

# **Living and Dying Well with Cancer** Successfully Integrating Palliative Care and Cancer Treatment



PROMOTING EXCELLENCE IN END-OF-LIFE CARE  
A NATIONAL PROGRAM OF  
THE ROBERT WOOD JOHNSON FOUNDATION

# Completing the Picture of Excellence



In 1997, The Robert Wood Johnson Foundation launched a national program *Promoting Excellence in End-of-Life Care* with a mission of improving care and quality of life for dying Americans and their families. We soon realized that the metaphor of a jigsaw puzzle seemed apt in describing our efforts to expand access to services and improve quality of care in a wide range of settings and with diverse populations. No single approach would suffice - a variety of strategies, models of care and stakeholders are necessary to successfully complete the picture. This monograph represents one aspect of our work and one piece of the puzzle of ensuring that the highest quality of care, including palliative care, is available to all seriously ill patients and their families.

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## Acknowledgements:

This publication was produced by *Promoting Excellence in End-of-Life Care*, a national program of The Robert Wood Johnson Foundation, directed by Ira Byock, M.D. Primary authors of this report are:

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Editorial assistance was provided by Karyn Collins, M.P.A., Communications Officer. We extend special appreciation to the individuals in the projects featured who gave their time to provide information for this report.

## About the Artists:

The black and white photographs included in this report were taken by Bastienne Schmidt and Philippe Cheng at the Rhode Island Hospital Intensive Care Unit in January 2001 as part of a project entitled "Compassionate Care in the ICU: Creating a Humane Environment," funded by Ortho Biotech and Critical Care/Surgery. The photographers are deeply indebted to Dr. Mitchell Levy and his staff at Rhode Island Hospital and especially to the patients and their families who allowed them into their lives during this time.

The Project ENABLE photo was taken by Amy Thompson, *Valley News*, Lebanon, N.H.

**April 2003**

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*“There is no argument that palliative care, from diagnosis to death, should be integrated into cancer care...”*

- NCPB Report, Improving Palliative Care for Cancer

## Introduction

Too many patients with cancer suffer needlessly at the end of their life. Focus on the *cure* too often has diverted attention from the *care* that patients need. As the National Cancer Policy Board (NCPB) of the Institute of Medicine noted in its 2001 report, Improving Palliative Care for Cancer: “Patients, their families and caregivers all suffer from the inadequate care available to patients in pain and distress.”

In the last several years, leaders in American medicine have put forth a new and hopeful vision for improving the comfort and quality of life for patients with advanced cancer and their families. This vision recognizes that optimal care requires attention to multiple sources of distress that are common in illnesses such as advanced cancer. It foresees a continuum of cancer care in which palliative skills and services ease physical and emotional suffering and enhance the quality of cancer patients’ and families’ lives throughout the course of treatment.

The Institute of Medicine has played a leading role in defining this bright vision. Its 1997 report Approaching Death, and subsequent NCPB reports, including Ensuring Quality Cancer Care and Improving Palliative Care for Cancer, document the shortcomings in care for patients with advanced, incurable illness and identify barriers to quality care at the end of life. As the NCPB notes in Improving Palliative Care for Cancer: “There is no argument that palliative care *should* be integrated into cancer care from diagnosis to death, but significant barriers – attitudinal, behavioral, economic, educational and legal – still limit this needed care for a large proportion of people with cancer.”

Collectively these reports call for policy changes and underscore the importance of research, including demonstration projects, to help chart the course.

The American Society of Clinical Oncology has also helped point the way to this new, comprehensive standard of care. In a 1998 policy statement it noted: “Cancer care optimizes quality of life throughout the course of an illness through meticulous attention to the myriad physical, spiritual and psychosocial needs of the patient and family.” National health care philanthropies, creative, forward-thinking clinicians and researchers and cancer survivors themselves, have all contributed to crafting a vision of this comprehensive continuum of care and lent their voices to a chorus calling for change.

Since 1997, *Promoting Excellence in End-of-Life Care*, a national program of The Robert Wood Johnson Foundation, has worked to advance the agenda for better end-of-life care through an array of innovative projects. The program is based at The University of Montana, Missoula under the leadership of Dr. Ira Byock. It includes an ambitious and broad-based effort to systematically build and carefully evaluate innovative models for delivering palliative care. Twenty-two projects from across the country were selected from a pool of more than 700 grant applicants to create new models that expand access to services and improve quality of care. The grantees spanned a variety of care settings, diseases and patient populations.

This monograph reports on the results of the four *Promoting Excellence in End-of-Life Care* demonstration projects that tested models of concurrent anti-cancer treatment and palliative care for patients with advanced cancer. Specifically, these models challenged the so-called “terrible choice” that patients living with cancer in the United States typically face. Either they can pursue cancer treatments in hope of extending their lives *or* they can “give up” and accept hospice care to relieve symptoms and to provide emotional and spiritual support for them and their families through the end of life.

