life portfolio from the outset and throughout. This line of work embodied Steve Schroeder's (then president of RWJF) belief that "This was a huge problem and we needed to put together a movement." The work in this area employed communications strategies, often in conjunction with coalitions at the national, state and local levels, to reach out and engage the public and professionals in efforts to improve end-of-life care.

In response to the successful promotion of the SUPPORT findings, the Foundation sought to build a "movement" of passionate advocates that could both influence the medical establishment to change and educate the public about their choices in end-of-life care. Through two major initiatives, Last Acts and *Community-State Partnerships*, the Foundation supported these advocates, provided them with information and resources, and then let them take the lead on issues they wanted to address in their own states and communities. The Foundation saw the local and state groups as a resource to both educate the public about their choices and use them to rally for changes in medical care and policy reform.

In 1995 the Foundation funded Last Acts, "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" (RWJF, 2004). Its charge was to "work through [national] organizations and the media" to promote end-of-life issues. Last Acts aided its partner organizations by serving as an information source on end-of-life issues, creating a community of people addressing the same issues and connected peer and complementary organizations; a catalyst for initiating or maintaining end-of-life efforts; and conducted activities to promote end-of-life issues geared to public as well as policy-maker audiences.

Partners reported that one key benefit from Last Acts was the sense of community, support and reinforcement it provided to them, as well as the legitimacy it offered their members and boards. For the first time, many advocates felt like they were part of something important and organized.

Another national program, *Community-State Partnerships to Improve End-of-Life Care*, also supported and built coalitions to engage professionals to promote change within their states. Funded in 1997, CSP was, in part, a response to requests from several organizations to address state-level issues. State coalitions directed their efforts at what they believed to be most important.

Among the more common approaches were efforts to improve training and provide continuing training opportunities for health care professionals; influence changes in policies and procedures at health care facilities; increase consumer knowledge, awareness and advocacy; engage clergy and faith communities in end-of-life care delivery; and reform care with more broad-based end-of-life policies. This program aided five states in making considerable strides to improve end-of-life care and help others progress their agendas.

Another prominent project was the Foundation's support of *On Our Own Terms*, a four-part public television series by journalist Bill Moyers. At the time it aired, this important series was viewed by more Americans than any other program in public television history. Again, the Foundation used local coalitions as a way to expand the reach of the series. A yearlong outreach effort was funded to increase viewership, generate dialogue and community action on end-of-life care issues, and promote in-depth conversations that enable individuals and families to address dying on a personal level.

Section 6

State of the Field Today

In 2009 the situation was dramatically different from the time the findings from SUPPORT were released. Consider the following indicators that palliative care has emerged as a legitimate field:

Approval of palliative medicine as an official medical subspecialty

- In 2006 the American Board of Medical Specialties approved palliative medicine as a medical subspecialty.
- In 2008 the Centers for Medicare & Medicaid Services followed suit.

Growing cadre of certified professionals

- In 2008, 2,883 physicians—plus 11,268 registered nurses and 394 nurse practitioners—held board certification in the practice of hospice and palliative medicine (Meier, Isaacs, Hughes, 2010).
- In 2008, 1,271 physicians received subspecialty certification in hospice and palliative medicine in the first certifying examination sanctioned by the American Board of Medical Specialties.

Increasing focus on palliative care in medical and nursing schools, post-graduate and continuing education programs

- Since the 1990s, there has been an increasing penetration of palliative care content in medical school, residency and nursing school curricula (Penrod and Morrison, 2004).
- The number of palliative medicine fellowship programs is up from 56 in 2007 to 74 in 2010. The programs offer 181 fellowship positions, including 27 research slots. Most are accredited by the ACGME and more fellowship programs are on the way.
- Continuing education reaches thousands of practitioners. After its first year of implementation, EPEC is estimated to have reached 120,000 professionals of all disciplines. Today, there are more than 2,000 EPEC trainers who have taught thousands more. ELNEC has trained over 11,750 nurses in 50 states (EPEC website and AACN, 2010).
- Approximately 2,300 hospitals and hospices and more than 5,000 clinicians and administrators have participated in seminars or training sponsored by the Center to Advance Palliative Care.

