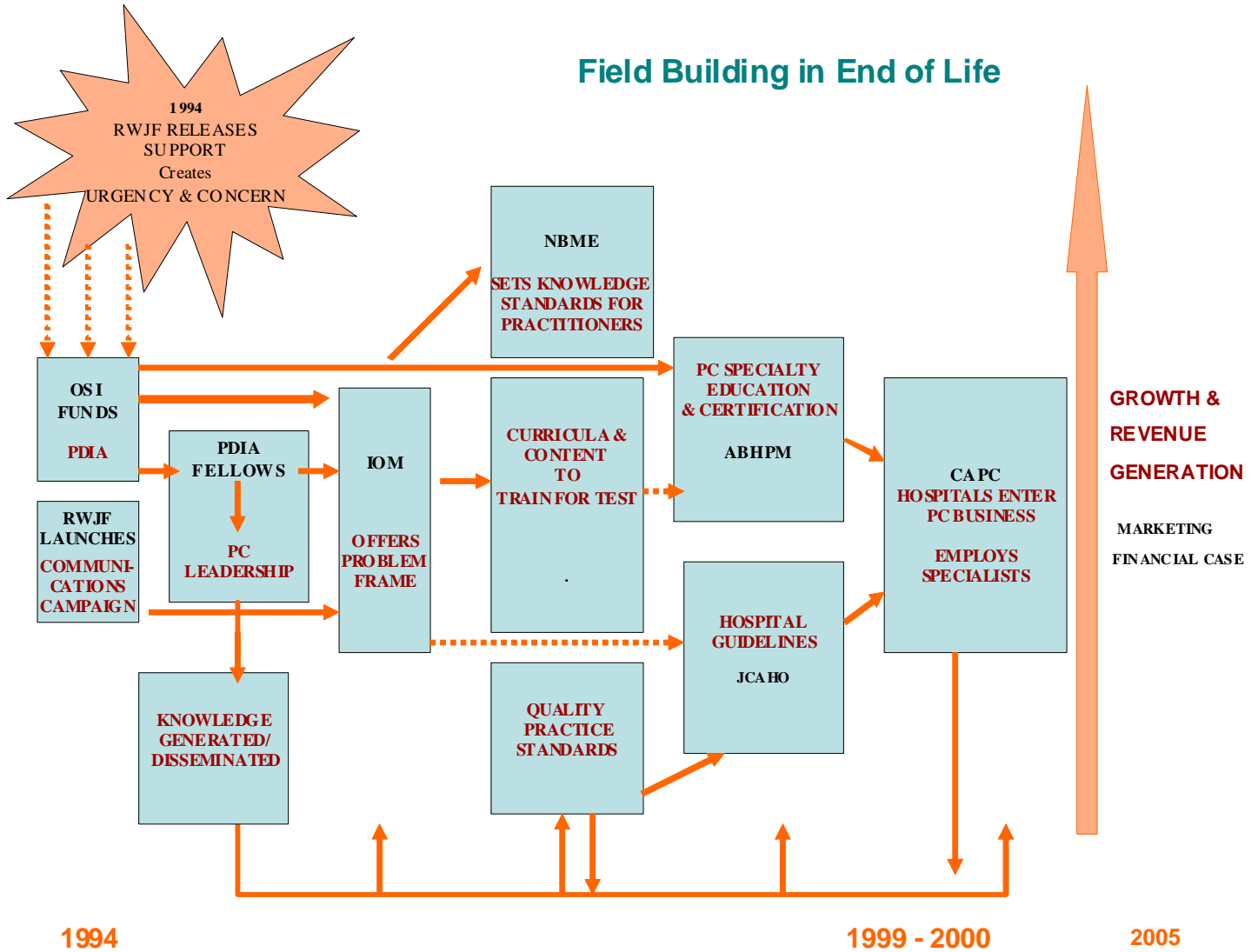


Death Is Certain. Strategy Isn't.

Assessing RWJF's End-of-Life Grantmaking



Presented at the Strategy Forum of the Evaluation Roundtable
May 21 – 23, 2008

Prepared for:
The Robert Wood Johnson Foundation

By:
Patricia Patrizi
Elizabeth Thompson
Abby Spector

Contents

A Story about Strategy: RWJF's End-of-Life Work	Page 1
Study Overview	Page 4
Evolution of the Strategy: From Confidence to Strategic Uncertainty:	Page 6
Assessment of Objective 1 Achievement: The Power of Inside Knowledge	Page 12
Assessment of Objective 2 Achievement: Moving Palliative Care Upstream	Page 24
Assessment of Objective 3 Achievement: The Importance of Purposeful Action	Page 39
Conclusion: Building the End-of-Life Field	Page 49
Appendices	Page 64

1

A Story about Strategy

An Assessment of 20 Years of Grantmaking

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

4

5 It's also a story about strategy.

6

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

11

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

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

21

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

31

32 This assessment shows how such breakthroughs can emerge within a field and how a
33 foundation can contribute to them. It also shows how a foundation can hinder progress
34 or foster indecision or dispersal of energy and resources.

35

1 Without question, strategy to overcome some of our country's most intractable social
2 problems is phenomenally difficult to construct and just as difficult to execute and
3 sustain. As much as uncertainty befuddles markets and industry, when crafting ways to
4 intervene in issues such as how people die, far greater challenges arise. For a foundation
5 strategy to have an impact on a significant social problem, numerous issues must be
6 addressed. To name three:

- 7
- 8 • **Setting a goal that can be achieved** and identifying where this goal is shared
9 with others. Who or what target to change? Who are the natural partners? How
10 to intervene? Where to intervene? What it will cost? How much change is likely
11 to occur given what is known about the problem and solutions? And how much
12 change is needed to make a significant difference?
- 13
- 14 • **Executing strategy.** Who can do the work? How to know that progress is being
15 made? How to resolve conflicts among partners? When to stick with a strategy
16 and when to alter direction and how to know one from the other? What if the
17 basic assumptions are wrong? What if the problem is far more complex than you
18 thought? How mistakes and successes can inform current and future work?
- 19
- 20 • **Sustaining effects over time.** For whatever strategy is chosen, how to ensure
21 durability, if warranted, and/ or proper adaptation? How to defend against
22 unintended dissipation of effects post funding? And is sustainability even
23 possible or desirable?
- 24

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

32

33 We are mindful that there is no one right way to construct a strategy. The most
34 productive approaches seem to land somewhere between the extremes of complete
35 uncertainty and complete certainty, between those program officers who throw up their
36 hands and say the world is too complex a place for planning to succeed and those who
37 act as if change can fairly easily be planned via tightly locked "if/then" statements and
38 logic models. The truth is that the level of planning certainty depends on the nature of
39 the problem and its circumstances. But the bigger point is that foundation management
40 has an important role in pushing for clarity in strategy even as it acknowledges
41 uncertainty, identifies where learning is needed, and explicitly makes calculated guesses
42 as new patterns emerge.

43

Evaluation Roundtable

- 1 Despite the uncertainty, each foundation must find its own way to making grants. Not
- 2 unlike death, payout is inevitable. Grants must be made. Clarity and alignment matter
- 3 because –like it or not– strategy will be inferred by the field as grants are made. As one
- 4 grantee put it, “Strategy is what you do, not what you say.”

1

Study Overview

Rationale and Method

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

9

10

Study methods

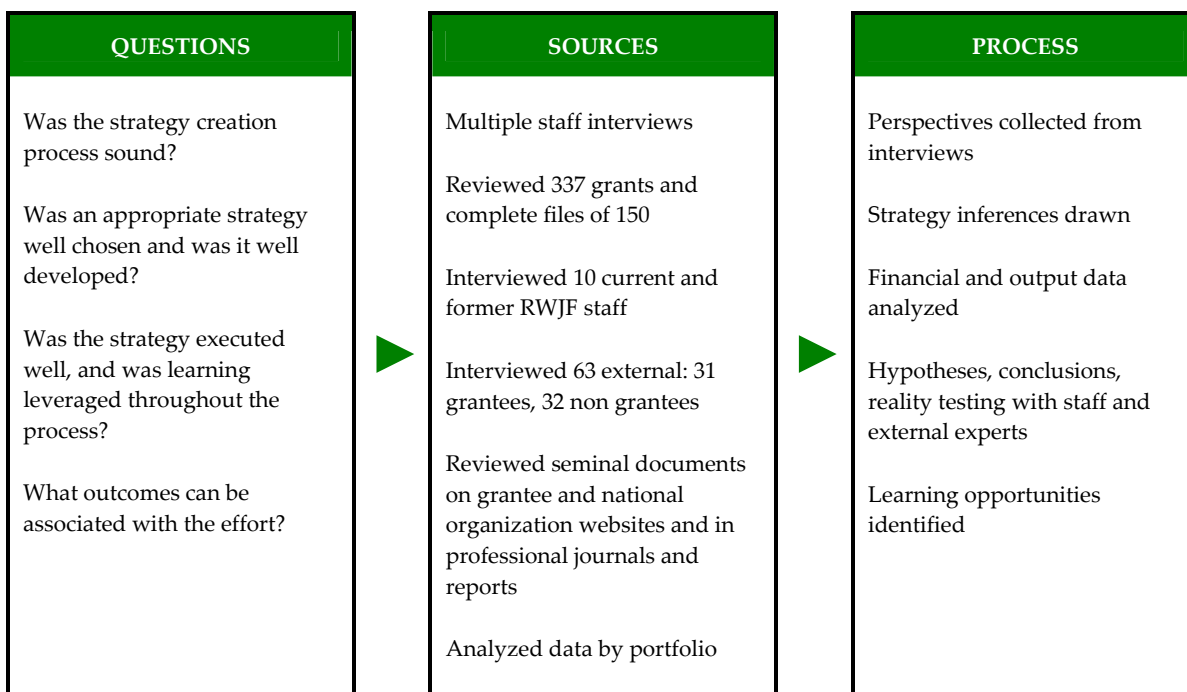
11

12

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

16

17



18

19

20 Foundation staff, past as well as present, spent extensive time with us discussing their
 21 motivations, intentions, perceptions, knowledge of the field and what they hoped to

1 achieve. None of those interviewed from the Foundation skimmed on the time needed to
2 address our questions. In Appendix 1, we include a list of our interviewees. A full list
3 of references is at the end of this report. (Appendix 7)

4

5 **Three caveats**

6

7 There are three important caveats to consider.

8

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

19

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

26

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

31

1

From Confidence to Strategic Uncertainty

Evolution of the Strategy

2 **The Prologue: SUPPORT**

3

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

9

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

15

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

23

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

30

31 “Physicians did not know what patients wanted with regard to resuscitation,
32 even though these patients were at high risk of cardiac arrest. Orders against
33 resuscitation were written in the last few days of life. Most patients who died in
34 the hospital spent most of their last days on ventilators in intensive care. We
35 had not expected to find the high levels of pain that were being reported,
36 especially in non-cancer illnesses. Except for the comatose, more than half of the
37 patients with any of the nine diseases were reported (by the family member of
38 the patient) to have substantial pain” (Lynn 1997).

1

2 At the end of Phase 1, researchers concluded that physicians were unable to predict
3 either severe disability or death and that they had an inadequate understanding of their
4 patients' wishes. Lewis Sandy, MD, who was to join the Foundation some time later as
5 Executive Vice President, understood the rationale for a second phase of SUPPORT as
6 addressing two key issues: the need for better "prognosticating about death" and the
7 need for decisions more in concert with the patient's wishes and trajectory.

8

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

17

18 The research team moved to a change strategy within six months of the end of the first
19 phase. "Convinced by the expert consensus that targeted interventions would work,"
20 the research team "designed a second phase aimed at fixing these problems" (Schroeder,
21 1999). Phase 2 instituted a controlled clinical trial involving an experimental group of
22 2,652 seriously ill patients and a comparison group of similar size. Three interventions
23 were offered:

24

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

31

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

35

36 It was not to be.

37

38 In 1994, researchers presented the totally unexpected and unequivocal finding of "no
39 effects" to a stunned Foundation staff. In hindsight, many say that the SUPPORT
40 strategy was overly "rational," and "underestimated the depth and complexity of the
41 problem."

42

1 **Failure becomes a case for change**

2

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

11

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

16

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

24

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

29

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

35

36

37 **From SUPPORT to the End-of-Life strategy**

38

39 Much debate and a number of landmark policies and decisions shaped the Foundation’s
40 work in this area. In the early 1990s, the nation was immersed in a struggle about care at
41 the end of life. New laws and high-profile court cases were making headlines. The 1990
42 Cruzan decision broke new ground by authorizing patients to reject medical treatment,

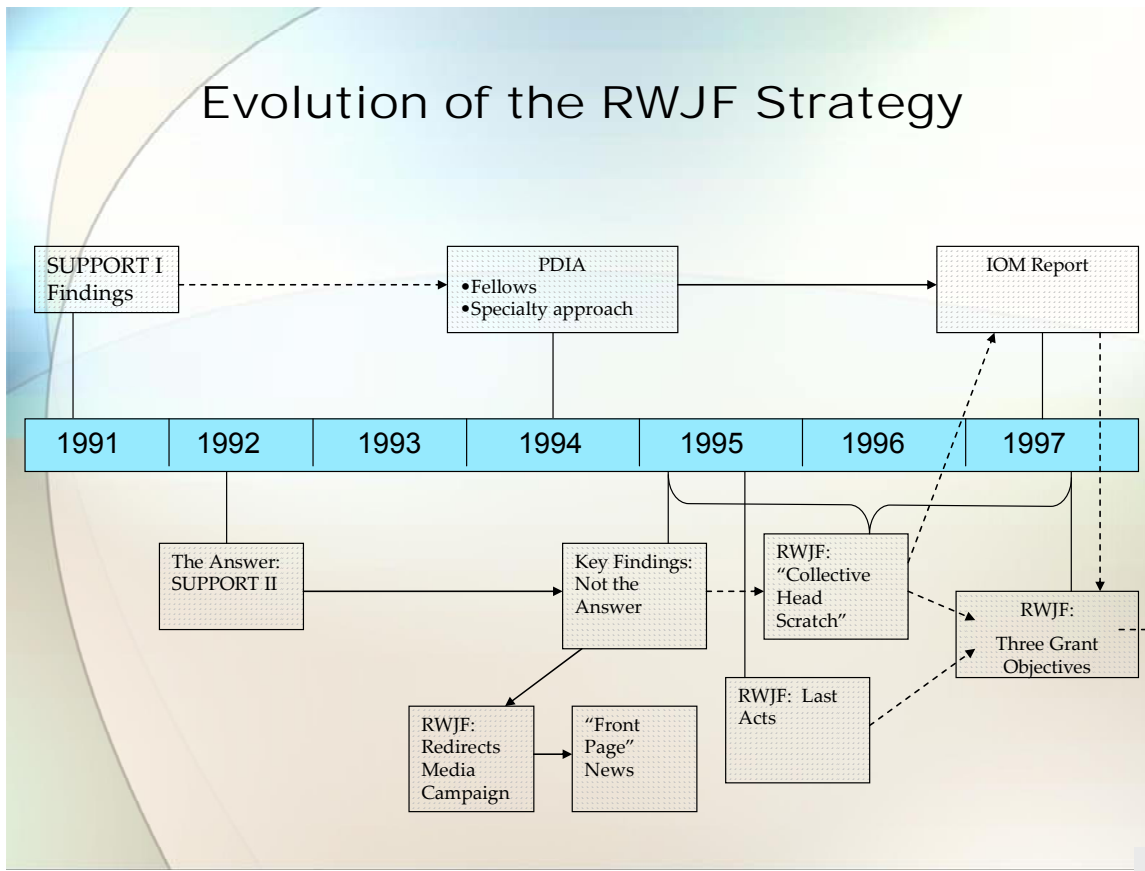
1 including food and water. Jack Kevorkian, or “Dr. Death” as he was known, came to
2 public attention with his first acknowledged assisted suicide. The Patient Self-
3 Determination Act came into law and required hospitals to inform patients of their right
4 to make treatment choices regarding resuscitation and other life-saving technology. In
5 1994, Oregon residents voted to approve the “Death with Dignity Act” to legalize
6 euthanasia. (See Appendix 2 for selected key events in the end-of-life care field.)

7
8 At the same time, health experts and the public pondered the implications of shifts in
9 demography, epidemiology and biomedical technology. The news media carried stories
10 about advancing life expectancy and the rise of chronic illnesses, such as heart disease,
11 cancer or stroke, as the leading causes of death. Biomedical technology was advancing
12 and high-tech care had become commonplace at the end of life, yet health-care costs
13 were mounting and were a source of real national concern. When should high-tech care
14 be used? What were the moral and economic principles that should guide our choices?

15
16 Medicare provided benefits for hospice care, yet relatively few people took advantage of
17 it. Only a small proportion of Americans had prepared advance directives to guide their
18 care. The SUPPORT study showed that many Americans were still dying in pain, but
19 SUPPORT’s intervention—which up to that point was the end-of-life care field’s best bet
20 at a solution—had failed to fix the problem.