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Hospice is currently the most developed and most available form of comprehensive palliative care, but Medicare regulations and many insurance companies' policies limit hospice services to patients with a prognosis of six months or less and require patients to forego any treatments aimed at extending life. In practical terms, patients must either refuse any further cancer treatment or exhaust all available treatments to receive hospice services. This sequential arrangement – all available disease-modifying treatment *and then* referral to hospice for palliative care – denies needed services to many patients and families at the most difficult time in their lives.

This arbitrary forced choice between disease-modifying treatment and care focused on comfort and quality of life ignores the real needs and legitimate desires of patients with progressive cancer, their families and often their physicians. It defies the reality that patients often want to pursue even long-shot efforts to stem the course of the disease, including entering clinical trials of experimental therapies, while also receiving care directed at their comfort and support for their family. Instead, the price patients pay for “continuing to fight” is loss of access to comprehensive care for their and their families' physical, emotional and spiritual needs. Many who do receive hospice services are typically served for about two weeks before death, too late for patients and families to fully benefit.

Successes in cancer research and treatment have transformed cancer from a disease that typically leads to death soon after diagnosis, as it was for most of the twentieth century, to a chronic disease that many patients live with for years. Still, at present, at least half of all people diagnosed with cancer will eventually die from the disease. The National Cancer Institute (NCI), which leads the nation's thirty-plus-year-old war on cancer, continues to focus solely on victory. It devotes less than 1% of its annual budget of about \$4 billion to any aspect of symptom control, palliative care or end-of-life research, according to the NCPB report [Improving Palliative Care for Cancer](#). As that report noted, “In accepting a single-minded focus on research toward cure, we have inadvertently devalued the critical need to care for and support patients with advanced disease.”

Surveys show that psychosocial issues are primary concerns among patients with life-limiting diseases such as cancer. Patients who are treated at one of our nation's 39 NCI-designated Comprehensive Cancer Centers understandably assume that they will receive top-of-the-line care. Yet NCI awards the vaulted Comprehensive Cancer Center designation solely on an institution's research prowess, and not on the basis of quality of care.

As a result, patients who are dying from cancer, particularly those suffering from pain, fatigue, breathlessness or emotional distress, may find themselves and their families to be refugees in the war against cancer, feeling forgotten, abandoned and alone.

### **Demonstration Projects: Applying Theory to Health Service Delivery and Practice**

The Institute of Medicine, its National Cancer Policy Board, The American Society of Clinical Oncology and a host of other leading voices in cancer care have called us to a new, higher vision that eliminates the “terrible choice.” *Promoting Excellence in End-of-Life Care*, in collaboration with leading institutions, clinicians and researchers around the country, has embraced the challenge of advancing that vision.

The four *Promoting Excellence* demonstration projects described in this monograph have translated theory into reality. Their efforts go directly to the questions of whether and how palliative care services can be integrated upstream in the continuum of cancer care.

Aggressive cancer care has been likened to a super-highway while hospice care is analogous to a country road. Meeting the challenge of concurrent care requires the melding of these very different curative and palliative cultures. Not surprisingly, some have wondered if it is feasible to merge the two. How can state-of-the-art cancer care with its focus on survival coexist with services that assist patients adapt to an uncertain future and support patients and families in planning and preparing for death? In a concurrent model of care, how will expanding access to palliative care affect quality of care? Will the additional services that palliative care provides result in excessive health care costs? How will palliative services that are associated with hospice care be received by patients, their families and providers?

Few studies have addressed these critical questions. The *Promoting Excellence in End-of-Life Care* demonstration projects described in this monograph begin to fill that void. Each project drew on the services of hospice to create unique integrated models of oncology treatment and palliative care. Together, they reached within a variety of settings, including NCI-designated Comprehensive Cancer Centers, community hospitals and community-based oncology practices.

The Ireland Cancer Center in Cleveland and the Hospice of the Western Reserve collaborated closely to provide palliative services within the oncology plan of care for lung cancer patients.

The University of California at Davis directly challenged the idea that patients enrolled in clinical trials

could not receive concurrent palliative care services.

The Comprehensive Cancer Center at the University of Michigan and Hospice of Michigan undertook a clinical trial to compare the outcomes of patients receiving standard cancer care with those who received standard care *plus* palliative services.

Dartmouth's Norris Cotton Cancer Center and Hospice of Vermont and New Hampshire brought palliative care to the university cancer center, a community-based oncology practice and a rural hospital, while providing patients tools to better manage their illness.

These demonstrations were completed in 2002 and some data are still being analyzed. The findings presented in this monograph must be considered preliminary. As small-scale pilot projects striving to build new models of care, often the sample size was too small to achieve statistical significance. But the programmatic results are intriguing in a hopeful way that demands broader study.