Approximately 1.5 million patients received hospice services in 2009, and 41 percent of all patients who died were under the care of a hospice program (NHPCO, 2010).

Rapid expansion of clinical practice and training sites

- Nearly one-third of hospitals (1,300 or 31%) nationally report having palliative care programs in 2008—double the number from 2000.
- Larger hospitals are more likely to offer palliative care—58 percent of hospitals with 50 or more beds, and 81 percent of hospitals with 300 or more beds, report having a palliative care program.
- All VA hospitals have palliative care teams.
- The number of hospice programs has grown from 3,300 in 2003 to 5,000 hospice programs in 2009. Approximately 1.5 million patients received hospice services in 2009, and 41 percent of all patients who died were under the care of a hospice program (NHPCO, 2010).
- The vast majority of medical schools (84%) report an affiliation with at least one hospital palliative care program (Goldsmith et al, 2008).

Evolving quality standards and quality assurance systems

- In 2004 The National Consensus Project for Quality Palliative Care—a coalition of major groups and experts in the field—published *Clinical Practice Guidelines for Quality Palliative Care*.
- In 2006 the National Quality Forum published *A National Framework and Preferred Practices for Palliative and Hospice Care Quality*. The preferred practices may be precursors to the development of palliative care standards, with implications for reimbursement, quality assessment, regulation, and accreditation.
- In 2008 the Center to Advance Palliative Care published a state-by-state report card on access to palliative care at the nation’s hospitals. Overall, the United States received a “C” grade, but half of hospitals received a good grade of “A” or “B” (Morrison, Dietrich, Meier, 2008).
- The Joint Commission (TJC), formerly known as the Joint Commission for the Accreditation of Hospitals, embeds national consensus guidelines on palliative care in its existing standards. JTC currently is assessing the market for a palliative care certification program.

Emergence of professional networks for practitioners and researchers

- Among the largest professional groups in the field are the American Academy of Hospice and Palliative Medicine with 4,100 physician, nurse and allied health profession members, and the Hospice and Palliative Nurses Association, with nearly 10,000 members (AAHPM and HPNA websites).
- The National Hospice and Palliative Care Organization, the Center to Advance Palliative Care and the National Palliative Care Research Center also are important.

Section 7

Reflecting on This Work

RWJF invested in many important elements of building a field to improve end-of-life care. We point out the following accomplishments, which are intrinsically important, but they also illustrate dynamics that activated the field such that the field made itself stronger.

- 1. Created a call to action that mobilized powerful voices in the medical community.** The release of SUPPORT and the communications campaign surrounding it has been described as a transformative moment for those working in the field. While there were deeply committed health care professionals already involved, many expressed a sense of isolation from the mainstream of medical care and from each other. The SUPPORT findings helped many practitioners articulate an assessment of medical care that was unknowingly shared by many others. *Promoting Excellence* further captured the moment and mobilized 200 leaders from specialty areas to consider the implications of end-of-life for their work.
- 2. Supported the creation of an agenda for the field and by the field.** Many credit RWJF for providing numerous opportunities for key leaders to come together and generate strategies, reframe problems as resolvable concerns, and generally advance an agenda forged by or with field leaders. An important feature was how the Foundation worked with others to develop an agenda. RWJF 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. The Foundation did not craft its own approach and then look for people to execute its strategies. Instead, RWJF staff worked in partnership with their grantees, respecting the on-the-ground experience and knowledge they contributed. As a result, the work was nuanced and effective.
- 3. Reframed the problem from end-of-life to palliative care, creating demand to provide care “upstream.”** The central instance of “reframing” the problem was captured by a shift in language and in service definition from “end-of-life” to palliative care. Patients and families often felt that physicians were abandoning them if hospice care was recommended. The notion of a “good death,” which hospice effectively enables for many people, has greatest salience after a loved one has died. Most people and families facing a serious illness do not want a good death; they want a cure. The frame of palliative care allowed patients, families and physicians to accept care and amelioration of pain while they pursued active treatment.