21
22 In this context, The Robert Wood Johnson Foundation entered the end-of-life care field,
23 anew.

Evolution of the RWJF Strategy



1

2

3 After SUPPORT ended in 1994, the Foundation was uncertain about how to move
 4 forward and began what one Foundation executive, called “a collective head scratch.”
 5 Unsure about what would work and wanting to address “a broad array of factors
 6 leading to social change,” staff sought to “activate an impassioned consumer
 7 movement” that would motivate the public as well as professionals and help transform
 8 the culture of institutions charged with delivering care to the critically ill (Weisfeld et al
 9 2000). The position of the Foundation was probably best articulated by Schroeder’s
 10 expression of the felt need for a “broad movement with simultaneous work on multiple
 11 fronts.”

12

13 Over the next year, a staff team was formed to address issues related to what came to be
 14 known at the Foundation as “End Of Life” or “EOL.” Although never articulated this
 15 way, two major streams of work emerged: one focused on communicating and
 16 activating the public and another dedicated to transforming care. The communications
 17 team was already in gear from its work on SUPPORT. The plans to transform care,
 18 however, did not formally emerge until after an Institute of Medicine report,
 19 *Approaching Death: Improving Care at the End of Life*, was issued in 1997, but significant
 20 staff reconnaissance took place for two years prior. Staff met with end-of-life care
 21 experts and members of interested organizations, such as the American Medical

1 Association and the American Nurses Association and representatives from the hospice
2 movement. It was not until sometime in 1997¹ that the Foundation formalized its
3 objectives for moving forward.

4

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

7

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

8

9

10 (See Appendix 3: Timeline of Major Grants)

11

12 In the sections that follow, we will:

13

- Describe the work accomplished under each objective

14

- Examine the rationale for the grantmaking

15

- Offer our assessment of the Foundation's role in this work.

¹ There are conflicting reports on the date that the three objectives emerged, although each officer references the IOM report, dated 1997, as central. Therefore, we used 1997 as the starting year for grantmaking under the three objectives.

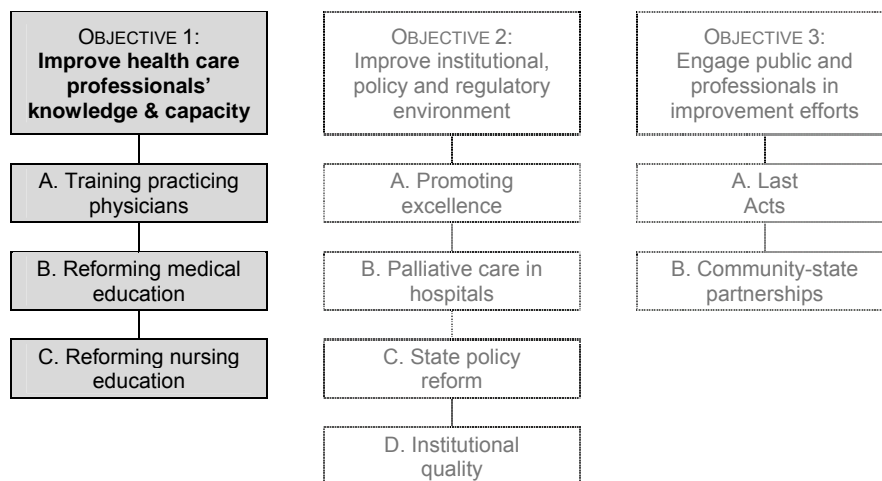
1

The Power of Inside Knowledge

Assessment of Objective 1 Achievement

2

3



4

5

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

Breakdown of Objective 1 Grantmaking

10

11 While the Foundation recognized that the
 12 range of practitioners who provide care at
 13 the end of life—including those in social
 14 work, pharmacy, and mental health—all
 15 needed more and better knowledge about
 16 the end of life, objective 1 work “started
 17 from [the Foundation’s] traditional
 18 strength—working primarily with
 19 doctors and nurses” (Weisfeld et al 2000).
 20 Although the objective broadly targets
 21 “health care professionals and others,”
 22 most of the resources -- 66 percent -- were
 23 invested in physicians and reforming
 24 medical education.

Component	Amount
Reforming Medical Education	\$8,788,848 (34% of Objective 1 portfolio)
Training practicing physicians	\$6,522,978 (25%)
Reforming Nursing Education	\$6,414,853 (25%)
Journals & Reports	\$2,711,979 (11%)
Other	\$1,223,647(5%)
Total	\$25,662,305

25

26 Staff believed that to change care in meaningful ways they needed to change physicians,
 27 and how they are educated, as the primary priority. Referring to hospice and palliative

1 care-related education, two of the field's early leaders wrote, "These programs won't
2 produce real change unless they also address the hidden curriculum of medical
3 schools—the values, attitudes and beliefs that constitute the basic culture of medicine"
4 (Sullivan and Block 2003). With this in mind, Foundation staff sought to focus its
5 attention on medicine.

6
7 To our knowledge, there were no overall internal strategy documents pertaining to
8 Objective 1, although an article in *Health Affairs* provided a good outline of the overall
9 goals with key lines of work and examples (Weisfeld 2000). The central analytic and
10 programmatic source document behind the objective's work, partially supported by
11 RWJF in 1996, was produced by the Institute of Medicine (IOM), "Approaching Death:
12 Improving Care at the End of Life." This study came to frame the clinical and related
13 system issues for the field. The report, written principally by clinicians, gives its best
14 guidance around shortfalls in clinical practice and the institutional structures
15 surrounding that care. It was, however, limited in offering the perspective of
16 economists and others who might have lent a view on larger system change issues.

17
18 Less formal but even more influential in shaping the medical education reform approach
19 under this objective was the relationship that developed between Kathleen Foley, MD,
20 and Rosemary Gibson, one of the lead program officers at the Foundation. Foley, a
21 neurologist specializing in pain at Memorial Sloan Kettering Cancer Center, was also the
22 director of Project on Death in America (PDIA). Her perspective on how medicine is
23 structured and influenced shaped much of RWJF's work. PDIA's most significant
24 investment, The Faculty Scholars Program, was to become the most important source of
25 leadership for RWJF's emerging program (See Appendix 5: PDIA Scholars' Roles in
26 RWFJ Programs).

27
28 The Foundation in the end focused on three core areas:

- 29
- 30 A. Training all practicing physicians to deliver better of end-of-life care
 - 31
 - 32 B. Reforming medical education
 - 33
 - 33 C. Reforming nursing education

34 Woven throughout each of these areas was an investment in building the body of
35 knowledge on end-of-life care.

36

1 **A tale of two theories**

2

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

7

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

12

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

15

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

24

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

34

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

1 **Area A: Training Practicing Physicians**

2

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

9

10 1. Develop a curriculum

11

12 2. Use the curriculum to train all
13 practicing physicians. Here EPEC

14 used a “train-the-trainer” model, forming a pyramid structure to reach its target
15 of all practicing physicians. It trained physicians and hoped that others in the
16 training would decide to lead more training sessions.

17

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

23

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

26

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

32

33 Observers believe that the Foundation and the grantee were unrealistic in their
34 assessment that all doctors could be persuaded to change. EPEC did not effectively
35 differentiate among those physicians likely to become advocates, those likely to remain
36 resistant, and those who would acknowledge the needs of the dying but would not want
37 to change their own practice to meet those needs. In all likelihood, affecting each of
38 these groups would have called for different change strategies (if in fact change could
39 have been achieved with all segments).

40

Area A Overview

- Aimed to reach all practicing physicians with a core curriculum delivered through a trained trainers
- \$6.5 million invested, 3.8% of the total portfolio

1 Second, EPEC did not take into account the time physicians have to devote to training.
2 Even if doctors were interested in learning about end-of-life care, many could not devote
3 the time to attend the full nine-module EPEC curriculum. As a result, the training
4 inevitably was watered down from the nine-modules in the design to one session that
5 mainly described the problem.

6
7 In 2003, EPEC reported that it had trained 1,500 of these source trainers and extrapolated
8 that these trainers, in turn, had trained 300,000. This extrapolation has not been actually
9 validated. These numbers appear to include training delivered largely to allied health
10 professionals rather than to the doctors themselves. About half of the trainers surveyed
11 in 2000 indicated that less than one-third of those they trained were physicians.

12
13 Third, some also questioned the efficacy of the program design itself as the training was
14 based on presentations and lacked hands-on experience. As two different interviewees
15 commented:

16
17 “I’m not sure about the long-term impact of EPEC. The curriculum is a good
18 resource for people, but is the model effective? “

19
20 “EPEC is not as effective as it could be...It is successful in raising awareness but not
21 as a learning mechanism. EPEC is a lecture-based program. More interactive works
22 the best. Effective educational practice has not been integrated into EPEC.”

23
24 On the upside, the EPEC curriculum has been adopted by other organizations better
25 positioned to reach and train physicians. EPEC has been replicated and modified for
26 many specialty groups, including emergency medicine and geriatrics. And the program
27 was modified by oncologists who created EPEC-O, funded by the National Cancer
28 Institute and the Lance Armstrong Foundation in partnership with the American Society
29 for Clinical Oncology and Oncology Nursing Society. The American Osteopathic
30 Association used the EPEC curriculum to train 45 faculty in 17 of the 19 osteopathic
31 medical schools. In July, 2003, the American Osteopathic Association elevated end-of-
32 life care to a standing committee, and in February, 2007, the American Osteopathic
33 Association Board approved a resolution to institute the equivalent of a subspecialty for
34 their system.

35
36 From a strategic perspective, it is well credited that EPEC laid the footprint for the
37 knowledge required by practicing physicians. As the program adjusted to address some
38 of the shortfalls evidenced by its train-the-trainer approach it engaged multiple
39 professional organizations, which by offering EPEC as part of their Continuing Medical
40 Education Curricula, endorsed and validated the need for the body of knowledge. On
41 the flip side of the coin, the program lost credibility as it failed to reach a goal, which
42 was never achievable in the first place. It is not at all unusual for a foundation to face
43 the claims of an enthusiastic and prominent grantee that it can undertake an

1 unreachable goal; a foundation, however, is in the position to reframe goals in a manner
2 that can support ambition and help redirect the organization toward more productive
3 efforts.

4 **Area B: Reforming Medical Education**

5
6 RWJF's approach to reform medical
7 education was jointly constructed by
8 Rosemary Gibson of the Foundation,
9 Kathleen Foley, MD of PDIA, Susan
10 Block, MD of Harvard Medical School
11 and a number of other key leaders in the
12 field. It was based on the following
13 theory:

- 14
- 15 • Institutions need external
- 16 motivation to change
- 17 • Changes in the medical licensing exam would provide an incentive to teach to
- 18 the test
- 19 • Changes in the exam would require new knowledge
- 20 • New knowledge would require researchers to produce it, a curriculum to
- 21 organize it and faculty trained to teach it

Area B Overview

- Sequence of reform involving use of licensing and certification incentives to create demand for new curricula, textbooks, journal, faculty, residency training, fellowships
- \$8.8 million invested, 5% of total portfolio

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

29
30 Key to all of this work was a small 1998 grant ¹ that the Foundation awarded to the
31 National Board of Medical Examiners to strengthen end-of-life content in medical
32 licensing exams. Students and later physicians take these exams at the end of the second
33 year of medical school on basic sciences, at the end of the fourth year on clinical sciences
34 and finally after one or more post-graduate years in preparation for acquiring a medical
35 license.

¹ \$98,000 was awarded

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

- 4
- 5 • UCSF: Stephen Mc Phee, MD, reviewed end-of-life content in top selling medical
6 textbooks and worked with publishers, editors and authors to make
7 improvements. A 2001 follow-up survey showed that 40 percent of publishers
8 and editors reported new content in existing chapters, and an additional 24
9 percent planned to make improvements.
- 10
- 11 • Medical College of Wisconsin: This national project helped internal medicine
12 residency programs meet what were then new requirements from the American
13 Board of Internal Medicine that they include end-of-life care training into the
14 curriculum for medical residents. As of the end of 2006, 347 programs had
15 completed the national residency end-of-life education project, which ultimately
16 grew to include family practice, neurology and surgery. With RWJF support, the
17 program is now developing course material for medical schools, as well.
- 18 • Medical College of Wisconsin: A national End-of-Life/Palliative Care Education
19 Resource Center was established. EPERC, as it is called, maintains a web site
20 containing peer-reviewed educational materials, recommended books and
21 articles, training opportunities, funding sources, conferences and links to other
22 resources, and an electronic newsletter. By mid-2004, the web site had 12,000
23 registered users from 104 countries and was getting more than 300,000 hits per
24 month.
- 25

26 The Foundation also made several grants to influence whole systems of care. The most
27 successful and important was a grant of \$943, 480 made to the Veterans Administration
28 in 1998. To Foundation staff, the VA represented a system serving a large number of
29 elderly and one that could have a relatively quick impact on its faculty and its residents.
30 Overall, the VA offers approximately 15 percent of the fellowship slots in palliative care
31 in the United States so the reach of this investment was potentially significant.

32
33

1 **It takes more than one foundation to build a field: an example**

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

6
7 PDIA and RWJF were not fully on the same page regarding the need for specialists in
8 palliative care. RWJF took an "agnostic" stance on the issue. Not wanting "to add to
9 medical divisiveness and fragmentation," the Foundation chose to abstain from taking a
10 position, to "let physicians do this themselves," and to respond to requests from the
11 field.

12
13 PDIA, on the other hand, wholly endorsed the creation of a subspecialty that could
14 assume status and position within medicine. PDIA's Kathleen Foley, MD believed in the
15 importance of following an "elite strategy." As she saw it, "The only way to address the
16 issue was to create a subspecialty informed by a clear and well-respected base of
17 knowledge. These specialists would be charged to create curriculum and teach. But to
18 be taken seriously, they would need the same credentials and quality of knowledge that
19 their colleagues commanded; from this would follow the demand for and earned
20 respect." Another source interviewed validated this opinion, saying, "It became clear
21 that physicians in the field felt they wouldn't be taken seriously until there was
22 recognition of hospice and palliative care as a specialty or sub-specialty."

23
24 RWJF straddled this issue by supporting The American Board of Hospice and Palliative
25 Medicine (ABHPM) to develop and standardize the accreditation process for fellowship
26 training programs in hospice and palliative medicine, improve the certification exam for
27 physicians in the field and adopt a plan for a recertification test.

28
29 The Project on Death in America also provided support during this period for ABHPM
30 to take a leadership role in formalizing recognition of hospice and palliative medicine.
31 With combined support from RWJF and PDIA, ABHPM helped hospice and palliative
32 medicine achieve recognition as a medical subspecialty in near record time. In 2006, the
33 American Board of Medical Specialties agreed to recognize hospice and palliative
34 medicine as a legitimate subspecialty, and the Accreditation Council for Graduate
35 Medical Education voted to accredit fellowship training programs.

36
37 The work on different aspects of the specialization effort is an example of the strength of
38 the RWJF—PDIA partnership and how it worked to great effects. As one grantee said,
39 two major funders allowed for two different roles for the use of the money. "The Soros
40 money (PDIA) let us focus on building our capacity to advocate for the field; the
41 Johnson money supported the development of standards, and built the knowledge
42 base." PDIA staff saw RWJF as a "strong partner in that it could offer support for the
43 substantive work" and "we were happy to fund the networking and convenings."

1 **Results for medical education reform**

2

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

6

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

9

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

16

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

23

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

28

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

33

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

37

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

40

41 • In 1988, the American Academy of Hospice and Palliative Medicine began with
42 250 founding members; it now has more than 2,600 members.

43

1 **Area C: Reforming Nursing Education**

2

3 The rationale and strategy for nursing
4 paralleled the approach employed in
5 medical education reform. As with
6 medicine, the nursing approach was
7 grounded in research illustrating that
8 nurses were inadequately prepared to
9 care for patients in pain or at the end of
10 life. The goal was to address this
11 deficiency by embedding end-of-life

12 care content into nursing textbooks, teaching, licensure and certification.