These projects dispel many concerns about the practicality of these models, the feasibility of merging curative and palliative clinical cultures and the general acceptance of concurrent care by patients, families, clinicians and cancer centers. They indicate that when patients undergoing treatment also receive palliative care they experience improved quality of care and the burden on their caregivers declines. In addition, intriguing early results suggest that concurrent care may actually reduce health care costs – or at least not increase them – and may even extend lives.

Clinicians participating in these demonstration projects discovered that cancer treatment and palliative care *do* go together. They became enthusiastic supporters of the concurrent models because they saw it improve the quality of care for their patients, thereby enhancing their own professional satisfaction as well. The culture of these centers shifted, ushering in a new mindset and expectations for the care of patients with advanced, incurable illness. Many of the partnering institutions involved are continuing the concurrent model of care beyond the life of The Robert Wood Johnson Foundation *Promoting Excellence in End-of-Life Care* grants. Several are pursuing additional research based on their successful pilot projects.

In integrating two seemingly disparate models of care, the programs addressed issues such as cultural gaps, patient and professional education and reimbursement challenges. Both in their successes and their struggles, these exciting experiments in care delivery provide jumping-off points for expanded efforts to bring comprehensive attention to comfort, quality of life and family caregiver support throughout the continuum of cancer care.

## Typical Features of Palliative Care in Promoting Excellence Projects

- 1 Ongoing communication among patients, families and providers
- 2 Advanced care planning and patient-centered decision making that is iterative and reflective of patients' values and preferences
- 3 Formal assessment and treatment of physical and psychosocial symptoms
- 4 Care coordination (also known as case management) to streamline access to services and monitor quality of care
- 5 Spiritual care
- 6 Anticipatory guidance in coping with illness and issues of life completion and life closure
- 7 Crisis prevention and early crisis management
- 8 Bereavement support
- 9 An interdisciplinary team approach to care
- 10 24/7 availability of a clinician knowledgeable about the case





*"We have learned that palliative care is just good cancer care."*

- Meri Armour, M.S.N., R.N., Ireland Cancer Center





## Ireland Cancer Center's Project Safe Conduct

Project Safe Conduct demonstrates how a hospice team can be successfully integrated into an ambulatory care cancer center. The partnership of the Hospice of the Western Reserve and Ireland Cancer Center (ICC) of Case Western Reserve University and University Hospitals of Cleveland proved to be an award-winning innovation.

Behind the success of Project Safe Conduct was the early recognition that bringing hospice into a cancer treatment center would entail challenges beyond merely offering patients some additional services. The merging of the different hospice and cancer care cultures took “incredible learning on both sides,” said Meri Armour, M.S.N., R.N., vice president of cancer services at ICC, an NCI-designated Comprehensive Cancer Center. “We talk to each other, we sit on each others’ boards, but we had no clue how naïve we were about each others’ worlds.” Most hospice people don’t understand cancer treatment, Armour said. As for the cancer center, “We didn’t realize how desperately in need of help and support our staff was.”

Thanks to the partners’ joint efforts, Project Safe Conduct transformed the culture of the cancer center, while creating a model for improving care to cancer patients and their caregivers. For its accomplishments, Project Safe Conduct won a 2002 Circle of Life award, given by the American Hospice Association and other sponsoring organizations, to honor innovative end-of-life programs. “It’s an outside-the-box approach and it’s making a difference,” the award citation noted. The project also won the National Hospice and Palliative Care Organization Award of Excellence in Education – Educational Program Designed to Increase Access to Hospice and Palliative Care.

“This was a process of growing and learning,” said Dr. James Willson, director of the ICC and Project Safe Conduct principal investigator. “What we learned is that good cancer care requires not only attention to acute management of the cancer patient, but also anticipating issues around the end of life and incorporating them early on in patient management.”

### **Innovating with Soul**

The name “Safe Conduct” comes from Avery Weisman’s book, Coping with Cancer, in which he defines safe conduct as “the dimension of care that guides a patient through a maze of uncertain, perplexing and distressing events.” Project Safe Conduct created a team to provide that guidance. The Safe Conduct Team (SCT) was composed of a social worker, an advanced practice nurse and a spiritual counselor from the Hospice of the Western Reserve (HWR), a large community-based hospice. A psychologist and a pain specialist from ICC served as consultants. A distinguishing characteristic of the program was the extent to which the external hospice team was fully integrated into the cancer center, even wearing badges identifying them as ICC staff. The team worked collaboratively with the medical staff at ICC as an interdisciplinary group, providing comprehensive services to patients enrolled in Project Safe Conduct.

Officials with the hospice and ICC spent months preparing for this merging of cultures. From the outset, the project had the strong backing of Willson and the unwavering support of David Simpson, the executive director of the HWR. Willson

even took the unusual step of suspending clinic visits for a day so that participating ICC oncologists could attend an educational retreat in preparation for the program. Safe Conduct colleagues agree that Willson's championing of the program was critical to its success.