Another key framing point for the public was that people tended to view their own experiences with poor end-of-life care for a loved one as an isolated personal situation. In its communications efforts, the Foundation worked to get beyond this perception, which had been fostered in part by media attention to individual cases.

This reframing broadened palliative care beyond the hospice movement, and made it more acceptable to the medical mainstream of hospital care. In effect, it legitimized the identity of palliative care as an important focus of care.

This reframing also helped RWJF grantees advocate for moving palliative care “upstream” to an earlier point in the continuum of medical care. The availability of palliative services throughout an illness yields better care and removes a powerful psychological barrier, allowing patients and families to seek the kind of care they need in the midst of extremely serious illness.

Another key framing point for the public was that people tended to view their own experiences with poor end-of-life care for a loved one as an isolated personal situation. In its communications efforts, the Foundation worked to get beyond this perception, which had been fostered in part by media attention to individual cases. RWJF sought to promote public awareness that the problems in the delivery of care were systemic and affected an untold number of American families.

4. Created a linked strategy of “pulls” that developed demand for palliative care training and research. When the National Board of Medical Examiners (NBME) added palliative care questions to tests for medical students and recent graduates, it created a chain of demand that pulled along each of the elements of the medical reform strategy. This particular device worked in this strategy because the NBME is a powerful force in the lives of all medical students and their teaching institutions.

All fields have pushes and pulls. The critical skill is to know what constitutes “push” or “pull” in different situations and what it takes to build sufficient demand. The strategic agenda supported by RWJF and its grantees was built on experience of how the medical field works and an appreciation of what “leverage points” can be used to apply pressure and demand for change.

5. Built the base and disseminated highly useful knowledge that could be applied immediately and build the audience for more knowledge. 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 *Journal of the American Medical Association* (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.

The research focused largely, but not exclusively, on several practical gaps in knowledge recognized by the field:

- *Practice and organizational models:* The *JAMA* series, “Perspectives on Care at the Close of Life” (which has run from 2000 through 2009), 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 NQF set standards for good practice, and researchers developed assessment instruments to measure changes in policy and institutional practice.

6. Fostered the development (and employment) of a highly influential network of leaders who emerged from the PDIA Faculty Scholars Program and went on to influence medicine in substantial ways. While PDIA identified and supported 87 faculty scholars, 20 of them were further supported by RWJF in assuming major roles in Foundation programs. According to Kathleen Foley, M.D., the Faculty Scholars Program identified and supported “outstanding clinical and academic leaders in medicine who could change medicine from the inside.”

7. Supported an institutional base for delivering palliative care that was financially viable, acceptable to hospital leadership, physicians, patients and families and therefore could be taken to scale. The core premise of CAPC was that a cost-effective service could be developed and accepted within U.S. hospitals. Demand was evidenced such that the Foundation supported PCLCs to spread the model to hundreds of hospitals throughout the United States.

8. Built into existing frameworks the standards and measures to track the performance of key systems, including those certifying or regulating medical education, hospitals and the training of graduate physicians and thereby creating and reinforcing desired change. Measuring and monitoring quality provides reinforcement to changes that have been agreed upon and assures that change continues over time. It also provides a strong basis for advocacy when standards are not met.

“A field is not just a category of activity, but a force to contend with, as fundamental an element to philanthropic strategy as the market is to business strategy.”
(Hirschhorn, Kelly and Gilmore, unpublished paper)

What is a “field” and how would one go about building it? Many speak about field building, yet relatively little has been written that defines, describes or advises on how to do it. After this work, we come away with the following understanding:

- 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 and more developed. Quality in the field can be understood and measured such that its absence is recognizable. A field needs places where the work happens and places where people, knowledge and practice intersect. A field can 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 and always changes.

- Perhaps the most significant lesson is that a field is more than a collection of structural entities focused on the same issue; its strength comes from the connections that hold its parts together.

Field building never starts with a clean slate—no one would invest in it unless there was already something happening to work with. It has both structural elements and dynamic forces that make one notice that it even exists in the first place.