13

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

18

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

25

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

32

- 33
- Design an evidence-based curriculum for nurses
 - 34 • Use the curriculum to train undergraduate nursing faculty and continuing
35 education providers throughout the US in end-of-life care
 - 36 • Prepare trainees to integrate what they learned into the education programs of
37 their home institutions

38

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

Area C Overview

- Phasing of licensing and certification requirements to build demand for new curricula, expertise and training programs
- \$6.4 million, 3.8% of the total portfolio

1 partnership with AACN was the instrument. As a membership organization of more
2 than 800 schools of nursing, it could engage nursing colleges effectively and bring
3 credibility to the ELNEC training. In turn, the City of Hope team provided the research
4 and content expertise in designing the end-of-life curriculum and led the effort to create
5 a pediatric version of end-of-life training.
6

7 **Results for nursing education reform**

8
9 Many accomplishments emerged, including:

- 10
11 • Palliative care competencies added to the essentials of baccalaureate nursing
12 education.
13
- 14 • In response to a RWJF-funded assessment showing that only 2 percent of the
15 major nursing textbooks addressed end-of-life issues, 40 percent of authors and
16 publishers had made changes or were in the process of doing so.
17
- 18 • By 2000, the National Council of State Boards of Nursing had adopted a revised
19 test plan that includes improved end-of-life content in the exam for registered
20 nurses.
21
- 22 • One year after their efforts, 10 of 48 boards reported changes to nursing school
23 curricula for pain and end-of-life care. An additional 24 boards anticipated
24 making changes in the future.
25
- 26 • The Hospice and Palliative Nurses Association (formerly Hospice Nurses
27 Association) started in 1987 and now has over 9,200 members (www.hpna.org)
28
- 29 • ELNEC developed a well-received curriculum, and nursing schools overall have
30 added 10 hours of end-of-life content to it. ELNEC was highly attentive to
31 evaluation, tracking real numbers and real progress. Within one year of ELNEC
32 training, 500 nurse faculty had trained 19,000 students. As of 2004, 1400 nurse
33 educators were trained, representing one-third of nursing schools in all 50 states.
34

35 ELNEC continues to try to meet the need even though RWJF funding ended in 2004. At
36 11 national conferences this year, ELNEC offered its core curriculum as well as specialty
37 courses in end-of-life care for graduate nursing, critical care, geriatrics, oncology and
38 pediatrics. Nevertheless, faculty from two-thirds of the nation's nursing schools
39 remains untrained in end-of-life care.
40

1 **Last words on both medical and nursing education strategies**

2

3 Each strategy was deliberate, built on evidence, led by high-profile and well-regarded
4 physicians and nurses, and embedded in elite organizations in medicine and nursing.

5 Each was clear, focused and well-financed. The work had low costs and high returns in
6 terms of what was accomplished.

7

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

9

10 • Taking lessons from history in planning the change effort

11 • Having clear objectives and outcomes, which were followed closely by those
12 with most at stake in the enterprise

13 • Being subtle and fast and maintaining strong, high quality partnerships

14 • Executing close to the ground, relying on field-based leadership and increasing
15 the chances that change would be institutionalized by using existing actors,
16 levers and organizations

17 • Ensuring that information flowed consistently from field leaders to the
18 Foundation

19

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

24

25

1

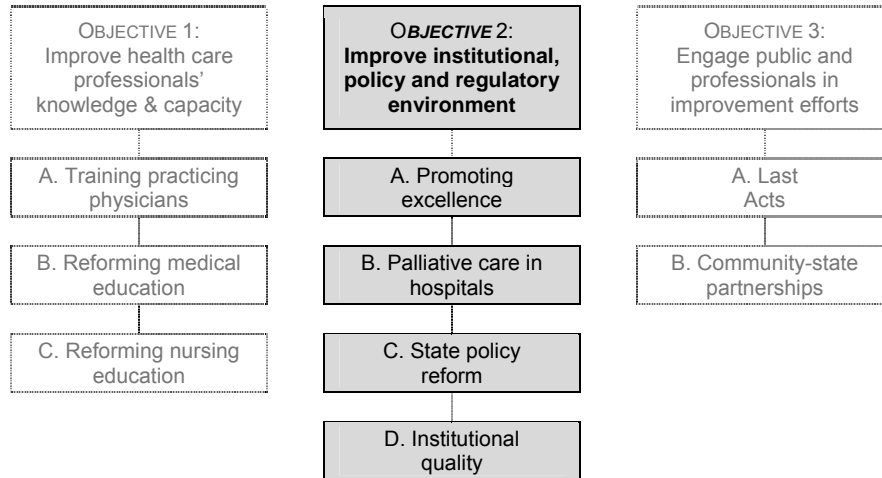
Moving Palliative Care Upstream

Assessment of Objective 2 Achievement

2

3

4



5

6

7

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

12

13

14

15

16

17

18

19

20

21

22

23

24

25

26

27

28

“Institutional change encompasses many features, such as having standard procedures in hospitals and nursing homes that make it easier to do what is right for the patient, not what is convenient for the staff; having in-house legal counsel who know the law regarding refusal or withdrawal of treatment and can give sound advice about stopping a ventilator or withdrawing a feeding tube; and repairing our health care financing system so that it adequately covers counseling and is not so fragmented.” (Weisfeld et. al. 2000)

Breakdown of Objective 2 Grantmaking

Component	Amount
Promoting Excellence	\$19,844,909 (31% of portfolio)
Palliative Care	\$29,083,604 (45%)
State Policy Reform	\$4,338,187 (7%)
Institutional Quality	\$7,320,172 (11%)
Other	\$3,838,772 (6%)
Total	\$64,425,644

1 While the objective remained broadly cast, over time the investments under Objective 2
2 focused on four major areas. These were:

3

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

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

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

23 D. *Institutional Quality.* Finally, the Foundation made 15 grants amounting to \$5.6
24 million to support the development and use of quality measurement and
25 improvement tools across clinical settings as well as to support public policy
26 work.

1 **Searching for a strategy**

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

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

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

21
22 The program was shaped in many ways by its proximity to the release of the SUPPORT
23 findings. The SUPPORT program was originally framed with what could be called an
24 overdose of confidence, both in the assumption that problems were well understood and
25 that solutions were fairly clear. After the SUPPORT evaluation indicated otherwise,
26 Promoting Excellence was cast as a search for “models that work.”

27
28 It very well may be that such a broad strategic approach was justified in light of the need
29 to learn more about what might work, but the Foundation did not have clear learning
30 objectives. While substantial experience emerged from the program, the yield for the
31 Foundation might have been limited by lack of clear intention about what it wanted to
32 learn, the huge variation among the projects, and the relatively weak use of evaluation.

33
34 Ira Byock, MD, Director of the Promoting Excellence National Program Office, ¹ is
35 described as a “passionate advocate” and “visionary.” His book, *Dying Well*, influenced
36 Rosemary Gibson. “He was well respected, was doing the work and had a vision.” As

Area A Overview

- To determine the practicality of new models and demonstrate that palliative care can be moved “upstream”
- Highly diverse portfolio of populations served, conditions and settings, 22 original sites + 4 ICU sites
- Support of Peer Workgroups of specialists chartered to change standards of care within their professional groups
- \$19.8 million, 11.7% of the total portfolio

¹ Byock directed the work initially out of The Missoula Demonstration Project, started in 1996, to study the experience of dying and the quality of life's end in one community and to serve as an example of what could be accomplished in any community.

1 an emergency medicine physician, he understood the importance of translating the need
2 for and practice of palliative care to physicians who were most on the line to save or
3 extend life.

4
5 By supporting projects reflecting a range of diseases, settings, patients and provider
6 characteristics, Promoting Excellence reached out to many different population groups,
7 thereby addressing the heterogeneity of those dying. Program leadership aimed to
8 demonstrate that palliative care services could be delivered in many different settings
9 and to people with vastly different conditions. The program portfolio was highly varied,
10 serving special populations including children, prisoners, Native Americans, the
11 seriously mentally ill, urban African Americans and others. It also focused on special
12 conditions and diseases including Alzheimer's, HIV/AIDS, and advanced renal, liver,
13 lung, heart and kidney disease. The projects were located in difficult settings, including
14 cancer centers, nursing homes, prisons, mental institutions and group homes, as well as
15 hard-to-serve rural and urban communities.

16
17 While all but two of the 26 projects continue in some form to this day, little patient
18 outcome data were collected or assessed. The projects, however, produced volumes of
19 articles addressing operational and clinical care issues.

20
21 Late in its evolution, Promoting Excellence took steps toward greater focus. Building on
22 the efforts of the Critical Care Peer Workgroup (discussed below), in 2003 Promoting
23 Excellence awarded grants to four health care institutions to develop innovative ways to
24 integrate palliative care services into critical care settings. This second phase of grants
25 had better-defined aims, as well as an agenda for common data collection and outcomes-
26 related research.

27

28 **An unanticipated success**

29

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

41

42 The Peer Workgroups emerged as an unanticipated success in developing palliative care
43 strongholds within specialty areas--generally not the most fertile ground for palliative

1 care. The workgroups energized key leaders in prominent specialty areas to
2 successfully take on the palliative care agenda. As one observer said, “The impact of the
3 work groups was breathtaking. The surgery and critical care groups were incredible at
4 digging in. They looked at the quality domains that were at the core of the discipline of
5 palliative care and said, ‘We have to integrate this.’”
6

7 The Promoting Excellence national program office translated the initial broad goals of
8 the program into a focus on demonstrating “the larger do-ability” of the premise that
9 palliative care could be acceptable to a broad range of clinicians and populations and
10 successfully administered earlier in the illness than most had previously assumed
11 possible. Byock, reflecting back on the start of the grants, said, “Nine years ago, there
12 were serious questions about whether it was even possible to provide palliative care at
13 the same time clinicians are actively treating cancer or heart problems. The Promoting
14 Excellence projects definitively demonstrated that you can provide concurrent palliative
15 care without requiring patients to give up active, disease modifying treatment. The
16 grantees’ programs showed that concurrent care is feasible and well-accepted in a
17 variety of settings and patient populations. Clinicians, patients, families and local health
18 systems all loved it.”
19

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

26 **Coming to strategic focus**

28 **Area B: Promoting Palliative Care in Hospitals**

30
32 The first grant to the Center to Advance Palliative
34 Care (CAPC) was made in 1999 and in many ways,
36 was an extension of the medical education reform
38 work supported under Objective 1. At the outset,
40 hospital palliative care centers were envisioned as
42 providing clinical sites for teaching residents.
44 While viewed modestly in the beginning, this line
46 of grantmaking evolved to become a significant
48 part of the portfolio and the main way to promote
50 and anchor palliative care in hospitals. CAPC is
52 the current lynchpin in the education and care
54 delivery system developed by the Foundation in
56 concert with PDIA and other leaders in the field.
58

Area B Overview

- Increase number of hospitals that provide quality Palliative Care
- Target -- 20% of all US hospitals by 2005
- \$29 million invested, 17% of total portfolio
- Primary support to Center to Advance Palliative Care
- Later support of Palliative Care Leadership Centers to extend dissemination potential

1 The grant to CAPC provides the on-the-ground connection between the work supported
2 under Objectives 1 and 2, if we consider the following:

- 3
- 4 • Palliative care centers have an essential role as training sites.
- 5 • Research conducted within palliative care centers translates into knowledge and
6 practices used in training physicians.
- 7 • Employment opportunities are developed for fellows or others with training in
8 palliative care.
- 9 • Centers are located in the heart of the health care system and help build the
10 demand for palliative care expertise within it.

11

12 **Why hospitals?**

13

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

21

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

- 24
- 25 • Hospitals are the site where most people die.
- 26
- 27 • The costs associated with the end of life are huge, and most of these costs are
28 associated with hospitals.
- 29
- 30 • Hospitals have some incentives to address these issues in that they need to find
31 ways to cut costs, and single outlier patients with palliative care needs can
32 absorb enormous resources.
- 33
- 34 • Physicians are often ill-equipped to deal with the nature and depth of demand
35 placed upon them by patients and families, and a solution that ameliorates this
36 burden, without pointing the finger at “inadequacies,” has appeal.
- 37
- 38

1 Staff also recognized that significant strategic barriers would make it difficult for the
2 Foundation (or at least a Foundation officer) to make large scale investments in other
3 settings. These included:

- 4
- 5 • The primary care system in America was seen as being in “shambles,” with
6 doctors unable to offer the kind of care and advice needed by patients facing the
7 end of their lives or long-term debilitating illnesses.
- 8
- 9 • There was no viable community health system that could adequately provide
10 palliative care. Effective scale-up would have been difficult to achieve and
11 strategies to do so are not easy to imagine or execute.
- 12
- 13 • Prospective reimbursement for home health was insufficient to cover good
14 palliative care, and there was no good system of delivery.
- 15
- 16 • Nursing homes, a logical focus for reform, lacked the stability, level and quantity
17 of professional staff that would allow for building a system of palliative care.
- 18
- 19 • Hospices, while addressing care needs of the dying, did not represent the
20 mainstream of medicine or a major component of the health care system.
- 21

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

35

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

1 Likewise, the Foundation communications staff could have helped shape
2 communications to lessen tensions that emerged.

3
4

5 **The role of the Center to Advance Palliative Care**

6

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

10

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

13

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

18

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

25

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

36

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

40

41 While the broad strategy was developed prior to CAPC receiving its grant, Diane Meier,
42 MD, CAPC's director, significantly refined and deepened it. She understood that she

1 had to “sell” palliative care and brought in marketing, business modeling and financial
2 expertise to do so. She continually adjusted and refined her strategy based on what she
3 was learning.

4
5 Important early marketing decisions helped position CAPC not as an advocacy
6 organization but as one with great technical skills and a strong product to sell. Early on,
7 Meier worked with Sutton Group,¹ a social marketing firm, to develop a segmented
8 market analysis of her audience, building upon a research-based analysis of who the
9 audiences are, what they want and the factors that influence their choices. With Sutton,
10 she identified six important but very different audiences for palliative care centers and
11 concluded that they had very different needs. These audiences and their needs were
12 identified by Meier as follows:

- 13 • **Health care professionals who care for patients but are not palliative care**
14 **specialists:** “Admitting physicians can be overwhelmed when they have just
15 one *really* sick patient in the hospital. It’s time consuming to work with patients
16 and families as they make decisions. CAPC says, ‘We’ll help you, doctor, with
17 the care of your patient.’ We do endless family meetings. It’s a labor intensive
18 process but it’s a necessity in hospital care.”
- 19 • **Practicing physicians who say they don’t need help managing pain:** “We hear
20 all the time that physicians need help answering all the pages from nurses and
21 the calls from family. We developed the “Got Pages” brochure for practicing
22 physicians. The message isn’t about incompetence or death and dying.”
- 23 • **Patients and families:** “Most hospice and end-of-life websites talk about care of
24 the dying and grief and bereavement, but no one defines him or herself as dying.
25 They won’t come. Bob Arnold at the University of Pittsburgh learned this lesson
26 from the Make A Wish Foundation. Parents would not self identify their
27 children as dying. In focus groups, parents would say, ‘My child isn’t eligible.’
28 Now the signs in airports say something like, “The power of a wish is to get
29 better.”
- 30 • **Hospital CEOs:** “Palliative care physicians often view CEOs as the enemy. We
31 teach that “you’re on the same side of the table as the hospital CEO. If the CEO
32 can’t keep the hospital doors open, your service will close. You can help your
33 CEO assure high quality care, through-put and highly technical efficiency. If you
34 look at payment by diagnosis for a hospital stay – if you have someone with a
35 sixty-day length of stay, that’s blocking 23 admissions and that’s a huge loss to
36 the hospital. It happens that palliative care improves operations.”

¹ Sutton Group had just completed a study of EPEC and applied this knowledge of physician preferences to their work with CAPC.

- 1 • **Philanthropists:** “Some palliative care people find it distasteful to ask for
2 money. We tell them to make the case to funders as follows: Invest in success,
3 leadership, vision and optimism. Explain why investing in you is a good venture
4 capital investment, and makes the foundation more successful as well. “
- 5 • **Palliative care professionals:** “We speak in a way that acknowledges the
6 transcendent and rewarding nature of their work. We recognize their
7 contribution and understand the difficulty of what they are doing.”

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

12
13 The market analysis influenced the strategy in several ways, helping CAPC to:

- 14
- 15 • Demonstrate that offering palliative care made financial sense. Financial models
16 were built and disseminated.
 - 17
 - 18 • Insert palliative care specialists to help admitting physicians on these issues (in
19 contrast to SUPPORT, which assumed that the majority of physicians could
20 change their decision making and practices).
 - 21
 - 22 • Market to admitting physicians in a way to meet their needs as defined by them.
 - 23
 - 24 • Reframe the problem and objective from offering care toward a “good death” to
25 providing care to those who are seriously ill in hospitals, thereby expanding both
26 the target population and the acceptability of the services of these centers.
 - 27

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

34
35 But the payoff has been noteworthy, as CAPC is as well regarded by CEOs as it is by
36 clinicians and advocates for care of this kind. The outcomes have been significant:

- 37
- 38 • 30% of all US hospitals, and 70% of hospitals with 250+ beds, have adopted
39 palliative care programs.
 - 40
 - 41 • CAPC, the American Academy of Hospice and Palliative Care, Hospice and
42 Palliative Nurses Association, Last Acts Partnership and National Hospice and

1 Palliative Care Organization developed the National Consensus Project (NCP)
2 Guidelines for Quality Palliative Care. In turn, these guidelines became the basis
3 for the National Quality Forum framework for palliative and hospice care. The
4 framework is intended to guide the selection of quality measures and preferred
5 practices in palliative and hospice care. This, too, was seen as setting the stage
6 for direct Medicare reimbursement.