"We lived with the question of how to bring palliative care into an acute care setting every day," said Willson, noting that in his own practice the transition to hospice was far from ideal. And so, he said, "We took the marvelous opportunity to work with hospice to build a new paradigm."

### Working Together, Learning Together

In the planning stages, leaders of the two groups met often. Throughout the project, Elizabeth Ford Pitorak, M.S.N., R.N., C.R.N., director of the HWR Hospice Institute and director of Project Safe Conduct, continued to meet with ICC's Armour weekly to address problems.

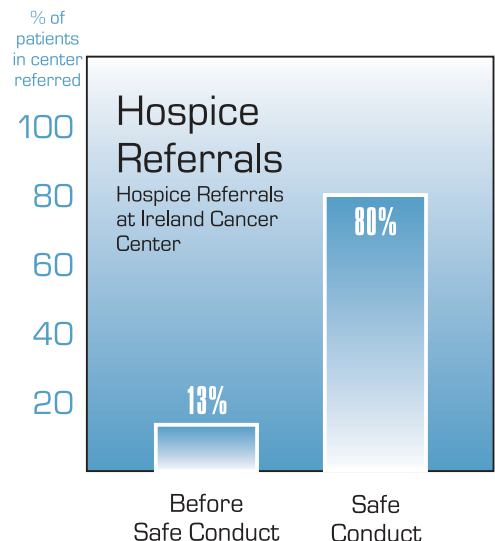
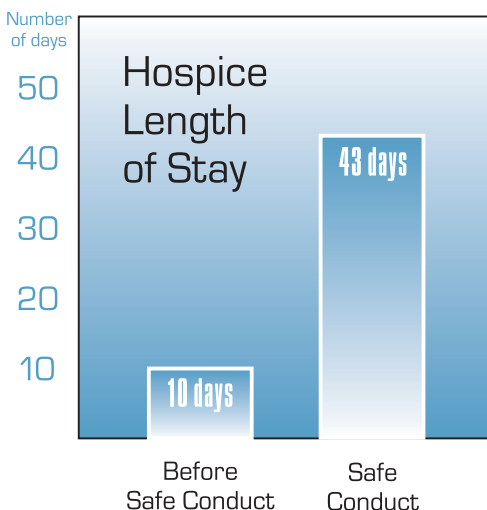
"I had anticipated many more barriers in integrating the two philosophies," Pitorak said. But there were hurdles to overcome. One concept that the ICC staff learned to embrace was the central role of the family. "In the acute care setting, you are there to take care of the patient, but at hospice, the unit is the patient and family, and on any given day we may spend more time

with family," she said. As in hospice, the unit of care for Project Safe Conduct was the patient and family.

It was also critical to find the right people for the team – hospice workers who could transition to the acute care setting. That took a couple of tries. Learning to function as an interdisciplinary – not multidisciplinary – team proved to be one of the toughest challenges, according to Pitorak. In a multidisciplinary approach, various clinical disciplines are involved in care planning, but an interdisciplinary team approaches care planning as a creative, collaborative process that makes the whole much more than the sum of its parts.

Learning on both sides occurred continuously. When a member of the SCT regarded a patient's not eating as a natural point in the dying process, she was taught how important nutrition is for patients undergoing chemotherapy. Similarly, when the hospital staff became concerned that the SCT member was upsetting a patient and causing her to cry, they learned that the patient had requested the team's help in preparing to tell her children about her prognosis. Tears were an appropriate part of that difficult discussion.

One of ICC's early priorities for the project was to improve pain management for its patients. The SCT developed a Pain Care Path model that took into



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- Dr. Nathan Levitan, Ireland Cancer Center

account not only pharmacological interventions, but also psychological and spiritual suffering. The model provided a decision tree to follow as well as guidelines and extensive information to guide assessment and management of pain. In addition, the team created a Pain Flow Sheet to document how a patient’s pain was being managed. Pain was assessed on every patient at each visit, something that had not occurred previously. These instruments were implemented beyond Project Safe Conduct to other parts of the ICC and University Hospitals, its satellites, as well as within the hospice.

### Hopeful Outcomes

Project Safe Conduct enrolled a total of 233 patients with advanced lung cancer (Stage IIIb or IV). The composition of the SCT patients was 39% minority, primarily African American, and 49% female. All were receiving chemotherapy or radiation and some were enrolled in Phase I or Phase II clinical trials. Except for a few patients early on, virtually all eligible patients chose to participate in the pilot study.

Soon after a patient enrolled, the SCT met with the patient and family. From then on, team members were available throughout the patient’s care at ICC. Prior to Safe Conduct, the typical pattern was for a patient to see a doctor, perhaps to be given chemotherapy by a nurse and, if the patient was noticeably upset, to be referred to a social worker, psychologist or psychiatrist. With Project Safe Conduct, a patient and family had access to the nurse, social worker or spiritual counselor every time they came for a physician visit, treatment or procedure. The team was also available to patients and their families at other times when they had concerns or questions.