- **Fields have structural elements including people, institutions, knowledge, networks, rules (e.g., policies, regulations, how resources are accessed).** The amount of structure varies, of course, as do the characteristics of the structure; for instance, the field might be densely populated with institutions or people. And its rules might include ideas about who is in or out, what constitutes legitimacy, how open or closed the field is, etc. The determination to advance palliative care at the hospital level was made carefully and came about after many parts of the system were in place and there was an expressed demand for clinical sites to train medical students and graduates. So, too, understanding the institutional features of medical education laid the groundwork for understanding the dynamic elements and the connections among them.
- **Field dynamics constitute much of the connective tissue holding the field together and shaping its evolution and development.** Field dynamics guide behavior and the emergence of ideas as well as provide the basis for the continuation of the field. Understanding and manipulating core dynamics may provide the basis of change within a field. In this work, an understanding of the formal characteristics of the field surfaced how and in what ways the structures connected to each other. For example, no intervention in medical education reform was thought about in isolation of the others. Foundation staff could appreciate how the field would respond to changes in the medical licensing exam—such that there would be effects on curriculum development and research and a need for faculty with the knowledge and skills to teach to the test. Change was activated by pull dynamics already existing in the field. RWJF advocates and staff assessed and engaged the powerful dynamics at play within the system of medical education and more broadly within the context of health care, either as forces to promote palliative care or as ways to minimize forces against the same.

As fields are always dynamic spaces, field building—more than other philanthropic enterprises—must be dedicated to approaches based on learning. Much of the strategy discussed in this paper was co-produced with leaders in the field. In many ways, RWJF's end-of-life portfolio exemplified a practice of leading from behind. Leading from behind is not easy: activists usually have strongly held beliefs. It takes time to hear them out as well as patience and wisdom to know when to intervene (or not).

So, too, foundations are given great kudos for “leading” change. This leading role, however, can do damage to emergent leadership in a field. As one author put it, “leading from behind is a complicated dance” (Hirschhorn, Kelly and Gilmore, unpublished paper). It requires a commitment to recognize and work with the way complex adaptive systems emerge. This approach has a number of major advantages:

- It encourages rather than quashes emergent leaders and organizations.
- It allows power battles to take place within the field where they can be resolved most effectively.
- It presents fewer challenges for sustainability as change is created within the natural processes, structures and dynamics of the field itself.
- It functions within natural systems of demand and supply.

Because of RWJF’s commitment to close strategic development in concert with the field, it was able to shape and frame an agenda for action with its key grantees, and based on the best kind of insider knowledge of how a system works. The resulting strategy was strong and subtle enough to identify real and powerful incentives as well as 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 field responds to demands for change.

Field building is a dynamic undertaking. It isn’t so much what one *does* as a funder but what one discovers and facilitates while finding exciting pockets of work and connecting them to each other.

Field building is a dynamic undertaking. It isn’t so much what one *does* as a funder but what one discovers and facilitates while finding exciting pockets of work and connecting them to each other. In RWJF’s case, it was the combination of tactics that worked—the interplay between listening to grantees and supporting their ideas, paying attention to the web of relationships that drove the system, supporting passionate people with visionary ideas, introducing incentives, marketing ideas and practices, and aggregating promising nodes of work.

To that mix, RWJF contributed a loud and credible voice calling for better end-of-life and palliative care. It kept national attention and pressure focused on end-of-life issues. It found creative people who cared passionately about end-of-life care and invested heavily in them, letting their emotional “juice” energize and mobilize both the Foundation and everyone else. And they learned by doing, bringing everyone else along. Out of this highly nonlinear but persistent process, a field came forward to build and establish itself.

Glossary of Programs and Organizations

Accreditation Council for Graduate Medical Education (ACGME): Accredits post-M.D. medical training programs in the United States. Accreditation is accomplished through a peer-review process and is based upon established standards and guidelines (www.acgme.org/acWebsite/home/home.asp).

American Association of Colleges of Nursing (AACN): A national association representing baccalaureate- and higher-degree nursing education programs. AACN co-administers the End-of-Life Nursing Education Consortium project (www.aacn.nche.edu).

American Academy of Hospice and Palliative Medicine (AAHPM): Professional organization for physicians, nurses and other health care providers specializing in hospice and palliative medicine (www.aahpm.org/about/default/index.html).