- 7
- 8 • The program trained 572 hospital teams. 88% of them started palliative care
9 programs within two years.
- 10
- 11 • CAPC collaborated with The Joint Commission on pain management standards.
- 12

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

19 **Keeping a foothold: When good work just emerges**

20 **Area C: State Policy Reform**

21
22 What emerged as a successful although
23 not central area of effort to change state
24 policy addressing pain management came
25 out of the work of two colleagues at the
26 University of Wisconsin: David Joranson,
27 MSW, director of the Pain and Policy
28 Studies Group, and June Dahl, Professor
29 of Pharmacology in the medical school.
30 Both had been long-time grantees of
31 RWJF and received RWJF support for
32 their pain management work prior to
33 RWJF's formally developing its end-of-life
34 portfolio.

35
36 Long an advocate of sound pain policies, Joranson helped establish the first state Cancer
37 Pain Initiative in Wisconsin, which has been emulated by 46 other states. Joranson had
38 received several grants from RWJF going back to the mid-1980s. His work produced one
39 of the most effective devices in the portfolio to create state change.

Area C Overview

- University of Wisconsin (Pain and Policy Studies Group and Medical School)
- CSP advocacy
- \$4.3 million, 2.5% of total portfolio (not including support to CSP) for Objective 2

1 From 2000 through 2007, the state pain policy progress report cards grading states on
2 the quality of the pain policies and regulations were an important catalyst toward
3 changing state policies and regulations. From 2000 to 2003, 16 states increased their
4 report card grade. From 2003 to 2006, 19 states improved at least one grade level. The
5 vast majority of states now have a grade above C, and no state's grade has decreased
6 since 2000. The report cards are now supported by the American Cancer Society, the
7 Susan G. Komen Foundation for the Cure and the Lance Armstrong Foundation.

8
9 As early as 1992, Dahl received RWJF support to develop a network of State Pain
10 Initiatives working to overcome barriers to pain relief through education, advocacy and
11 institutional improvements. In 1996, a national organization, the Alliance of State Pain
12 Initiatives, was established. Later grants supported expansion of the pain management
13 work to hospitals, long-term care facilities and home health agencies.

14
15 With Joranson, Dahl worked with the federal Drug Enforcement Agency to develop a
16 statement calling for a balance between addressing abuse and diversion of prescription
17 pain medicines on the one hand and maintaining access for patients on the other. As a
18 result of this collaboration, the DEA issued a joint statement in 2001 with a coalition of
19 health care and pain prevention organizations that called for a more balanced opioid
20 medication policy. Unfortunately, the dialogue between the DEA and pain community
21 came to a halt a few years after this statement, as the DEA appeared to pull back from its
22 earlier commitment (Duensing, 2006).

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

30
31 In addition to working on pain policies, a number of partnerships addressed state
32 policies in related areas such as those related to advance directives, Medicaid
33 reimbursement and nursing-home quality. Interviewees and Foundation staff generally
34 recognized five partnerships as achieving significant accomplishments in changing state
35 policies, including updating advance directives and removing conflicting provisions
36 from legislation and regulations. However, many other coalitions faced difficulties and
37 did not make much headway. A larger discussion of the CSP program is included in
38 Objective 3 as many of the partnerships focused on "engaging the public."

1 **Area D: Improving Institutional Quality**

2 The Foundation invested \$5.6 million, or
3 3.4 percent of the entire end-of-life care
4 portfolio, in grants designed to enhance
5 quality measurement across clinical care
6 settings. The grants had three general
7 aims: to address quality needs in hospices
8 and nursing homes, to advance quality
9 standards developed for palliative care in
10 hospitals, and to monitor state and
11 national trends in care at the end of life.
12 Projects in this part of the portfolio
13 produced data, benchmarks and
14 standards useful to service providers,
15 health care administrators, policymakers
16 and payers. As with investments in
17 support of policy changes to pain
18 management, grants made to promote
19 quality were not *central* to the concerns of staff. They, however, recognized these efforts
20 as having potential to address many segments of the field that did not otherwise fit into
21 the grantmaking.

22
23 The Foundation made two major investments in institutional quality.

24
25 The first was in the work of Joan Teno, MD, Associate Director of Brown University
26 Medical School's Center for Gerontology and Health Care Research. A highly respected
27 expert in quality measurement, Dr. Teno received 7 grants totaling \$3.5 million from
28 1997 through 2006. Joan Teno's work was to create and test new instruments to measure
29 the care that institutions provide at the end of life, and create a web interface where
30 health care providers can download instruments, submit data, and get results back
31 evaluating their quality of care.

32
33 In 2004, the National Hospice and Palliative Care Organization (NHPCO), which
34 represents 80 percent of hospices nationwide, took over and adapted the family
35 interview component of Teno's toolkit. The group now analyzes the data for its
36 members.

37
38 In addition, Teno received a grant to disseminate national, state and local indicators of
39 change in end-of-life care. The resulting *Facts on Dying* website contains a variety of
40 policy-relevant information, including trends in site of death, family perceptions of end-
41 of-life care as well as other important indicators, such as the presence of pain, advance
42 directives, do-not-resuscitate orders and feeding tubes for nursing home residents and

Area D Overview

- To develop tools for quality measurement, quality standards for hospitals and other settings, as well as producing policy-relevant information
- \$5.6 million, 3.4% of total portfolio
- Grants supported Joint Commission pain standards for hospitals, national framework for palliative care quality improvement initiatives, quality measurement tool development, and website with data for public policy

1 the severely cognitively impaired. The data are useful for advocates as well as national
2 and state policymakers.

3
4 The second major investment was to the University of Wisconsin's June Dahl, to
5 improve the quality of pain care and create standards for its management. During a
6 meeting in 1996, Dahl and others acknowledged that education alone does not change
7 practice and that it would be necessary to mandate change by making pain management
8 a priority in the nation's health care facilities. Dahl worked with The Joint Commission
9 to integrate pain assessment and management into the standards used to accredit health
10 care facilities across the U.S. The standards primarily affect hospitals but increasingly
11 long-term care and home health programs are seeking Joint Commission accreditation.

12
13 According to numerous interviewees, the work on improving institutional quality has
14 significantly advanced the field. Said one, "[There has been] tremendous uptake [in
15 quality]. I can honestly say that Teno has redefined how we think about quality related
16 to palliative care and has been instrumental in thinking about quality from the patient
17 and family's perspective."

19 **Final thoughts on Objective 2**

20
21 As CAPC emerged as the centerpiece of the work under Objective 2, it is possible to see
22 the direct links to the earlier work to reform medical education. In many ways CAPC
23 continued the "elite strategy" described by Kathleen Foley, MD when she noted that
24 influencing medicine meant speaking to powerful institutions in terms that they
25 understood and from vantage points they appreciated. The focus on hospitals gave the
26 work the institutional anchor it needed as well as a base for clinical training and
27 research. It maintained and strengthened what was then an area of distinctive
28 competence gained by the Foundation through its investment in and name recognition
29 related to SUPPORT: knowledge of how hospitals treat those who are seriously ill and
30 dying.

31
32 The other work, such as that in pain and quality, were good investments not just for
33 their accomplishments but also for their relevance to the range of institutions not
34 supported by the Foundation to any great extent—hospices, nursing homes and
35 community health providers.

36
37 While the Foundation made important investments in the area of pain, it is
38 disappointing that, although much was accomplished with relatively little money, the
39 strategy was not driven home sufficiently to ensure enduring results.

40
41 Much excellent work was aimed both at addressing the under-treatment of pain and
42 striking a better balance between regulators' concerns about diversion and abuse of
43 controlled substances and physicians' ability to prescribe medication for pain

1 management without fear of undue scrutiny. But with the recent prosecution of some
2 physicians for their prescribing practices, and the lack of clarity about the moral
3 rectitude of administering medication to those in pain, there seems to be significant risk
4 that ground will be lost.

5
6 The investments in improving quality of palliative care were on the whole important in
7 solidifying the substance and practice of palliative care. The work cut across many of
8 the divides in the field serving hospice as well as hospital, community as well as
9 institutional care. The quality initiatives addressed the needs of organizations such as
10 nursing homes and hospices, which, although not central to the portfolio, allowed these
11 organizations to benefit from the Foundation's investment in end-of-life care.

1

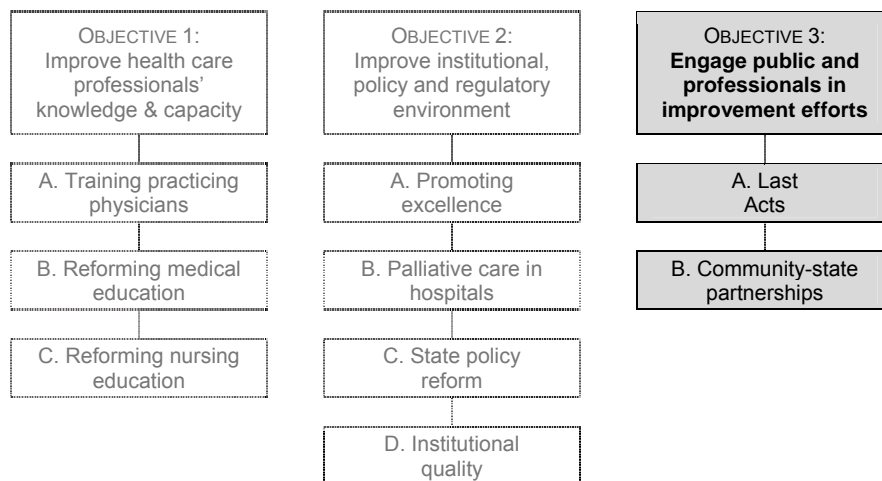
The Importance of Purposeful Action

Assessment of Objective 3 Achievement

2

3

4



5

6 Work to advance Objective 3 —engage the public and professionals in efforts to improve end-
7 of-life care—employed communication strategies, often in conjunction with coalitions at
8 the national, state and local levels, to reach out and engage the public and professionals.
9 There were two major programs supported under this objective: Last Acts¹ and
10 Community State Partnerships.

11

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

19

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

Breakdown of Objective 3 Grantmaking

Component	Amount
Last Acts and related grants	\$54,459,973 (69% of portfolio)
Community-State Partnerships	\$15,806,657 (20%)
Direct Media	\$6,299,709 (8%)
Advance Directives	\$2,441,857 (3%)
Total	\$79,008,196

¹ There is an important caveat to apply to this part of the assessment. At the request of the Foundation, our review was not to include the major effort supported under Objective 3: Last Acts and its related programs. Although we conducted an interview and a short follow-up call with the program officer in charge of this work, we did not have the ongoing dialogue with this person that we had with the other lead staff persons working on end-of-life objectives. Many of those interviewed, however, talked extensively about Last Acts. We captured these comments but did not follow up with related questioning. In light of these constraints, we focus our attention on the broader strategic issues surrounding the goals, objectives, and tactics employed as part of Objective 3.

1 outcomes from the SUPPORT study, this work changed direction but stayed in full gear.
2 The resulting Foundation-coordinated press campaign helped to get SUPPORT findings
3 covered in a front-page story in the *Boston Globe* and on the ABC nightly news with Peter
4 Jennings.

5

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

9

10 **A Coalition Approach**

11

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

19

20 **Area A: Last Acts**

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

31

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

36

- 37 1. To create and maintain a climate of interest and support for improvements in
38 end-of-life care and caring while raising expectations and demand for good care.
- 39 2. To strengthen Last Acts’ infrastructure and collaboration, in order to facilitate
40 change in end-of-life policy and practice.

- 1 3. To promote specific improvements in medical care and spiritual and psycho-
- 2 social caring near the end of life.
- 3 4. To create and operate a management structure that supports and facilitates all
- 4 Last Acts strengths, growth and activity.

5

6 **Area B: Community State Partnerships**

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

- 26 • Hospice and palliative care insurance
- 28 benefits
- 30 • Standards and regulations for nursing
- 32 homes and other health care facilities
- 34 • Regulations around pain medications
- 36 • Medical and nursing school curriculum.

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

44
45 In addition to the two large programs, the Foundation also invested in several other
46 efforts to motivate and/or educate the public directly. The most prominent of these was
47 support of *On Our Own Terms*, a four-part public television series by journalist Bill
48 Moyers. At the time of its airing, this important series was viewed by more Americans
49 than any other program in public television history.

50 Other grants included:

CSP Coalition Strategies

1. Curriculum change for healthcare professional training
2. Continuing education for practicing healthcare professionals
3. Changes in policies and procedures at healthcare facilities
4. Increasing consumer knowledge awareness and advocacy
5. Engaging clergy and faith communities in end-of-life care delivery
6. Broad-based public policy reform
7. Development of new reimbursement models

- 1 • *Finding Our Way: Living with Dying in America*, a 15 article series that appeared in
2 major newspapers across the nation
- 3 • *Wit*, a major motion picture about a doctor diagnosed with cancer and grappling
4 with the indignities of the disease and the health care system
- 5 • A documentary on Dame Cicely Saunders, founder of the hospice movement

6
7 To increase the impact of the Moyers' series, the Foundation supported outreach to help
8 organize and activate local coalitions to take actions in their communities to improve
9 care at the end of life. CSP became a key force in developing these local coalitions.
10 "About two-thirds of the more than 300 community coalitions developed for the Moyers
11 special were spawned by CSP projects" according to the CSP Grant Results Report.
12
13 Finally, the Foundation made grants to organizations to promote improvements to and
14 the use of advance directives.¹

15 16 **Strategic Considerations**

17
18 Despite instances of excellence, particularly in bringing attention to end-of-life care and
19 creating a supportive environment for professionals to focus on the issue, this line of
20 work evoked the greatest degree of criticism from those interviewed. Many of the
21 comments highlighted concerns that the work was unfocused and lacked direction.
22

23 Still, there were notable successes, including:

- 24
25 • Five of the 23 CSP coalitions achieved significant progress, mostly in the area of
26 state-policy change addressing issues of policy related to pain management,
27 advance directives and reimbursement (see discussion on Objective 2).
- 28 • Individuals seem to pay more attention to planning for their end-of-life care:
29 *Five Wishes*, an advance directive, is legally binding in 40 states and has
30 distributed over 9 million copies.
- 31 • This portfolio also created many tools and resources for advocates use in
32 addressing end-of-life issues. Many interviewees spoke of the importance of
33 these resources and materials, such as the report *Means to a Better End* (2002),
34 which came out of this work.
- 35 • Most importantly, perhaps, the communication work resulted in significant
36 media coverage and brought the issue squarely to the attention of the medical

¹ An advance directive tells your doctor what kind of care you would like to have if you become unable to make medical decisions.

1 community and likely influenced how they viewed the issue. Although the
2 general public did not recall much of the Moyers' series, key professionals within
3 the field likely did. The week after the airing of the series, CAPC received over
4 1,200 calls from hospitals around the country. We also heard that the coalitions
5 helped professionals on the ground feel part of something larger than
6 themselves.

7

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

11

12 **1. Lack of clear goals and objectives**

13

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

17

18 "We were constantly trying to get them to clarify their objectives and be
19 thoughtful about whether their interventions would get them to those
20 objectives."

21

22 Many of those interviewed described how this affected the work:

23

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

30

31 "Many of the [CSP] sites didn't have solid benchmarks, and many had unclear
32 goals."

33

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

37

38 "Last Acts and related efforts were not effective because they didn't focus
39 enough. Letting a thousand flowers bloom is okay to start, but then you need to
40 focus farther on."

41

42 "Last Acts goals were vague. Start a national dialogue about what? To what
43 end?"

1 As described by Gibson in the CSP Grant Results Report, a key problem was “the
2 program perhaps erred on the side of being too inclusive. The projects got everyone at
3 the table, with the result that it became difficult to focus on two or three strategic
4 moves. Perhaps there were too many interests, too many people in the process.”
5
6

7 **2. A disconnect between objective 3 and the other objectives**

8

9 Communication and public engagement are best understood as tools used to accomplish
10 larger goals. Actions sought under Objective 3— whether to be taken up by
11 professionals or a segment of the public— may have yielded more if they had been tied
12 to the work being done under the other two objectives focused on systems change.
13

14 Unfortunately, the connections were not as strong as they should have been.
15

16 RWJF documents hypothesized about two reasons for engaging the public:
17

- 18 1. Need for external pressure on the medical system. The push for medical system
19 change from within the medical establishment would go only so far; to get the
20 medical establishment to make significant system-wide change, the public
21 needed to demand changes and put pressure on medical leadership. This
22 problem statement was the one most often cited in written documents.
23
- 24 2. Need for individuals to plan better. Individuals don’t plan for end-of-life care,
25 and they need to increase their individual planning, mainly through knowing
26 about hospice/palliative care and asking for it when appropriate; completing
27 advance directives and medical power of attorney; and being aware of how pain
28 can be managed.
29

30 Although the first rationale for systems-focused change was cited more often, most of
31 the work supported under this objective appeared focused on individual change.
32

1 Perhaps a good way to illustrate this point is by looking at the calls-to-action included in
2 the message strategy developed for the Last Acts press conference (See box on Last Acts
3 Campaign, March 1999) shortly before Kevorkian's trial. Most of the calls focused on
4 how individuals can plan better for themselves or their loved ones. The need for the
5 public to put pressure on the medical system to change was not raised. Nor were the
7 calls connected to the work being
9 done as part of the other objectives.