Team members represented different skills and personalities. ICC oncologist Dr. Nathan Levitan saw this as a big benefit, increasing the chance that the patients and their families would find a caregiver they could connect with emotionally. “Cancer care is a very intimate kind of care,” said Levitan. “Patients talk about fear of dying, family gets involved and personalities need to click between caregiver, family and patient. If you only have one doctor doing all the interacting, you can’t meet all those needs – time-wise or in terms of personality style.”

Not uncommonly, in talking to the patient, a member of the SCT discovered important information that might not otherwise have surfaced. In one case, a patient continued to report pain even though she had been prescribed a strong pain reliever. She subsequently revealed to the team’s social worker, with whom she had a close relationship, that she could not afford to fill the prescription and also pay her rent. An effective, but less costly, alternative was prescribed so she could manage both expenses.

The SCT monitored patients closely and met weekly as a team to update patients’ care plans. Team members were aware of news the physician would be giving a patient at an appointment and were available for support afterwards. A doctor might give the patient and family discouraging chemotherapy results and then add, “The team is here to help you.” Before a physician appointment, an SCT member often talked to the patient and family, inquiring about pain and physical discomfort, assessing how well they were eating and sleeping, listening to caregiving issues and exploring emotional or spiritual concerns. They would alert the physician to important information that might affect the care plan.

Levitan said Project Safe Conduct introduced clinicians to a very different way to take care of patients. “Physicians started to assess the patients’ level of distress and determine their psychosocial needs very early,” he said. “Even before anything happens with patient care, physicians now are attuned to dimensions of care that may not have previously been in their mindset.”

### Helping Physicians as Well as Patients

Project Safe Conduct also included family conferences where the oncologist, patient, family and at least one member of the SCT discussed end-of-life options. In the past, if such conferences occurred at all, the discussions were left to the oncologist, who often felt uncomfortable dealing alone with the psychological and spiritual issues involved. “We have wonderful doctors, and they wanted to help,” said Armour, “but they didn’t have the skill set or support to do it.” Adds Levitan, “In medical school doctors are taught how to take a medical history, but no one ever

## *“We took the marvelous opportunity to work with hospice to build a new paradigm.”*

-Dr. James Willson, Ireland Cancer Center

taught us how to take a religious or spiritual history.”

Increasingly, oncologists began to appreciate and rely on the services of the SCT. “It’s very lonely for the oncologist being the sole one in the room with the patient and family and everyone is looking at you asking, ‘can’t you help?’” said Armour. “So we put a group of people around them.”

Levitan agrees that the program helped physicians as well as patients, educating them and also allowing them to be more efficient with their time, knowing the team could handle certain issues. He adds that it also helped physicians when they got overwhelmed by a patient’s or family’s needs. “In the past, a care provider might feel ‘this is driving me crazy’ and there was a tendency to become irritated with a family member. But with the team, a clinician can say: ‘I’m overwhelmed here. I need some help.’ Instead of seeing an annoying problem, it is interpreted properly as a sign of needing help, and there are resources to provide it.”

“Project Safe Conduct brought an expertise into a cancer center that we really learned to value,” said Willson, “and I think reciprocally, participating in a cancer center environment expanded the hospice members’ understanding. We grew together as a group and that was extraordinary.”

### **Discovering the Spiritual Dimension**

Perhaps the most surprising effect of the project was the cancer center’s embrace of the importance of spiritual support services. This included discussion of such issues as the meaning and purpose of the patient’s life, relationships and reconciliation.

When Armour and Pitorak developed the Project Safe Conduct grant proposal, Armour kept insisting that the budget was too tight to include a spiritual counselor. But Pitorak held firm, determined to make the position a critical part of the team. “I would roll my eyes,” recalls Armour. “She was driving me nuts.”

But Armour and her colleagues at ICC freely acknowledge that they came to regard spiritual care as one of the most important contributions of Project Safe Conduct, educating doctors and nurses to be attentive to something they typically ignored, and providing a highly valued service to patients.

One sign of the interest in spiritual care among oncologists and other ICC staff was the standing room only crowd for an ICC Grand Rounds on spirituality. ICC staff are continuing their interest in the effect of spirituality with an NCI-funded trial that randomizes patients to receive spiritual counseling or not.