American Board of Hospice and Palliative Medicine (ABHPM): Established standards for certification of physicians practicing hospice and palliative medicine, and accreditation of physician training in this discipline. ABMS and ACGME now carry these responsibilities (www.ncbi.nlm.nih.gov/pubmed/15859696).

American Board of Internal Medicine (ABIM): certifies physicians who practice internal medicine and one or more of its 19 subspecialties. ABIM is a nonprofit, independent physician evaluation organization committed to continuously improving the profession for the public good (www.abim.org/pdf/publications/about-ABIM.pdf).

American Board of Medical Specialties (ABMS): Assists 24 approved medical specialty boards in the development and use of standards in the ongoing evaluation and certification of physicians. ABMS is recognized as the “gold standard” in physician certification (www.abms.org/).

American Osteopathic Association (AOA): Professional association for osteopathic physicians and osteopathic medical students. AOA serves as the primary certifying body for osteopathic medicine and the accrediting agency for all osteopathic medical colleges and health care facilities (www.osteopathic.org/inside-aoa/about/Pages/default.aspx).

Center to Advance Palliative Care (CAPC): Provides health care professionals with the tools, training and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings. CAPC started with RWJF support, and is based at Mount Sinai School of Medicine, New York (www.capc.org).

Centers for Medicare & Medicaid Services (CMS): A branch of the U.S. Department of Health and Human Services, CMS is the agency that administers the Medicare program and monitors state Medicaid programs (http://questions.cms.hhs.gov/app/answers/detail/a_id/1/session/L3NpZC9uUFU0ckVkarw%3D%3D).

Community-State Partnerships to Improve End-of-Life Care (CSP): A national program funded by RWJF from 1997 to 2003, CSP supported the work of state-based commissions and task forces to identify and implement changes in policy and practice to improve care for the terminally ill. The Midwest Bioethics Center of Kansas City, Mo. served as national program office (www.rwjf.org/reports/npreports/csp.htm).

Education in Palliative and End-of-Life Care (EPEC): Educates health care professionals on the essential clinical competencies in palliative care. Started with RWJF support, EPEC was designed as a train-the-trainer program to teach both content and educational approaches. Initially, EPEC was based at the American Medical Association but now is housed at Northwestern University (www.rwjf.org/reports/grr/040507.htm), (www.epec.net/EPEC/webpages/index.cfm).

End-of-Life Care Nursing Education Consortium (ELNEC): A national education program to improve end-of-life care by nurses. Started with funding from RWJF, the ELNEC curriculum prepares nurse educators to provide end-of-life education for nursing students and practicing nurses (www.aacn.nche.edu/elneccurriculum.htm).

End-of-Life/Palliative Education Resource Center (EPEC): Shares educational resource material among the community of health professional educators involved in palliative care education. EPERC began with an RWJF grant and is based at Medical College of Wisconsin (www.eperc.mcw.edu/EPEC/AboutEPEC).

Hospice and Palliative Nurses Association (HPNA): A national membership organization providing resources and support for advanced practice nurses, registered nurses, licensed practical nurses, and nursing assistants who care for people with life-limiting and terminal illness (www.hpna.org/DisplayPage.aspx?Title=About%20HPNA).

Institute of Medicine (IOM): An independent, nonprofit organization that works outside of government to provide unbiased and authoritative advice to decision-makers and the public. The 1997 IOM report, *Approaching Death: Improving Care at the End of Life*, was partially funded by RWJF and proved to be a seminal document for the field (www.iom.edu/About-IOM.aspx).

The Joint Commission: Accredits and certifies more than 18,000 health care organizations and programs in the United States. Joint Commission accreditation and certification is recognized nationwide as a symbol of quality that reflects an organization's commitment to meeting certain performance standards (www.jointcommission.org/AboutUs/).

Last Acts®: An RWJF-funded national communications campaign between 1995 and 2005. Last Acts developed a coalition of more than 800 national health and consumer groups that worked to improve communication and decision-making for consumers about their own death, change the culture of health care institutions, and change American culture and attitudes toward death (www.rwjf.org/pr/product.jsp?id=17504).