11
13 The communications work arguably
15 could have been better aligned with
17 Objective 2 by focusing on
19 increasing public demand for
21 palliative care. A call-to-action
23 might have been, "Make sure that
25 your loved one is being cared for in
27 a hospital that has a palliative care
29 center. Visit the CAPC website to
31 find out which hospitals in your
33 area do." Another important call-to-
35 action might have drawn attention
37 to the need for more balanced state
39 pain policies.

41
43 A similar example of a lost
45 opportunity for direct public action
47 can be found in the content of the
49 15-part newspaper series "Finding
51 Our Way: Living with Dying in
53 America." The series highlighted a
55 broad range of stories from dealing
57 with the loss of a child to coping
59 with widowhood. Although well
61 received and published in many
63 national papers, calls-to-action were
65 rare and, where offered, focused on
67 individual action, rather than
69 promoting the kind of system
71 change envisioned by work under
73 the other two objectives.

75
77 Similarly, while the Moyer series
79 was watched by many, in part
81 because of the time and effort spent

EXAMPLE OF MESSAGES FROM THE LAST ACTS CAMPAIGN March 1999

MAIN MESSAGE: There are things you can do!

Sub-messages

1. Start talking about end of life care in your family. Start before someone is seriously ill. You don't want family members to have to guess your wishes if you can't speak for yourself. Living will and health care proxies help.
2. If you have a doctor you feel you can talk to about your wishes, do so—before you become seriously ill. Let your doctor know what is important to you about the end-of-life care you get.
3. Seriously ill patients should speak explicitly with their doctors about pain control, life support and where they want to spend their final days.
4. Don't let someone you love be in pain. Make sure that their pain is treated.
5. Be a volunteer. Help out a local nursing home or hospice; do something for a friend or relative who is a caregiver, start a discussion group in your church or senior center.
6. Be an advocate for change. Work with any of several national organizations trying to improve care of the dying.
7. Become informed about good end of life care. To take a simple example, when people buy a new car, they talk about it with their friend, family members, and co-workers; they check consumer information; they read up; and some check the Internet. When families are faced with a serious illness, these same activities are needed. It may take some digging, but many organizations are ready, willing and able to help.
8. Be prepared to ask tough questions. Again and again

1 by the coalitions, the evaluator of the program found that viewers did not remember
2 specific messages from the series and “recalled little beyond an emotional recollection”
3 of the key themes (Balch, 2002). The impact of the series on health professionals,
4 however, was likely greater; calls to CAPC increased dramatically. Although the
5 evaluator found that the series impact “did not ripple deep, long or far to the general
6 public or health professionals.”
7

8 **3. No way for the public to voice discontent**

9

10 One of the biggest disappointments expressed by those interviewed was that the work
11 did not allow advocates a platform to voice their discontent with the current system.
12 Several comments underscore this point:
13

14 “What’s missing in the field, and what I worry about daily, is still today the
15 virtual absence of an engaged citizen voice. The National Hospice and Palliative
16 Care Organization is not a consumer organization. RWJF made a good-faith
17 effort with the Partnership for Caring program. It had been designed to be a
18 consumer watchdog and activist organization, able to take strong consumer
19 action and able to withstand the heat. Unfortunately, the initial activist thrust of
20 Partnership for Caring was diluted when it was folded into Last Acts. Once that
21 happened, the unique intended value of Partnership for Caring was lost.”
22

23 “Absent a citizen consumer voice in the mix, I worry that all that has been done
24 will only move the needle so far.... We need group pressure [on the medical
25 system].”
26

27 “People who have had these types of experiences are mad. They want to do
28 something about it and don’t want others to have to deal with the same issues.
29 But they just don’t know how. There was so much that could have been done
30 here.”
31

32 “There is still a huge gap. Individuals who want and need end-of-life care and
33 still don’t know how to get it and be their own advocates.”
34
35

36 **4. Promotion is just one part of advocacy**

37

38 Although research was done to understand better the public’s interest and perception of
39 end-of-life issues, most of the analyses focused on how to promote these issues. But
40 promotion is just one part of advocacy, and good communication strategies do more
41 than just promote a topic. Effective strategies need to incorporate understanding about
42 how to motivate people to take actions that can lead to the change sought.
43

1 Although staff understood the challenges related to engaging and motivating the public
2 around end-of-life issues, there seemed to be little translation of this understanding into
3 ways to overcome barriers. While providing more information may get some attention,
4 it is not likely to overcome the obstacles to real engagement and action.

5
6 While grantees in other parts of the portfolio made substantial headway in addressing
7 these issues, those lessons were not incorporated into the work done under this
8 objective. For example, CAPC achieved significant advances in this regard by moving
9 away from talking about dying and “end-of-life” to “getting the care you need.”

11 **5. Too little guidance from the Foundation**

12
13 Many of those interviewed who received grants under this objective wanted clearer
14 direction and focus from the Foundation concerning priorities. Instead, the Foundation
15 delegated agenda setting to each coalition.

16
17 Perhaps because of a lack of certainty about what the Foundation should do after
18 SUPPORT, the approach taken was to let each coalition decide what would work in their
19 communities. This could be a sound approach, yet without guidance from the
20 foundation about what it sought to learn about, coalitions tended to work on many
21 things at once, resources were therefore diffused and many were without the capacity to
22 tackle the most difficult issues.

24 **Overall Objective 3 Conclusions**

25
26 The use of coalitions was one of the two central strategies employed under this objective,
27 yet their suitability for the work was never examined. Perhaps because the Foundation
28 found themselves without a strategy after the failure of SUPPORT or because the RWJF
29 used coalitions repeatedly to address many and varied issues, or because the officer in
30 charge of this work believed that only communities themselves could decide what they
31 needed—or all three—coalitions were chosen to address a vast array of issues in their
32 communities. Underneath all of this, however, was still the belief that the coalitions had
33 the potential to apply enough pressure on the systems that regulated or delivered care to
34 create change.

35
36 With few exceptions, what evolved was a potpourri of activities. Some coalitions in fact
37 did undertake the difficult work of policy change but these were the exceptions. And
38 the hoped for relentless force for systems change did not emerge.

39
40 Undoubtedly, the Foundation’s national program office offered assistance to help
41 coalitions understand their capacities and build capacity where there was little. But no
42 office could support the vast array of activities undertaken by the coalitions. Further,
43 resources were diffused in a corresponding manner.

- 1 The questions that make sense then to consider are: when can coalitions best address a
- 2 problem, how can they be supported to focus their attentions on what they can achieve
- 3 and how can they be supported to do well what they can.

1

Building the End-of-Life Field

Conclusion

2

3 What did the Foundation accomplish?

4

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

12

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

15

- 16 1. Creating demand for enhanced knowledge and skills in end-of-life care by
17 identifying and pushing key levers within the medical and nursing education
18 systems. By engaging and convincing the National Board of Medical Examiners
19 and National Council of State Boards of Nursing to include questions on
20 palliative care in their licensing exams for physicians and nurses, grantees were
21 able to set off the creation of a series of incentives which went far to align the rest
22 of the system.
- 23 2. Enabling The Joint Commission¹ to develop a new standard for assessment and
24 treatment and of pain.
- 25 3. Creating a supply of knowledge to meet new demand by supporting research,
26 publishing, curricula development and approaches to training faculty
- 27 4. Creating an institutional driver, the Center to Advance Palliative Care at Mount
28 Sinai School of Medicine in New York, to meet increased demand for knowledge
29 of palliative care within the hospital setting, and doing it in a way that was
30 acceptable to hospital CEOs, admitting physicians and specialists alike.
- 31
- 32
- 33
- 34

¹ Throughout this document, we refer to The Joint Commission, which had been called the Joint Commission on Accreditation of Health Care Organizations (JCAHO) during the period from 1987 through 2006.

- 1 5. Supporting some of the core infrastructure needs of an emerging field by
2 developing standards of care and the capacity to assess and monitor those
3 standards across institutional settings.
4
- 5 6. Bringing attention to the quality of pain treatment in states with regulatory
6 policies that inhibit physicians in caring properly for patients in pain.
7
- 8 7. Fostering, in partnership with the Project on Death in America, the advancement
9 of careers and emerging leadership in a relatively undeveloped field.
10
- 11 8. Creating an enormous base of knowledge in a relatively short period of time,
12 particularly in areas of clinical care and organization and delivery of services.
13

14 By helping create demand for knowledge and building the capacity to produce that
15 knowledge, the Foundation created a linked system of supply and demand that nearly
16 all interviewed say “put the field on the map.”
17

- 18 • “Over the ten years of RWJF grantmaking, they have created a groundswell.”
19
- 20 • “There is a generational difference in EOL care today. RWJF has significantly
21 influenced the shift.”
22
- 23 • “Few foundations can say they built a field of medicine, but RWJF can... The
24 effect is that they built a very important field of medicine that hadn’t existed
25 before.”
26

27 But what exactly is “field building,” anyhow? Many speak the phrase. Few have
28 formally defined it. Yet most have a sense of what it is (and what it isn’t), a sense we
29 might unpack as follows:
30

31 A field has an identity with discernable edges; those in it know they are in it. It is
32 populated by individuals with different roles. There are leaders and followers,
33 knowledge producers and knowledge appliers. Professional fields have trained
34 practitioners, researchers and educators as well as institutions where training, research
35 and education occur.
36

37 A field has a body of knowledge and practice which, as it matures, becomes more
38 organized. It develops and applies standards. Quality and its absence become more
39 recognizable. A field needs places where the work happens and places where people,
40 knowledge and practice intersect. A field has the means to foster collaboration and
41 focused action. A field often has strong emotional overtones leading practitioners to
42 become advocates who work to sustain its identity. A field grows.
43

1 Perhaps most significant, a field is more than individual organizations focused on the
2 same issue; its strength comes from the connections holding organizations together.
3 These connections can take the form of shared ideas, identity, purpose, language and
4 incentives.

5

6 **The Foundation's impact on the field**

7

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

9

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

12

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

18

- 19 • To work within the accepted culture of medicine, they forwarded what one
20 field leader called an "elite strategy," i.e., funding the best to do the best
21 based on research of high quality
- 22
- 23 • To broaden palliative care beyond the hospice movement, they moved it into
24 the medical mainstream
- 25
- 26 • To reframe palliative care as care for the living as well as the dying, they
27 thereby aligned it better with the training and instincts of physicians.
- 28

29

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

42

43 The research focused on several key areas in the development of field:

- 1 • *Practice and organizational models:* The Journal of the American Medical
2 Association series, “Perspectives on Care at the Close of Life” (which ran
3 from 2000 through 2007), shared case studies and clinical approaches, while
4 Promoting Excellence disseminated numerous articles on the delivery of
5 palliative services. CAPC has broadly distributed “how to” manuals on most
6 aspects of running hospital-based palliative care and related issues.
- 7 • *Curricula:* EPEC, the Medical College of Wisconsin and Harvard Medical
8 School developed curricula for practicing physicians as well as those at
9 various stages of training.
- 10 • *Institutional standards:* The Joint Commission, the National Consensus Project
11 for Quality Palliative Care and the National Quality Forum set standards for
12 good practice, and researchers developed assessment instruments to measure
13 changes in policy and institutional practice.
- 14
- 15 3. **Fostering the development of a highly influential network of leaders emerging**
16 **from the Project on Death in America’s Faculty Scholars Program.** Of the 87
17 faculty scholars supported by PDIA, 20 went on to assume major roles in Robert
18 Wood Johnson Foundation programs. According to Foley, the Faculty Scholars
19 Program identified and supported “outstanding clinical and academic leaders in
20 medicine who could change medicine from the inside.” Simply put, RWJF and
21 PDIA had one of the best-executed partnerships in philanthropy. PDIA
22 identified the leaders, and RWJF put them to work (See Appendix 5: PDIA
23 Scholars’ Roles in RWJF Programs)
- 24
- 25 4. **Supporting the creation of an agenda for the field.** Many credit the Foundation
26 for providing opportunities for key leaders to come together and craft strategies,
27 reframe problems as resolvable concerns, and generally advance an agenda
28 forged with field leaders. In addition, the Foundation supported agenda-setting
29 documents, such as the Institute of Medicine reports that framed issues and
30 provided a basis for discussion and negotiation among key actors and potential
31 grantees.
- 32
- 33 5. **Building the institutional base of practice for palliative care in a medical**
34 **setting,** primarily through the Center to Advance Palliative Care. CAPC’s
35 activities simultaneously helped to increase the availability of palliative care for
36 patients and families across the US, and reinforce the clinical base for training.
- 37
- 38 6. **Developing core clinical and institutional practice standards,** which also
39 provides a strong basis for advocacy when standards are not being met.
- 40

1 7. **Motivating medicine to act** by making the case to physicians both that their
2 decisions have severe consequences for how their patients die and that there are
3 reasonable potential alternatives.

4
5

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

9

- 10 • The number of hospitals with palliative care programs increased 96% from 632 to
11 1240 between 2000 and 2005 (Kuehn 2007). As of the beginning of 2007, 30% of
12 all U.S. hospitals, and 70% of hospitals with 250 or more beds, have adopted
13 palliative care programs (Center to Advance Palliative Care). Almost all
14 hospitals within the Veterans Health Administration have a palliative care
15 program (National Palliative Care Research Center website).
- 16
- 17 • The field of palliative and hospice care was formally recognized as a subspecialty
18 by the American Board of Medical Specialties in 2006, and 10 specialty boards
19 have accepted it as a subspecialty (Kuehn 2007).
- 20
- 21 • There are now 56 active fellowship programs in hospice and palliative care, with
22 five more in formation, offering a total of 140 fellowship positions, including 20
23 research slots (American Academy of Hospice and Palliative Medicine website).
- 24
- 25 • The Accreditation Council for Graduate Medical Education (ACGME) made the
26 decision in 2006 to accredit hospice and palliative medicine fellowship programs.
27 Starting in 2008, physicians can become board-certified in hospice and palliative
28 care, and fellowship programs can pursue ACGME accreditation (Kuehn 2007).
- 29
- 30 • Between 1996 through 2006, more than 2,800 physicians obtained certification
31 from the American Board of Hospice and Palliative Medicine (ABHPM website).
- 32
- 33 • The American Academy of Hospice and Palliative Medicine began in 1988 with
34 250 founding members, and has grown to include 2,600 members (AAHPM
35 website, Kuehn 2007).
- 36
- 37 • Early studies, some produced by RWJF grantees, indicate improved clinical,
38 satisfaction and utilization outcomes related to palliative care services (Meier
39 2006).
- 40

- 1 • There is also evidence that palliative care programs based in both hospital and
2 community settings have led to increases in hospice referral rates and hospice
3 length of stay (Meier 2006).
4
- 5 • Between 1990 and 2000, US census data show a 17% decrease in the number of
6 individuals who died in a hospital (Kuehn 2007). More than 75% of adult deaths
7 occur in institutional settings—more than 50% in hospitals and 25% in nursing
8 homes. Meanwhile, 85% of pediatric deaths occur in hospitals. These trends run
9 counter to the end of life preferences of Americans, more than 90% of whom say
10 they would prefer to die at home (Meier 2006).