### **Documenting Improvements**

Project Safe Conduct’s positive impact on patients and caregivers emerges in several areas, based on preliminary data comparing these patients to lung cancer patients receiving care at ICC a year prior to the introduction of the SCT:

- *The number of hospice referrals increased from 13% to 80%. The hospice length of stay increased from an average of 10 days to 43 days.*
- *The hospital admission rate (number of hospitalizations per patient per year) was 3.20 before Project Safe Conduct and dropped to 1.05 for SCT patients.*
- *Unplanned hospitalizations and emergency room visits dropped from 6.3 per patient to 3.1.*
- *75% of SCT patients died at home, where most patients prefer to be at the end of life.*
- *Average per-day pharmaceutical costs dropped from \$60.90 per patient to \$18.45.*
- *Caregivers of SCT patients reported reduced burdens in interviews conducted after the death of their loved one.*

Project Safe Conduct wanted to see if it could match the high quality of life scores reported in the literature for patients receiving hospice care. Data from the Missoula-VITAS Quality of Life Index, which are still being analyzed and interpreted, suggest that Safe Conduct patient perceptions may be as good or better.

Data were not kept on the length of time patients stayed in clinical trials, but some ICC staff are convinced that addition of the palliative services enabled some patients to stay in the trials longer.

Although the project was not directly evaluating costs, the reductions in hospital stays and emergency room visits clearly translate into reduced overall health care expenditures. The reduction in burden experienced by caregivers also probably leads to reduced health care costs, given studies showing an increase in use of health services by stressed caregivers.



The apparent financial savings align with enhanced quality and access to palliative care, said Willson, who notes that less frequent use of the emergency room and fewer hospitalizations reflect better patient management. “Our emergency rooms are very busy and not an ideal site for cancer care,” he said. “Safe Conduct patients used the hospital and ER less because there was a mechanism in place to anticipate and address problems as they arose.”

The financial implications for the individual institution are less clear. Willson notes this but adds, “You have to make investments to realize benefits.” He also emphasizes that The Robert Wood Johnson Foundation *Promoting Excellence in End-of-Life Care* grant was critical to developing the program.

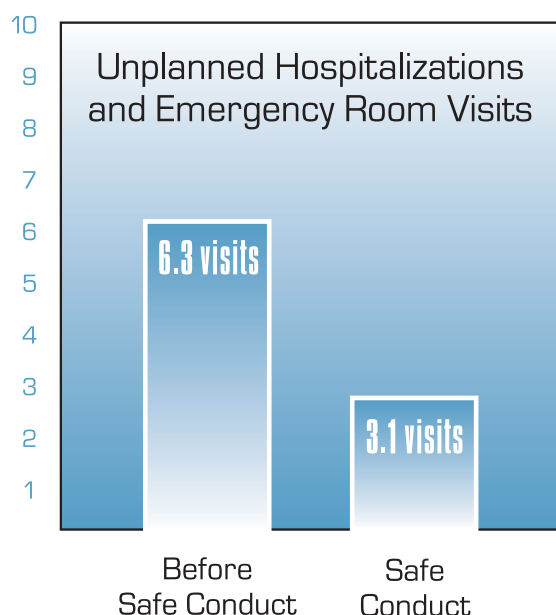
Armour is concerned that some institutions may be reluctant to make the investment and cites the need for a new formula for cancer care support that takes into account the range of needs of dying patients, and the costs averted by programs like Project Safe Conduct. “Cancer centers need to consider this an essential a part of our mission and

take it as seriously as we do the charge to find a cure,” she said.

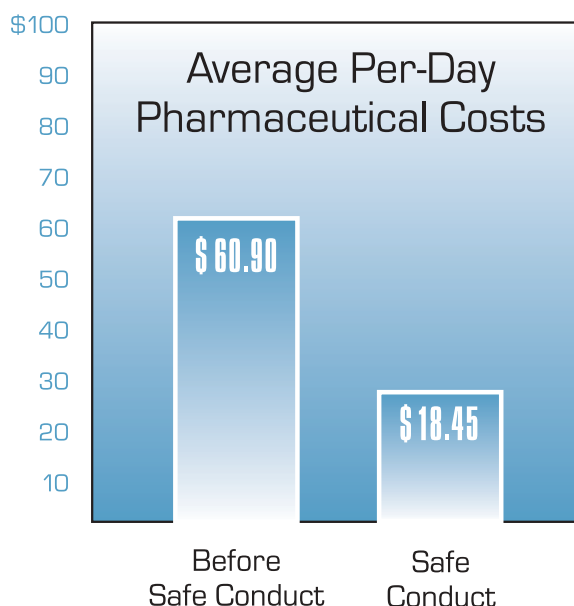
The Ireland Cancer Center believes so strongly in what it has accomplished that it is continuing the program beyond the *Promoting Excellence* grant. It hired the Safe Conduct Team so they can continue their work. “The culture here has been transformed,” Willson said. He notes, for example, that early referral to hospice is now the standard of care. Project staff are also looking at how to extend the model beyond their tertiary care center to community-based providers affiliated with ICC. In addition, they have secured grants to pursue studies of issues that arose in the course of Project Safe Conduct, such as family communication and discord at the end of life.

“We have learned that palliative care is just good cancer care. We’re continuing Project Safe Conduct at Ireland because once you look at the data you just can’t take these services away,” said Armour. Levitan agreed. “Project Safe Conduct is the ideal we should strive for with all of our patients.”