National Board of Medical Examiners (NBME): Creates standardized exams required for medical licensure in the United States. The four tests that make up the system are collectively known as the U.S. Medical Licensing Examination (www.ama-assn.org/ama1/pub/upload/mm/15/nbme_issue_brief.pdf).

National Consensus Project for Quality Palliative Care (NCP): Developed and disseminated two versions of the *Clinical Practice Guidelines for Quality Palliative Care* (2004 and 2009). These guidelines have served as a foundation for the NQF Preferred Practices, and have become a hallmark within the field (www.nationalconsensusproject.org).

National Council of State Boards of Nursing (NCSBN): Develops licensure examinations used to test the entry-level nursing competence of candidates for licensure as registered nurses and as licensed practical/vocational nurses (www.ncsbn.org/nclex.htm).

National Hospice and Palliative Care Organization (NHPCO): The largest nonprofit membership organization representing U.S. hospice and palliative care programs and professionals (www.nhpco.org/i4a/pages/index.cfm?pageid=3253&openpage=3253).

National Palliative Care Research Center: Works to stimulate, develop and fund research directed at improving care for seriously ill patients and their families. Collaborates with CAPC to translate its research findings into improved clinical care (www.npcrc.org).

National Quality Forum (NQF): Convenes public and private sector leaders to set national priorities and goals for performance improvement, and endorses national consensus standards for measuring and reporting publicly on quality and efficiency of health care in the United States (www.qualityforum.org/About_NQF/Mission_and_Vision.aspx).

Open Society Institute (OSI): Works to build vibrant and tolerant democracies whose governments are accountable to their citizens. The Open Society Institute was founded by George Soros and sponsored the Project on Death in America (www.soros.org/about).

Palliative Care Leadership Centers (PCLC): Provide training and mentoring to help start and expand hospital palliative care programs in the United States. PCLCs represent diverse settings and regions. PCLCs were established in 2004 by CAPC and RWJF (www.capc.org/palliative-care-leadership-initiative/curriculum/pclc_core/document_view).

Project on Death in America (PDIA): From 1994 to 2003, OSI's Project on Death in America worked to understand and transform the culture and experience of dying and bereavement. PDIA created funding initiatives in professional and public education, the arts, research, clinical care, and public policy (www.soros.org/resources/articles_publications/publications/pdia_20040101).

PDIA Faculty Scholars Program: PDIA identified outstanding clinical faculty who were committed to improving end-of-life care, and provided support for disseminating existing models of good care, developing new models for improving care, and developing new approaches to the education of health professionals about the care of dying patients and their families (www.soros.org/newsroom/news/grants_20010702).

Promoting Excellence in End-of-Life Care: An RWJF national program with 22 demonstration projects developing innovative models of palliative and hospice care for diverse populations and in settings where these services were underutilized or unavailable. One objective was to provide quality palliative care earlier in the course of illness, concurrent with life-extending care. The national program office was based at the University of Montana Center for Ethics (www.rwjf.org/pr/product.jsp?id=30011).

Robert Wood Johnson Foundation (RWJF): The nation's largest philanthropy devoted solely to the public's health. Foundation efforts focus on improving both the health of everyone in America, and their health care. Between 1996 and 2005, RWJF made 337 grants, and invested nearly \$170 million to improve care at the end of life (www.rwjf.org/about/mission.jsp).

SUPPORT: A national Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. RWJF invested more than \$29 million in SUPPORT, the first large-scale prospective study of dying patients in the United States.

Veterans Administration (now called U.S. Department of Veterans Affairs) (VA): The VA health care system includes 171 medical centers, more than 350 outpatient, community, and outreach clinics, 126 nursing home care units and 35 domiciliaries (www.va.gov/about_va/vahistory.asp).

Key Players in End-of-Life Care

Ira Byock, M.D., co-founded the Missoula Demonstration Project on end-of-life care, and, from 1996 through 2006, served as director of *Promoting Excellence in End-of-Life Care*. Currently, Dr. Byock is Director of Palliative Medicine at Dartmouth-Hitchcock Medical Center in Lebanon, N.H. and Professor of Anesthesiology and Community & Family Medicine at Dartmouth Medical School.