11 **A critical moment**

12 According to many interviewed, the end-of-life field is at a turning point, likely to falter
13 if the second wave of leadership goes unsupported. “This is only a beginning,” said one
14 leader. “All we’ll have done is to establish a nascent field.”
15
16

17
18 A soon-to-be-released article illustrates the point that there are few sources of funding to
19 attract and develop young and mid- career faculty (Gelfman and Morrison, in press).
20 Between 2003 and 2005, 25% of published research was conducted without extramural
21 funding, and 50% of the studies were supported by foundations, including RWJF. As
22 the level of investment from foundations for End of Life is quite low, we can extrapolate
23 that the overall amount of support available for research in the field is negligible.
24

25 In other words, it is not at all clear whether a next tier of professional leaders will be able
26 to establish themselves as academic and clinical leaders in this field. The ripple effects of
27 this problem may threaten all aspects of accomplishments to date, as hospital-based
28 palliative care jobs go unfilled for lack of qualified faculty.
29

30 The field faces two sustainability challenges in particular:

31
32 First, after PDIA and RWJF ceased their support toward end-of-life issues, no
33 foundation has replaced them either in terms of providing philanthropic leadership or
34 substantial dollars. Based on a review of grants listed in the Foundation Center
35 database for 2004 and 2005, it is clear that the vast majority of grants in those years were
36 very small—under \$25,000. Appendix 7 shows the 15 foundations making the largest
37 grants in 2004 and 2005. RWJF’s investments clearly dwarf those of other funders. The
38 Emily Davie and Joseph S. Kornfeld Foundation has made a substantial commitment in
39 the field, but even their investment supporting faculty scholars, \$3,025,000 over seven
40 years, pales in comparison to the investments of RWJF and PDIA.
41

42 Second, government has offered little support to build either careers or the base of
43 knowledge in the field. Between 2001 and 2005, the National Institutes of Health made

1 only 418 total grants for Palliative Care Research (Gelfman and Morrison, in press).
2 During this same time period, only 0.1% of total NIH funding supported Palliative Care.
3

4 **What is the role of a foundation in strategy development?**

5
6 The Foundation clearly had the wherewithal and fortitude to pursue an important issue
7 at a moment when it occupied the attention of the public in dramatic ways. Yet it was
8 more than just good timing. Foundation staff played a critical role in making these
9 advances possible, and they did so with more than just the provision of funds.

10
11 The Foundation officer most responsible for much of the portfolio played a pivotal and
12 strategic role. Leaders in the field recognize that her contributions go well beyond those
13 of the typical program officer. Most of those interviewed credit her with working closely
14 with key actors in the field to shape a vision and then help translate that vision into
15 strategy. This work was neither what is known in foundation parlance as “proactive” or
16 “reactive” grantmaking. She didn’t create strategy from whole cloth. Nor did she
17 simply respond to what came to her. She was in the mix, and helped to create the mix.
18 In essence, she facilitated the shaping and framing of an agenda for action based on the
19 best kind of insider knowledge of how a system works. This role is important, and it
20 was done well.

21
22 The resulting strategy, therefore, was informed and subtle enough to identify real and
23 powerful incentives and leverage points that could magnify small actions into far larger-
24 than-expected effects. The intelligence of this work came from a deep understanding of
25 the ways that relationships and dynamics affect how a system responds to demands for
26 change.

27
28 The strategy also was very intently focused. It identified a few key leverage points,
29 chosen because they had power to entrain other subsequent actions and effects. If
30 achieved, supported efforts—like changes in physician licensing—would set off ripple
31 effects throughout the system. To some extent, this “systems approach” obviated the
32 need to worry about “institutionalizing” the Foundation’s work. As the work was being
33 done, it was built into existing structures and positions. For the most part, new
34 organizations were not created; rather, existing organizations were given incentives to
35 align with the goals of the effort, thereby mitigating issues of sustainability. Grantees
36 were often chosen because of their credibility and power to influence key decision
37 makers.

38
39 The strategy also considered where change was most likely to occur, and weighed the
40 potential investments based on their relative risks. Where strong players were not in
41 place and opportunities to advance change less likely, investments were not made.

42

1 We don't want to exaggerate the positive outcomes of the work — either how it was
2 done or the consequences of some of the decisions made:

3

4 • It evolved and got better over time. There were some weak choices, particularly
5 early on, but staff learned from them and applied the lessons. The objectives as
6 cast were very broad and stayed that way. Some work never really came to
7 fruition.

8 • To some extent, the best work was happenstance. But when good work was
9 occurring, the officer recognized it and made the most out of it.

10 • The officer could disappoint many as she applied her high standards for
11 identifying good work and good people and kept a relentless eye on discerning
12 whether and what kind of change was achievable. When high-leverage projects
13 were identified, the officer supported them well, and consequently said no or
14 delayed response to many others.

15

16 • The strength of the work came not just from the Foundation, but from the
17 strength of its ties to the field, an approach that is not well appreciated in
18 philanthropy for its subtlety and lack of bravado.

19

20

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

22

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

26

27 Five key points emerged from the assessment.

28

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

33

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

38

39 Given that the Foundation found itself without a clear direction at the time, it
40 was a thoroughly legitimate strategic stance for it to delay establishing explicit
41 goals, objectives or approaches until it learned enough to become more specific
42 about its intent. However, there was no system within the Foundation to reflect

1 on what it was learning and refine its objectives accordingly. And the goals, at
2 least as described in the Foundation's written objectives, never did become more
3 focused than they were at the outset.

4

5

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

8

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

15

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

19

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

28

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

35

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

38

39 Innovation requires a certain amount of freedom, but it also requires some
40 direction and quality control. Foundation leadership everywhere has an
41 important role to play in examining strategy clarity, alignment and adequacy of
42 financing. Grantees recognized differences between the officers' approaches and
43 were outspoken about their confusion and concerns. Yet many interviewees

1 expressed frustration that they had no place to bring their concerns other than to
2 the program officer.

3

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

9

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

16

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

21

22

23 **Implications for Foundation Strategy**

24

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

30

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

41

42 **2. Foundations need to discover ways of engaging talented program staff around the**
43 **quality of the decisions they make.** Foundation managers across philanthropy

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

8

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

18

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

23

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

29

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

35

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

41

- 42 • Do we have the problem right and have we framed it in a way that it is
43 understandable, solvable and of interest to target audiences?

- 1 • Are pursued solutions garnering interest, showing results, and are they
- 2 scaleable?
- 3 • Where are obstacles emerging and what solutions are coming forward in
- 4 relation to them?
- 5 • Where can we experiment with ways to learn from the field?

6

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

10

11 **5. Insert the concept of portfolio information management into team strategy**

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

22

23 **6. Assess the costs of a program relative to what it is likely to achieve.** All

24 foundations need to do a better job of asking questions about the reasonableness of
25 an investment and whether continued investment is worth it. Below are the costs
26 associated with major efforts funded by the Foundation (from highest to lowest):

27

- 28 • \$54.5 million: Last Acts and related efforts
- 29 • \$29 million: CAPC
- 30 • \$19.8 million: Promoting Excellence
- 31 • \$15.8 million: Community-State Partnerships
- 32 • \$8.8 million: Medical education
- 33 • \$7.3 million: Quality
- 34 • \$6.5 million: EPEC
- 35 • \$6.4: Nursing
- 36 • \$6.3 million: Direct media outreach
- 37 • \$4.3 million: State policy advocacy/pain

37

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

39

- 40 • Are the purposes and goals clear enough to justify a large investment? In this
- 41 portfolio, the highest investment went into the least defined of the three
- 42 objectives—that of public and professional engagement.

43

- 1 • If we are unsure about an approach, what type of investments or assessments
2 will help us learn more? What specific areas and questions do we need to learn
3 more about? Defining areas for learning and specifying learning objectives help
4 ensure that lessons will be captured and applied toward strategy development as
5 it evolves over time.
- 6
- 7 • What justifies large expenditures? The Foundation made several large grants
8 early on before it knew what it wanted to achieve and without clear learning
9 objectives (e.g., Promoting Excellence). Although some significant results came
10 out of this program, many of them came from a small investment in the working
11 groups. A key issue here: why invest so much money without knowing what
12 needs to be done? On the other hand, the CAPC investments started small and
13 grew over time. When making large investments, a range of issues need to be
14 considered such as: grantee capacity and also the capacity of the field to absorb
15 an intervention in a sustainable way; appropriateness of the intervention;
16 alignment with other parts of the strategy.
- 17
- 18 • How realistic are the promises being made? Inserting more realism into the
19 grant process, even with a “back of the envelope costing out” is needed. These
20 discussions should go beyond the amount that the Foundation has at hand. A
21 chapter in the most recent anthology discusses the importance of what the author
22 called a “denominator exercise.” All foundations need to do better at estimating
23 what it will cost to accomplish their goals. It is only with this kind of realism that
24 a foundation can make strategic decisions about its capacity to fund an array of
25 different projects and/or the need to adjust its goals.
- 26

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

33
34 The Foundation is not alone in this problem. While many foundations have
35 processes to discuss and approve grants, few have adopted approaches to review
36 strategy and even fewer have found ways to resolve problems identified in the
37 strategy. More often than not, questions are raised that officers address only
38 peripherally.

39
40 We appreciate, too, that not every problem has an identifiable solution, nor will
41 every solution work. The challenge for foundations is to be both tough about what
42 will suffice for good strategy and willing to suspend disbelief when an approach of
43 trial and error is warranted. But strategies that fall into the latter category need to be

1 monitored closely for evidence of market uptake, capacity to execute and effects. Too
2 often, strategy problems that appear early are glossed over and overlooked, only to
3 rear up in more significant ways as time goes by.

4

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

14

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

20

21 **Concrete Results**

22

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

31

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

38

39 Still, the Robert Wood Johnson Foundation advanced a field rich with talent and ideas—
40 not through luck (or luck alone) but through strategy. It was not the kind of strategy
41 based on the inputs, outputs and outcomes derived from “logic models,” but strategy
42 built on close-to-the-ground reconnaissance, intimate understanding of how systems

Evaluation Roundtable

- 1 work and develop, and, most important, a deep appreciation of and willingness to work
- 2 side-by-side with talent in the field.

APPENDIX 1:
EXPERTS INTERVIEWED*

- 1
2
3
4
5 Steven Albert, PhD, Associate Chair for Research and Science, Graduate School of Public
6 Health, University of Pittsburgh
7
8 Katya Andresen, Vice President for Marketing, Network for Good
9
10 George Balch, PhD, Principal, Balch Associates
11
12 Scott Bane, Program Manager, Jhet Foundation
13
14 Susan Block, MD, Co-Director, Harvard Medical School Center for Palliative Care, Chief,
15 Division of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute
16
17 Ira Byock, MD, Director, Palliative Medicine, Dartmouth-Hitchcock Medical Center
18
19 Joel Cantor, ScD, Director, Center for State Health Policy, Rutgers, The State University
20 of New Jersey
21
22 Myra Christopher, President and Chief Executive Officer, Center for Practical Bioethics
23
24 David Clark, PhD, Director, International Observatory on End of Life Care
25
26 Karyn Collins, MPA, former Director of Communications, Promoting Excellence
27 National Program Office, Center for Ethics, University of Montana
28
29 J. Randall Curtis, MD, MPH, Professor of Pulmonary and Critical Care Medicine,
30 Director, Harborview/University of Washington End-of-Life Research Program
31
32 June Dahl, PhD, Professor, University of Wisconsin School of Medicine and Public
33 Health
34
35 W.A. Drew Edmonson, JD, Oklahoma State Attorney General
36
37 Linda Emanuel, MD, PhD, Buehler Professor of Geriatric Medicine, Director, Buehler
38 Center on Aging, Health and Society, Feinberg School of Medicine, Northwestern
39 University
40
41 Seth Emont, PhD, Principal, White Mountain Research Associates, LLC

* Titles and affiliations as of April 2007.

- 1
- 2 Betty Ferrell, PhD, Professor, Nursing Research and Education, Research Scientist, City
- 3 of Hope National Medical Center
- 4
- 5 Kathleen Foley, MD, Chair and Attending Neurologist, Pain and Palliative Care Service,
- 6 The Society of Memorial Sloan-Kettering Cancer Center
- 7
- 8 Mary Ellen Foti, MD, State Medical Director, Massachusetts Department of Mental
- 9 Health
- 10
- 11 Rosemary Gibson, MSc, Senior Program Officer, The Robert Wood Johnson Foundation
- 12
- 13 Elinor Ginzler, Director, Livable Communities, Office of Social Impact, American
- 14 Association of Retired Persons
- 15
- 16 James Hallenbeck, MD, Assistant Professor, Stanford School of Medicine, Director,
- 17 Palliative Care Service, Palo Alto Veterans Affairs Health Care System
- 18
- 19 Bernard Hammes, PhD, Director, Medical Humanities, Gundersen Lutheran Medical
- 20 Foundation
- 21
- 22 Bob Hughes, PhD, Chief Learning Officer, Robert Wood Johnson Foundation
- 23
- 24 Hollye Jacobs, BSN, Project Coordinator, ELNEC Pediatric Palliative Care Training
- 25 Program
- 26
- 27 Bruce Jennings, MA, Senior Consultant, The Hastings Center
- 28
- 29 David Joranson, MSSW, Director, Pain and Policy Studies Group, University of
- 30 Wisconsin Comprehensive Cancer Center
- 31
- 32 Mary Jane Koren, MD, Assistant Vice President, Quality of Care for Frail Elders, The
- 33 Commonwealth Fund
- 34
- 35 James Knickman, PhD, President and Chief Executive Officer, New York State Health
- 36 Foundation
- 37
- 38 Michelle Larkin, MS, Senior Program Officer, The Robert Wood Johnson Foundation
- 39
- 40 Allen Lichter, MD, Executive Vice President and Chief Executive Officer, American
- 41 Society of Clinical Oncology
- 42
- 43 Bobye List, Executive Director, The Emily Davie and Joseph S. Kornfeld Foundation

- 1
- 2 Dale Lupu, PhD, Chief Executive Officer, American Board of Hospice and Palliative
- 3 Medicine
- 4
- 5 Joanne Lynn, MD, Medical Officer, Office of Clinical Standards and Quality, Centers for
- 6 Medicare and Medicaid Services
- 7
- 8 Jay Mahoney, Principal, Summit Business Group, LLC
- 9
- 10 Sharon McGill, MPH, Director, Department of Quality and Research, American
- 11 Osteopathic Association
- 12
- 13 Diane Meier, MD, Chief, Division of Geriatrics, Department of Medicine, Director,
- 14 Center to Advance Palliative Care, Mount Sinai Medical Center
- 15
- 16 Melanie Merriman, PhD, President, Touchtone Consulting
- 17
- 18 Robert Milch, MD, Professor of Clinical Family Medicine and General Surgery, State
- 19 University of New York - Buffalo School of Medicine, Medical Director, The Center for
- 20 Hospice and Palliative Care
- 21
- 22 Dorothy Moga, MPH, Consultant, American Board of Hospice and Palliative Medicine
- 23
- 24 Sean Morrison, MD, Director, National Palliative Care Research Center, and Hermann
- 25 Merkin Professor of Palliative Care, Mount Sinai School of Medicine
- 26
- 27 David Morse, Vice President, Communications, Robert Wood Johnson Foundation
- 28
- 29 Anne Mosenthal, MD, Chief, Surgical Critical Care, University of Medicine and
- 30 Dentistry of New Jersey
- 31
- 32 Alvin Moss, MD, Professor of Medicine, Director, Center for Health Ethics and Law,
- 33 West Virginia University
- 34
- 35 Dennis O'Leary, MD, President, The Joint Commission
- 36
- 37 Kate O'Malley, MS, Senior Program Officer, California Healthcare Foundation
- 38
- 39 Richard Payne, MD, Director, Duke Institute on Care at the End of Life, Duke Divinity
- 40 School
- 41
- 42 Russell Portenoy, MD, Chairman, Department of Pain Medicine and Palliative Care,
- 43 Beth Israel Medical Center

- 1
- 2 Kandyce Powell, MSN, Executive Director, Maine Hospice Council
- 3
- 4 Jaiya Rao, Medical Epidemiologist, Division of Adult and Community Health, Centers
5 for Disease Control
- 6
- 7 Carol Raphael, MPA, Chief Executive Officer, Visiting Nurse Service of NYC
- 8
- 9 Anne Rhome, MPH, Former Deputy Executive Director, American Association of
10 Colleges of Nursing
- 11
- 12 True Ryndes, MPH, Vice President for Public Policy and Advocacy, San Diego Hospice
13 and Palliative Care Corporation
- 14
- 15 Charlie Sabatino, JD, Assistant Director, American Bar Association, Commission on Law
16 and Aging
- 17
- 18 Elyse Salend, MSW, Program Officer, Archstone Foundation
- 19
- 20 Lewis Sandy, MD, Executive Vice President, Clinical Strategies and Policy,
21 UnitedHealthcare
- 22
- 23 Steven A. Schroeder, MD, Distinguished Professor of Health and Health Care, Division
24 of General Internal Medicine, Department of Medicine University of California San
25 Francisco
- 26
- 27 J. Donald Schumacher, PsyD, President and Chief Executive Officer, National Hospice
28 and Palliative Care Organization
- 29
- 30 Jack Schwartz, JD, Assistant Attorney General, Director, Health Policy, Maryland
31 Attorney General's Office
- 32
- 33 Thomas Smith, MD, Professor and Chairman, Hematology/Oncology and Palliative
34 Care, Massey Cancer Center, Virginia Commonwealth University
- 35
- 36 Lynn Hill Spragens, MBA, President and Chief Executive Officer, Spragens and
37 Associates, LLC
- 38
- 39 Mildred Z. Solomon, EdD, Vice President, Education Development Center Inc.
- 40
- 41 Sharyn Sutton, PhD, President, Sutton Group
- 42