ER visits  
per  
patient



Dollars  
per day



*"The doctors not only embraced the intervention but they came to expect it. When the study stopped, they were all very disappointed."*

- Dr. Frederick J. Meyers, UC Davis



## University of California Davis' Simultaneous Care Project

Not surprisingly, patients with advanced cancer who have exhausted all proven therapies but aren't willing to "give up" often look to the pipeline of new drugs still being tested for some hope of extending their life. But because of Medicare regulations and insurance policies' restrictions, by entering an early-stage trial, patients in terminal phases of cancer are effectively excluded from receiving the array of hospice services that they and their families need. If clinical trial patients and their families receive hospice care at all, it is often within just a few days of their death.

"It's been an either-or choice," said Dr. Frederick J. Meyers, professor and chair of internal medicine at the University of California Davis Health System. "Patients with advanced cancer have been told they can be in a clinical trial *or* they can focus on quality of life. We don't think that is an acceptable choice. Why can't patients have both?"

Meyers and his colleagues sought to answer that question in their Simultaneous Care demonstration project at UC Davis School of Medicine. It compared a group of clinical trial participants receiving usual oncology care to a group receiving usual care *plus* palliative care services. Meyers is the principal investigator of the project, which challenged the notion that providing services focusing on pain control, symptom management, psychosocial issues and end-of-life planning might somehow disrupt participation in clinical trials. In fact, Meyers notes, if patients are in pain, they and their caregivers are less likely to focus on adhering to their therapeutic regime.

Simultaneous Care addressed important questions such as: How does concurrent palliative care affect the quality of life of patients in drug trials and their families? Does it affect their continued participation in studies? Are patients who are reaching out to experimental treatments in the hope of prolonging their life even interested in the services that hospice provides?

The study found that patients welcomed the palliative care intervention. Preliminary data also indicate that the quality of life of those receiving those services surpassed that of patients not provided concurrent palliative interventions. The patients receiving palliative care while in research trials adhered equally well to chemotherapy regimens, and they had a dramatically higher rate of subsequent hospice admissions compared to patients receiving usual care.

### The Study Design

Simultaneous Care enrolled patients participating in Phase I and Phase II clinical trials of investigational chemotherapy treatments. Phase I drug trials test the toxicity and maximum tolerated dose of compounds that have not previously been given to humans. They are not designed or intended to have therapeutic effects. Instead, by helping to identify safe doses of new medications, these trials offer patients an opportunity to make an altruistic contribution to improving care for future patients. Phase II trials measure the activity of a compound against the disease in humans for the first time.

All of the patients enrolled in Simultaneous Care had a prognosis of one year or less to live. One of the study's hypotheses was that hospice-type palliative care and support services would increase the quality of life of patients enrolled in these studies and increase successful transition to hospice programs without adversely affecting the investigational trials.

A total of 44 patients were enrolled in the experimental group that received usual oncology care plus palliative services, and 20 patients were in a comparison group that received usual care only. The patients in the experimental arm became part of an interdisciplinary program that focused on symptom management, emotional support and discussion of end-of-life issues. Home visits were an

*“Symptom control and quality of life were valued as much as investigational approaches to cancer therapy. We are doing a lot of patients in this country a disservice by denying them the opportunity to receive hospice while they receive investigational therapy, based solely on finances or regulatory concerns.”*

-Dr. Primo Lara, UC Davis

important part of the program. Both the nurse case manager and medical social worker who visited patients in their home were experienced in palliative care. Each was trained to observe for toxicity of chemotherapy and to address questions within the scope of their particular discipline about pain, emotional issues and end-of-life issues, such as financial planning and wills.

Another key element of the project was that the Simultaneous Care nurse or social worker accompanied the patient to appointments with oncologists. If a patient forgot or was reluctant to tell the doctor about symptoms, such as pain or severe nausea, the nurse could remind or encourage her. If a caregiver was upset, he could talk to the social worker and be better able to assist the patient in making treatment decisions or following a therapeutic course. The nurse and social worker were available to support patients and their caregivers 24 hours a day, seven days a week.

Other members of the Simultaneous Care Team included a social worker who facilitated completion of follow-up surveys, the medical director, clinical research assistants and the Cancer Center research nurse. Throughout the project, the Simultaneous Care interdisciplinary team met weekly to discuss Simultaneous Care patients, including current physical and psychosocial assessments. The team was housed in the Cancer Center and routinely met with patients in the clinical area, making the team a regular, and soon trusted, part of the Cancer Center staff.

Meyers and his Simultaneous Care team spent three months planning for the project before enrolling patients. Institutional leadership was the key to their success, they say. Meyers and his colleagues reached out to cancer physicians and other staff in the hospital. The Simultaneous Care team met with each oncologist to discuss the project, emphasizing that palliative services could complement the care physicians and others were providing. Meyers said that their extensive outreach efforts were critical because this approach represented a fundamental change in the culture of the Cancer Center and project staff expected some resistance. As it turned out, project staff had few problems persuading clinical cancer staff of the utility of this approach.