June Dahl, Ph.D., with RWJF funding, and assistance from The Joint Commission, Dahl drafted standards to encourage systemwide changes in pain management in hospitals. Also, she co-founded the Wisconsin Cancer Pain Initiative with David Joranson, and served as adviser to the Alliance of State Pain Initiatives. Currently, she is Professor of Pharmacology at the University of Wisconsin School of Medicine and Public Health.

Kathleen Foley, M.D., is past Director of the Project on Death in America of the Open Society Institute. She serves as an Attending Neurologist in the Pain and Palliative Care Service at Memorial Sloan-Kettering Cancer Center in New York City and Professor of Neurology, Neuroscience, and Clinical Pharmacology at Weill Medical College of Cornell University.

Rosemary Gibson served as senior program officer at the Robert Wood Johnson Foundation for 16 years, and was chief architect of its \$200 million national strategy to establish palliative care in the mainstream of the U.S. health care system. She is a nationally known expert on health care quality.

David Joranson, M.S.W., is past Director of the Pain & Policy Studies Group at the University of Wisconsin, and co-founded the Wisconsin Cancer Pain Initiative. With RWJF support, Joranson studied federal and state policies on pain management, and developed a report card to show states' progress in adopting more balanced policies.

Joanne Lynn directed the SUPPORT project, based at The George Washington University Medical Center and funded by RWJF. Currently, she is with the Centers for Medicare & Medicaid Services.

Stephen McPhee, M.D., is Professor of Medicine, Division of General Internal Medicine, University of California, San Francisco. With RWJF support, he developed a *JAMA* series, "Perspectives on Care at the Close of Life" and conducted a project to review and strengthen end-of-life content in medical textbooks.

Diane Meier, M.D., is Director of the Center to Advance Palliative Care (CAPC), which began with RWJF support. She also serves as Director, Hertzberg Palliative Care Institute; and Professor, Geriatrics and Internal Medicine, Mount Sinai School of Medicine.

Steven Schroeder, M.D., is Distinguished Professor in Health and Health Care, University of California, San Francisco, School of Medicine. He served as president of RWJF from 1990 to 2002.

Sharyn Sutton was president of Sutton Group, which received RWJF funding to assess the EPEC project. The findings helped to inform a strategic plan for the program's future expansion. Currently, Sutton is vice president of strategy and communications for the AARP Foundation.

Joan Teno, M.D., is Professor of Community Health and Medicine and Associate Director of the Center for Gerontology and Health Care Research at the Brown University Medical School. With RWJF support, Dr. Teno developed a Toolkit of Instruments to Measure Care at the End of Life (TIME) as well as a website with policy-relevant data on end-of-life care.

Victoria Weisfeld served as a senior communications officer for RWJF and oversaw much of the grantmaking.

Endnotes

- ¹ Physicians certified in Hospice and Palliative Medicine “have special knowledge and skills to prevent and relieve the suffering experienced by patients with life-limiting illnesses. This specialist works with an interdisciplinary hospice or palliative care team to maximize quality of life while addressing physical, psychological, social and spiritual needs of both patient and family throughout the course of the disease, including through the dying process and subsequent family grieving. This care can occur within or outside of a formal hospice or palliative care team. This specialist has expertise in the assessment of patients with advanced disease and catastrophic injury; the relief of distressing symptoms; the coordination of interdisciplinary patient and family-centered care in diverse settings; the use of specialized care systems including hospice; the management of the imminently dying patient; and legal and ethical decision-making in end-of-life care.” (ABMS website)
- ² Phase 2 instituted a randomized controlled clinical trial involving an experimental group of 2,652 seriously ill patients and a control 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 relay them to physicians and nurses involved. Detailed written instructions about patients and families’ wishes regarding treatment were given to physicians.
- ³ Steven Schroeder, interview.
- ⁴ Victoria Weisfeld, interview.
- ⁵ Rosemary Gibson, interview.
- ⁶ 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.

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