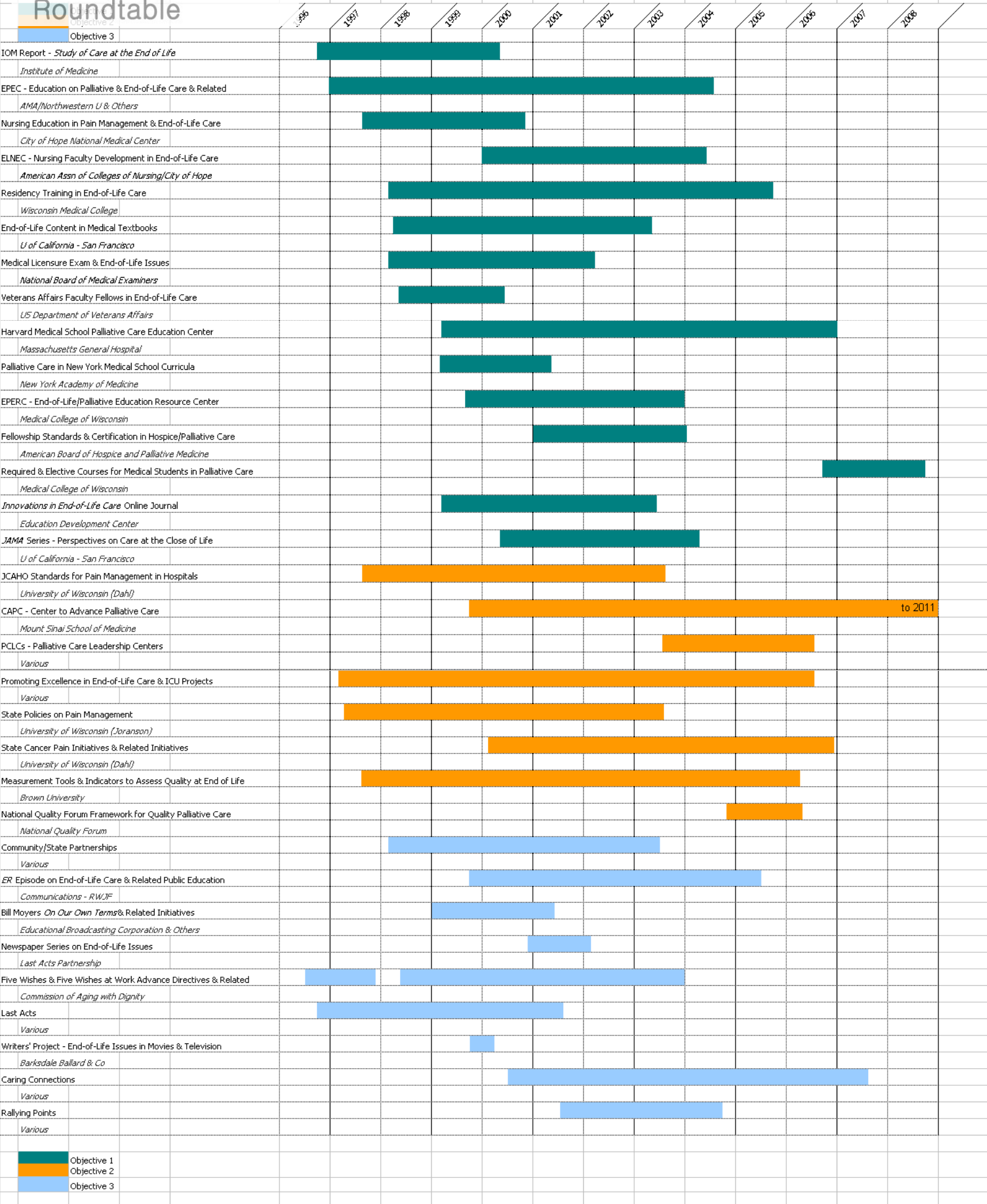
- 1 Joan Teno, MD, Professor of Community Health and Medicine, Associate Director for
- 2 Gerontology and Health Care Research, Brown University School of Medicine
- 3
- 4 Susan Tolle, MD, Director, Center for Ethics in Health Care at Oregon Health and
- 5 Science University
- 6
- 7 Jim Towey, JD, President, St. Vincent College
- 8
- 9 Jeanne Twohig, MPA, Deputy Director, Duke Institute on Care at the End of Life, Duke
- 10 Divinity School
- 11
- 12 Julio Urbina, Senior Program Officer, Health Care Program, The Fan Fox and Leslie R.
- 13 Samuels Foundation, Inc.
- 14
- 15 Charles Von Gunten, MD, Medical Director, Center for Palliative Studies, San Diego
- 16 Hospice and Palliative Care Corporation
- 17
- 18 Jamie Von Roenn, MD, Professor, Division of Hematology/Oncology, Director, Palliative
- 19 Care Center, Northwestern Memorial Hospital, Professor, Northwestern University
- 20
- 21 Victoria Weisfeld, MPH, Independent Consultant
- 22
- 23 David Weissman, MD, Director, Palliative Care Center, Medical College of Wisconsin
- 24 Palliative Care Center
- 25
- 26 John Wennberg, MD, Director, Peggy Y. Thomson Chair for the Evaluative Clinical
- 27 Sciences, Professor, Department of Community and Family Medicine, Dartmouth
- 28 Medical School
- 29
- 30 Diana J. Wilkie, PhD, Professor and Harriet Werley Endowed Chair for Nursing
- 31 Research, Department of Medical-Surgical Nursing, College of Nursing, University of
- 32 Illinois at Chicago
- 33
- 34

1 **APPENDIX 2:**
2 **SELECTED KEY EVENTS IN THE END-OF-LIFE CARE FIELD**

3	4	5
6	7	8
9	10	11
12	13	14
15	16	17
18	19	20
21	22	23
24	25	26
27	28	29
30	31	32
33	34	35
36	37	38

Evaluation Roundtable

- 1 2006 American Board of Medical Specialties (ABMS) recognizes hospice and
2 palliative as subspecialty
- 3 2006 Accreditation Council of Graduate Medical Education votes to accredit
4 Palliative care fellowship training programs
- 5 2008 ABMS to offer its first certification exam for hospice and palliative
6 medicine



- Objective 1
- Objective 2
- Objective 3

APPENDIX 4:
Building Knowledge

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

- *Approaching Death: Improving Care at the End of Life*, Institute of Medicine/National Academies of Science (1998) (mean rating: 2.82, where 3=very important, 2=moderately important, 1=not that important, DK=haven't read it or not comfortable making a judgment)
- *Joint Commission on Accreditation of Healthcare Organizations Standards for Assessment and Management of Pain*, Joint Commission (2001) (mean rating: 2.75)
- *CAPC Manual, Everything You Wanted to Know About Establishing a Palliative Care Program But Were Afraid to Ask*, Mount Sinai Medical Center (2001) (mean rating: 2.73)
- *Perspectives on the Close of Life Series*, Journal of the American Medical Association (2000-2007) (mean rating: 2.64)
- *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*, Institute of Medicine, Board of Health Sciences Policy (2003) (mean rating: 2.6)

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

- The IOM report clearly was a defining document for the field as well as RWJF.
- The Joint Commission standards on pain were a stimulus for changes in clinical practice, as well as hospital interest in palliative care services.
- The CAPC manual is a how-to guide for the rapidly growing number of hospitals developing palliative care programs.
- The *JAMA* series was designed to increase physician knowledge and awareness of end of life concerns, and also raised the field's credibility in medicine.

1

2 We also compared our ratings to the findings of a Meiers/Isaacs survey (2007), which
3 asked respondents to suggest important articles/research in the field.

4

5 In both studies, it is clear that respondents placed a high value on literature produced by
6 the SUPPORT project. Experts in our survey gave a high rating to Joanne Lynn's *JAGS*
7 (2000) article (it came in sixth in our study) while a series of SUPPORT articles received
8 more mentions than any other in the Meiers/Isaacs data.

1
2

APPENDIX 5:

PDIA Faculty Scholars' Role in RWJF Programs

PDIA CLASS:	ROBERT WOOD JOHNSON FUNDED PROGRAMS			
1995				
Billings, J. Andrew, MD	Palliative Care Education Center			
Goodlin, Sarah J. MD	End-Stage Heart Disease Project			
Meier, Diane Eve MD	Promoting Excellence	Center to Advance Palliative Care	Palliative Care Leadership Centers	National Consensus Project for Palliative Care
Morrison, R. Sean M.D	Center to Advance Palliative Care			
Smith, Thomas, J. M.D, FACP	Palliative Care Leadership Center			
Von Gunten, Charles F. MD	Education on Palliative and End-of-Life Care (EPEC)	Center to Advance Palliative Care		
Weissman, Davis E. MD	Residency Training	End-of-Life/ Palliative Education Resource Center (EPEC)	Palliative Care Leadership Center	Medical Student Training
1996				
Shuster, Jr., John Lee MD	Community/State Partnerships			
1997				
Curtis, J. Randall MD, MPH	Promoting Excellence	Quality of Death and Dying Instrument	Promoting Excellence/ICU	
Wenger, Neil S. MD, MPH	SUPPORT			
1998				
Back, Anthony MD	Promoting Excellence			
Cohen, Lewis M. MD	Promoting Excellence			
Pantilat, Steven Z. MD	Palliative Care Leadership Center			
1999				
Prendergast, Thomas J. MD	Survey of Critical Care Fellows			
2000				
Kurent, Jerome E. MD	Promoting Excellence			
Mosenthal, Anne C. MD, FACS	Promoting Excellence/ICU			

Evaluation Roundtable

Rosenfeld, Kenneth E. MD	Promoting Excellence	<i>Wit for Medical Students</i>	
2002			
Bailey, F. Amos MD	Promoting Excellence		
Miller, Susan C. Ph.D, MBA	Best Practices for Nursing Home Care		
Rabow, Michael W. MD	Promoting Excellence		

1

APPENDIX 6: Top Funders in End-of-Life Giving

Top 15 FOUNDATIONS - 2004[^]

Grants \$100,000+*

Foundation	2004
<i>Johnson Foundation, Robert Wood</i>	7,377,735
Cannon Foundation, Inc.	1,800,000
Kresge Foundation	1,150,000
UniHealth Foundation	1,004,558
Duke Endowment	978,975
Altman Foundation	889,500
Reynolds Charitable Trust	750,000
Charitable Leadership Foundation, NY	578,892
Perkins-Prothro Foundation	497,426
Davis Foundation, Arthur Vining	400,000
Bristol-Meyers Squibb	326,203
Kornfeld Foundation	300,000
Offield Family Foundation	300,000
San Diego Foundation	300,000
Richardson Foundation	265,000

Top 15 FOUNDATIONS - 2005[^]

Grants \$100,000+*

Foundation	2005
<i>Johnson Foundation, Robert Wood</i>	7,401,160
San Diego Foundation	2,300,000
Kresge Foundation	1,900,000
McCabe Foundation	1,500,000
UniHealth Foundation	1,373,492
Walker Charitable Foundation, Inc.	1,000,000
Altman Foundation	869,000
Reynolds Charitable Trust	800,000
Hall Family Foundation	750,000
Duke Endowment	718,500
Kellog Foundation	600,000
Benedum Foundation	500,000
Mabee Foundation	500,000
Community Foundation of Sarasota County/Silicon Valley	481,937
Quantum Foundation	450,000

[^] Data from the Foundation Center Database

* For each foundation we list the total of grants of \$100,000 or more.

APPENDIX 7:
REFERENCE NOTES

- 1
2
3
4
5 Appleby, Julie. "Debate Surrounds End-of-Life Health Care Costs." *USA Today*, October
6 18, 2006.
7
8 Austin, Bonnie J., Austin J.D., and Lisa K. Fleisher. "Financing End-of-Life Care,
9 Challenges for An Aging Population." *Changes in Health Care Financing and*
10 *Organization*. Academy Health: February 2003.
11
12 Balch Associates. *Coalitions and Change in 3 Communities: Natural Histories of*
13 *Reactions to 'On Our Own Terms': Final Report.* Oak Park, IL: Balch Associates,
14 August 2002.
15
16 Barr, Michael et al., "The Advanced Medical Home: A Patient-Centered, Physician-
17 Guided Model of Health Care." Philadelphia: *American College of Physicians*, 2006.
18
19 Bronner, Ethan. "The Foundation's End-of-Life Programs: Changing the American Way
20 of Death." *The Robert Wood Johnson Foundation Anthology, To Improve Health and Health*
21 *Care*. Vol. 6 (2003).
22
23 Byock, Ira. "Improving Palliative Care in Intensive Care Units: Identifying Strategies
24 and Interventions that Work." *Critical Care Medicine*. Vol. 34, No. 11: S302-S305 (2006).
25
26 Byock, Ira, Jeanne Sheils Twohig, Melanie Merriman, Karyn Collins. "Promoting
27 Excellence in End-of-Life Care: A Report on Innovative Models of Palliative Care."
28 *Journal of Palliative Medicine*. Vol. 9, No. 1 (2006).
29
30 Byock, Ira, Jeanne Sheils Twohig, Melanie Merriman, Karyn Collins. "Peer-Professional
31 Workgroups in Palliative Care: A Strategy for Advancing Professional Discourse and
32 Practice." *Journal of Palliative Medicine* (2006): Vol. 9. No. 4, 934-947.
33
34 Caring Connections. "Planning Ahead." National Hospice and Palliative Care
35 Organization. <http://www.caringinfo.org/PlanningAhead.htm> (accessed May 2007).
36
37 Caring Connections. "Who Pays for Hospice and Palliative Care?" National Hospice
38 and Palliative Care Organization.
39 <http://www.caringinfo.org/i4a/pages/index.cfm?pageis=3486> (accessed May 2007).
40
41 Center to Advance Palliative Care and Sutton Group. "Crosswalk of JCAHO Standards
42 and Palliative Care – with PC Policies, Procedures and Assessment Tools."

- 1 *Comprehensive Accreditation Manual for Hospitals*. Center to Advance Palliative Care and
2 Sutton Group: February 18, 2004.
3
- 4 Chochinov, Harvey Max, and William Breitbart. *Handbook of Psychiatry in Palliative*
5 *Medicine*, New York: Oxford University Press, 2000.
6
- 7 Community-State Partnerships to Improve End-of-Life Care. "Advances in State Pain
8 Policy and Medical Practice." *State Initiatives in End-of-Life Care*, Issue 4. Midwest
9 Bioethics Center: April 1999.
10
- 11 Curtis, Randall J., and Robert A Burt. "Why are Critical Care Clinicians so Powerfully
12 Distressed by Family Demands for Critical Care?" *Journal of Critical Care*, (2005): 20, 22-
13 24.
14
- 15 Curtis, J. Randall et al., "Intensive Care Unit Quality Improvement: A 'How-to' Guide
16 for the Interdisciplinary Team." *Critical Care Medicine* (2006): Vol. 34, No.1.
17
- 18 Dahl, June, et. al. "Success of the State Pain Initiatives." *Cancer Practice*. Vol. 10: S9-S13
19 (May/June 2002).
20
- 21 Duensing, Lennie. "Talking with June L. Dahl, Ph.D.: The Impact of Legislative and
22 Regulatory Policy on the Practice of Pain Management in the United States." *The Pain*
23 *Practitioner*. Vol. 16, No. 4: 27-30 (Winter 2006).
24
- 25 Emanuel EJ. "Cost Savings at the End of Life: What Do the Data Show?" *Journal of the*
26 *American Medical Association* (1996): 275, 1907-1914. Cited in *Center to Advance Palliative*
27 *Care Manual*. <http://64.85.16.230/educate/content.html> (accessed May 2007).
28
- 29 Emanuel, Ezekiel. "Improving How Americans Die, End Goal." *The New Republic*,
30 (posted March 29, 2006). <http://www.tnr.com/doc.mhtml?i=w060327&s=emanuel032906>.
31
- 32 Emont, Seth. "Promoting Palliative Care Excellence in Intensive Care Cross-Site
33 Synthesis Report." White Mountain Research Associates: June 2006.
34
- 35 End of Life / Palliative Education Resource Center. "Links." Medical College of
36 Wisconsin. <http://www.eperc.mcw.edu/links/index.htm> (accessed May 1, 2007).
37
- 38 "Faculty Development Program Combines Teaching and Learning About End-of-Life."
39 Dana-Farber Cancer Institute. [http://www.dfci.harvard.edu/pat/adult/pain/faculty-](http://www.dfci.harvard.edu/pat/adult/pain/faculty-development-program-combines-teaching-and-learning-about-end-of-life-care.html)
40 [development-program-combines-teaching-and-learning-about-end-of-life-care.html](http://www.dfci.harvard.edu/pat/adult/pain/faculty-development-program-combines-teaching-and-learning-about-end-of-life-care.html)
41 (accessed May 2007).
42

- 1 Fagerlin, Angela and Carl E. Schneider. "Enough, the Failure of the Living Will." The
2 Hastings Center Report: March-April 2004.
3
- 4 Field, Marilyn, and Christine K. Cassel, eds. *Approaching Death, Improving Care at the End
5 of Life*. Committee on Care at the End of Life. Division of Health Care Services, Institute
6 of Medicine. Washington, D.C: National Academies Press, 1997.
7
- 8 Field, Marilyn J., and Richard E. Behrman, eds. *When Children Die: Improving Palliative
9 and End-of-Life Care for Children and Their Families*. Washington, D.C.: National
10 Academies Press: 2003.
11
- 12 Foley, Kathleen M., "The Past and Future of Palliative Care." *Hastings Center Report*.
13 (2005) November-December: S-42-56.
14
- 15 Foti, Mary Ellen. "Do it Your Way: A Demonstration Project on End-of-Life Care for
16 Persons with Serious Mental Illness." *Journal of Palliative Medicine*. (2003) 6(4): 661-669.
17
- 18 Gelfman and Morrison, *Journal of Palliative Medicine*, in press.
19
- 20 Gibson, Rosemary. "The Robert Wood Johnson Foundation Grant-making Strategies to
21 Improve Care at the End of Life." *Journal of Palliative Medicine*. (1998), 1(4): 415-417.
22
- 23 Gilbert, Susan. "Study Finds Doctors Refuse Patients' Requests on Death." *New York
24 Times*, November 22, 1995.
25
- 26 Harrington, Charlene, and Janis O'Meara. "Hospice in California: A Look at Cost and
27 Quality." Oakland: California HealthCare Foundation, 2006.
28
- 29 Henig Marantz, Robin. "Will We Ever Arrive at the Good Death?" *New York Times*,
30 August 7, 2005.
31
- 32 "Improving End-of-Life Care in the Intensive Care Unit." *Critical Care Medicine* (2002):
33 Vol. 34, No. 11 (Suppl.).
34
- 35 "Improving End-of-Life Experiences for Pennsylvanians. Pennsylvania Department of
36 Aging." February 5, 2007. [http://www.aging.state.pa.us/aging/lib/aging/DOA-
37 102forweb.pdf](http://www.aging.state.pa.us/aging/lib/aging/DOA-102forweb.pdf) (accessed February 2007).
38
39
- 40 Institute for HealthCare Improvement: Last Phase of Life. "Last Phase of Life." IHI.org,
41 A Resource from the Institute of Healthcare Improvement.
42 <http://www.ihl.org/IHI/Topics/LastPhaseofLife/>. (accessed February 2007).
43

- 1 Institute of Medicine. *Working Together, We Can Help People Get Good Care When They are*
2 *Dying*. Washington, D.C.: National Academies Press, 2000.
- 3
- 4 Issacs, Stephen and Diane Meier. Unpublished interview data e-mailed to the authors,
5 June 12, 2007.
- 6
- 7 Issacs, Stephen and James R. Knickman. "Field Building: Lessons from the Robert Wood
8 Johnson Foundation's Anthology Series." *Health Affairs*, Vol. 24, No. 4 (2005): 1161-1165.
9 <http://content.healthaffairs.org/cgi/content/abstract/24/4/1161> (accessed October 2007)
- 10
- 11 JCAHO Pain Standards Scoring. The Joint Commission, 2001.
- 12
- 13 Jennings, Bruce, Gregory E. Kaebnick, and Thomas H. Murray, eds. "Improving End of
14 Life Care: Why Has it Been So Difficult?" Special supplement to the *Hastings Center*
15 *Report*. Vol. 35, No. 6, Nov-Dec 2005.
- 16
- 17 Jennings, Bruce, True Ryndes, Carol D'Onofrio, Mary Ann Baily. "Access to Hospice:
18 Expanding Boundaries, Overcoming Boundaries." Special supplement to the *Hastings*
19 *Center Report*. Mar-Apr 2003.
- 20
- 21 "Joint Principles of the Patient-Centered Medical Home." *American Academy of Family*
22 *Physicians, American Academy of Pediatrics, American College of Physicians, American*
23 *Osteopathic Association*. February 2007.
- 24
- 25 Kaufman, Sharon R. ...*And a Time to Die, How Hospitals Shape the End of Life*. New York:
26 Scribner, 2005.
- 27
- 28 Kiernan, Stephen P. *Last Rights, Rescuing the End of Life from the Medical System*. New
29 York: St. Martin's Press, 2006.
- 30
- 31 Knox, Richard A. "Project to Diminish Pain for Dying Called a Failure." *Boston Globe*,
32 November 22, 1995.
- 33
- 34 Kuehn, Bridget. "Hospitals Embrace Palliative Care." *Medical News & Perspectives*. Vol.
35 298, No. 11: 1263-1265 (September 19, 2007).
- 36
- 37 Last Acts National Program Office. "Means to a Better End: A Report on Dying in
38 America Today." Washington D.C.: Last Acts, 2002.
- 39
- 40 Levy, Mitchell M., Curtis Randall. "Improving End of Life Care in the ICU." *Critical Care*
41 *Medicine* Vol. 34, No. 11 (2006).
- 42

- 1 Lilly, Craig M., and Barbara J. Daly. "The Healing Power of Listening in the ICU." *New*
2 *England Journal of Medicine* Vol. 365:313-515, No. 5, Feb 1, 2007.
- 3
- 4 Lorenz K, Lynn J, Morton SC, Dy S, Mularski R, Shugarman L, Sun V, Wilkinson AM,
5 Maglione M, Shekelle PG. "Agency for Healthcare Research and Quality, Evidence
6 Report/Technology Assessment No. 110: End of Life Care and Outcomes." *Agency for*
7 *Healthcare Research and Quality* No. 05-E004-2, Dec. 2004.
- 8
- 9 Lori McGlinchey, ed. "Project on Death in America Comes to an End." Project on Death
10 in America Newsletter. Fall 2003, No. 11.
- 11
- 12 Lubitz, J and Riely G. "Trends in Medicare Payments in the Last Year of Life." *New*
13 *England Journal of Medicine*. 1993:328:1092-6. Cited in "Approaching Death Improving
14 Care at the End of Life, Committee on Care at the End of Life, Division of Health Care
15 Services." *Institute of Medicine*. Washington, D.C: National Academies Press, 1997.
- 16
- 17 Lunney, June R., Kathleen M. Foley, Thomas J. Smith, and Hellen Gelband, eds.
18 "Describing Death in America, What we Need to Know." Washington D.C.: National
19 Academies Press, 2003.
- 20
- 21 Lynn, Joanne, Hal R. Arkes, Marguerite Stevens, Felicia Cohn, Barbara Koenig, Ellen
22 Fox, Neal V. Dawson, Russell S. Phillips, Mary Beth Hamel, and Joel Tsevat.
23 "Perspectives and Reviews of SUPPORT: Rethinking Fundamental Assumptions:
24 SUPPORT's Implications for Future Reform." *Journal of the American Geriatrics Society*
25 Vol. 28, No. 5, May 2000.
- 26
- 27 Lynn, Joanne. "Unexpected Returns, Insights from SUPPORT." *To Improve Health and*
28 *Health Care*, edited by Stephen L. Isaacs and James R. Knickman, Vol. 1. Princeton:
29 Robert Wood Johnson Foundation, 1997.
- 30
- 31 Lynn, Joanne. *Sick To Death and Not Going to Take It Anymore! Reforming Health Care for the*
32 *Last Years of Life*. Berkeley: University of California Press, 2004.
- 33
- 34 Meier, Diane. "Editorial: Variability in end of life care." *British Medical Journal*, 328,
35 E296-#297 (15 May), 2004, doi:10.1136/bmj.328.7449.E296.
- 36
- 37 Meier, Diane. *Palliative Care in Hospitals: A Report from the Center to Advance Palliative*
38 *Care*. New York: Mount Sinai School of Medicine, www.capc.org, June 8, 2007.
- 39
- 40 Meier, Diane. *Quality 101: Palliative Care and the Quality Imperative*. PowerPoint
41 presentation. New York, N.Y.: Center to Advance Palliative Care and Palliative Care
42 Leadership Centers, 2007. From the *Center to Advance Palliative Care* website. Adobe

- 1 Reader, [http://www.capc.org/support-from-capc/audio-conf/04-25-07-](http://www.capc.org/support-from-capc/audio-conf/04-25-07-audio/view?searchterm=quality%20101)
2 [audio/view?searchterm=quality%20101](http://www.capc.org/support-from-capc/audio-conf/04-25-07-audio/view?searchterm=quality%20101).
3
- 4 Meier, Diane. "Palliative Care in Hospitals." *Journal of Hospital Medicine*, 1, 1, Jan/Feb
5 2006, DOI10.1002/jhm.3, www.interscience.wiley.com.
6
- 7 Morrison, S., Maroney-Galin, C., Kralovec, P., Meier, D. "The Growth of Palliative Care
8 Programs in United States Hospitals." *Journal of Palliative Medicine*. 8 (6): 1127-1134,
9 2005. doi:10.1089/jpm.2005.8.1127
10
- 11 Moss, Alvin A., Zandra Dillion, and Susan Jo Bumagin. "End Stage Renal Disease
12 Workgroup: Recommendations to the Field." *Missoula: Promoting Excellence in End-of-*
13 *Life Care*, 2000.
14
- 15 National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for*
16 *Quality Palliative Care*. Pittsburgh: National Consensus Project for Quality Palliative
17 Care, 2004.
18
- 19 *National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-*
20 *Life Care*. From the *State-of-the-Science Conference*, December 6-8, 2004.
21 <http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm> (accessed February
22 2007).
23
- 24 National Quality Forum, A National Framework and Preferred Practices for Palliative
25 and Hospice Care Quality, A Consensus Report. Washington, D.C.: National Quality
26 Forum, 2006.
27
- 28 "NHPCO's Facts and Figures – 2005 Findings." *National Hospice and Palliative Care*
29 *Organization*. November 2006. [http://www.nhpc.org/files/public/2005-facts-and-](http://www.nhpc.org/files/public/2005-facts-and-figures.pdf)
30 [figures.pdf](http://www.nhpc.org/files/public/2005-facts-and-figures.pdf). (accessed May 2007).
31
- 32 O'Neill, Joseph F., Peter A Selwyn, Helen Schietinger, Eds. "A Clinical Guide on
33 Supportive Palliative Care for People with HIV/AIDS." U.S. Department of Health and
34 Human Services, 2003. <http://hab.hrsa.gov/tools/palliative/>. (accessed March 2007).
35
- 36 Open Society Institute. "Project on Death in America Report of Activities July 1994 –
37 December 1997." Open Society Institute, Project on Death in America, 1995.
38 [http://www.soros.org/initiatives/pdia/articles_publications/publications/report_1997120](http://www.soros.org/initiatives/pdia/articles_publications/publications/report_19971201)
39 [1](http://www.soros.org/initiatives/pdia/articles_publications/publications/report_19971201). (accessed March 2007).
40
- 41 Ott, Barbara B. "Advance Directives: The Emerging Body of Research" *American Journal*
42 *of Critical Care* Vol. 8, No. 1 (1999). Cited in *Advance Directives: The Emerging Body of*
43 *Research*. http://www.osbf.net/advancedirectives/stories_012.html.

1

2 "Perspectives on Care at the Close of Life." A Series by the *Journal of the American Medical*
3 *Association*: 2000-2007.

4

5 Promoting Excellence in End-of-Life Care. "Innovative Models and Approaches for
6 Palliative Care." Promoting Excellence in End-of-Life Care.

7 <http://www.promotingexcellence.org/i4a/pages/index.cfm?pageid=1> (accessed July
8 2007).

9

10 Romer, Anna L., Karen S. Heller, David E. Weissman, and Mildred Z. Solomon, eds.
11 *Innovations in End-of-Life Care, Practical Strategies & International Perspectives*. Vol. 3. New
12 Rochelle: Mary Ann Liebert, Inc., 2002.

13

14 Schroeder, Steven A. "The Legacy of SUPPORT." *Annals of Internal Medicine* (1999): Vol.
15 131, No. 10, 780-782.

16

17 Schroeder, Steven. A. "When Execution Trumps Strategy: Looking Back on Twelve
18 Years at the Robert Wood Johnson Foundation." *Just Money: A Critique of Contemporary*
19 *American Philanthropy*. Karoff, HP, editor. TPI Editions, Boston, 2004

20

21 Shugarman, Lisa R., Karl Lorenz and Joanne Lynn. "End-of-Life Care: An Agenda for
22 Policy Improvement." *Clinics in Geriatric Medicine* (2005): 255-272, Vol. 21.

23

24 Solomon, Mildred Z., Anna L. Romer and Karen S. Heller, Eds. *Innovations in End-of-Life*
25 *Care, Practical Strategies & International Perspectives*. Vol. 1. New Rochelle: Mary Ann
26 Liebert, Inc., 2000.

27

28 Solomon, Mildred Z., Anna L. Romer, Karen S. Heller and David E. Weisman Eds.
29 *Innovations in End-of-Life Care, Practical Strategies & International Perspectives*. Vol. 2. New
30 Rochelle: Mary Ann Liebert, Inc., 2001.

31

32 Sullivan, Amy. M., Matthew D. Lakoma, and Susan D. Block. "The Status of Medical
33 Education in End-of-Life Care." *Journal of General Internal Medicine*. Vol. 18: 685-695
34 (September 2003).

35

36 Sutton Group, *EPEC Marketing Research, Topline Findings*. Microsoft PowerPoint
37 presentation. Washington, D.C.: Sutton Group, 2000.

38

39 *Taking Care: Ethical Caregiving in Our Aging Society*. Washington, D.C.: The President's
40 Council on Bioethics, 2005.

41

- 1 Teno, Joan M, Sally Neylan Okun, Virginia Casey, and Lisa C. Welch. *Toolkit of*
2 *Instruments to Measure End of Life Care, Resource Guide: Achieving Quality of Care at Life's*
3 *End*. Providence: Joan Teno, 2001.
4
- 5 The Dartmouth Atlas Project. "The Dartmouth Atlas of Health Care." Center for the
6 Evaluative Clinical Sciences at Dartmouth Medical School.
7 <http://www.dartmouthatlas.org>. (accessed May 2007).
8
- 9 "The Legacy of Support." *Annals of Internal Medicine* Vol. 131; No. 10: 780-782, November
10 16, 2999.
11
- 12 "Thirty-Five Leaders Map the Future of Reform." *State Initiatives in End-of-Life Care*.
13 Issue 25, May 2006. Center for Practical Bioethics.
14 http://www.practicalbioethics.org/FileUploads/si_issue25_final.pdf. (accessed May
15 2007).
16
- 17 Trafford, Abigail. "The Subject of Dying." *The Washington Post*, October 21, 1997.
18
- 19 "Transforming the Culture of Dying, The Project on Death in America, October 1994 to
20 December 2003." Open Society Institute, 2004.
21
- 22 U.S. Department of Health and Human Services, Centers for Disease Control and
23 Prevention, National Center for Health Statistics. "Fasts Stats S to Z, Deaths/Mortality."
24 <http://www.cdc.gov/nchs/fastats/deaths.htm>. (accessed June 2007).
25
- 26 U.S. Department of Health and Human Services, Health Resources and Services
27 Administration, HIV/AIDS Bureau. A Resource Guide for Providing Palliative Care
28 Services Through the Ryan White Care Act. "Organizing and Financing Palliative Care."
29 <http://hab.hrsa.gov/tools/res/organizing.htm> (accessed May 2007).
30
- 31 Vitez, Michael. "Let Us Not Forsake the Dying, Says Pa. Report." *Philadelphia Inquirer*,
32 February 05, 2007.
33
- 34 von Gunten Charles F, Frank D. Ferris, Russell K. Portenoy, Myra Glajchen, eds.
35 *CAPCManual: How to Establish A Palliative Care Program*. New York, NY: Center to
36 Advance Palliative Care, 2001.
37
- 38 von Gunten, Charles F. Notes from the Editor: "Never Argue with a Pig." *Journal of*
39 *Palliative Medicine*. Vol. 9, No. 3, 614-615, 2006.
40
- 41 Webb, Marilyn. *The Good Death: The New American Search to Reshape the End of Life*. New
42 York, NY: Bantam, 1997.
43

1 Weisfeld, Victoria, et. al. "Improving Care at the End of Life: What Does it Take?" *Health*
2 *Affairs*. Vol. 19, No. 6: 277-283 (November/December 2000).

3

4 Wennberg, J., Thomson, P., Fisher, E., Stukel, T., Skinner, J., Sharp, S., Bronner, K. "Use
5 of hospitals, physician visits, and hospice care during last six months of life among
6 cohorts loyal to highly respected hospitals in the United States." *British Medical Journal*,
7 328:607 (13 March), 2004, doi: 10.1136.bmj.328.7440.607.

8

9