## **Promising Findings**

For the Simultaneous Care Team the study put to rest the idea that patients opting for clinical trials do not want to think about end-of-life issues. “One of the critical lessons learned is that you can raise issues of mortality within the clinical trials population,” said John Linder, M.S.W., a social worker on the team. “In fact, if patients who want to focus on quality of life don’t have to reject research trials, it might broaden the pool of potential research subjects quite a lot.”

The UC Davis team also found that the addition of palliative services did not affect compliance with the experimental regime. Completion rates for chemotherapy were similar in the experimental and control groups. There was no statistical difference in the average number of cycles of chemotherapy completed.

Investigators also closely monitored the quality of life of trial participants. Patients in both groups completed a quality of life survey at the beginning of the seven-month trial and then at one-month intervals. Patients receiving palliative services showed an increase in the quality of life indicators as time went on, while patients in the control group showed a decrease, though these differences were not statistically significant.

As hypothesized, transition to hospice also increased for the experimental group. Fifty-three percent of the usual care group was referred to hospice compared to 92% of the Simultaneous Care patients. Median length of stay in hospice for the Simultaneous Care patients was 54.5 days compared to 37 days for patients receiving usual care. The study suggests that clinical trial patients would likely choose hospice services during far-advanced stages of illness if health care professionals supported and introduced the palliative care to them.

## **Dispelling Old Ideas**

Dr. Primo Lara, who cares for patients on clinical trials at UC Davis, said the study provides evidence that bringing palliation and anti-cancer treatment together works. “This project showed us that this was feasible, it was doable, it was effective and it enhanced the outcome measures that we had identified,



such as quality of life,” Lara said. “It may change the standard of care. I am one of the converted. It has rubbed off on all of us. We all got on the bandwagon.”

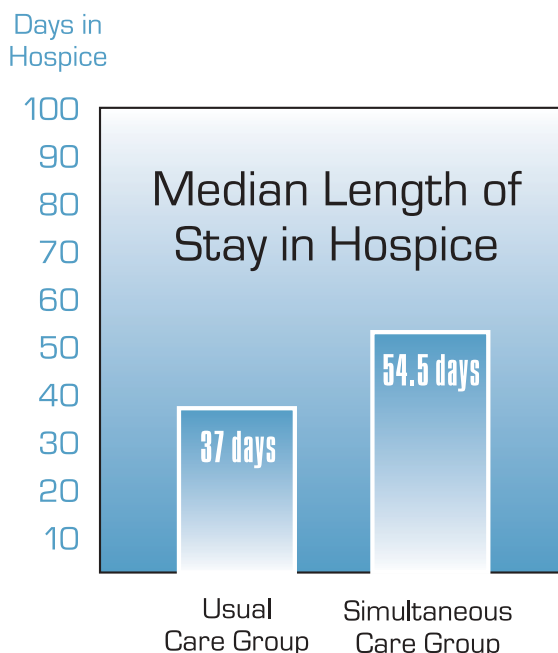
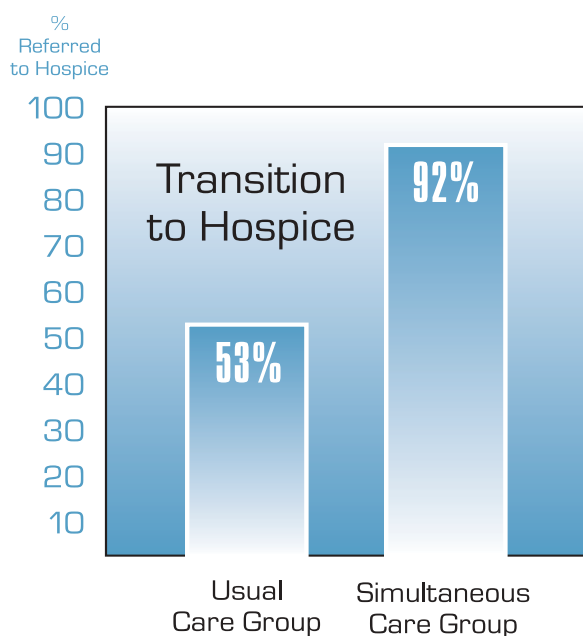
“One of the big paradoxes in our society is that investigational drugs are considered incompatible with palliative care and hospice intervention and that patients on clinical trials cannot simultaneously be given hospice care,” Lara adds. “This is what Simultaneous Care was providing to us. Symptom control and quality of life were valued as much as investigational approaches to cancer therapy. We are doing a lot of patients in this country a disservice by denying them the opportunity to receive hospice while they receive investigational therapy, based solely on finances or regulatory concerns.”

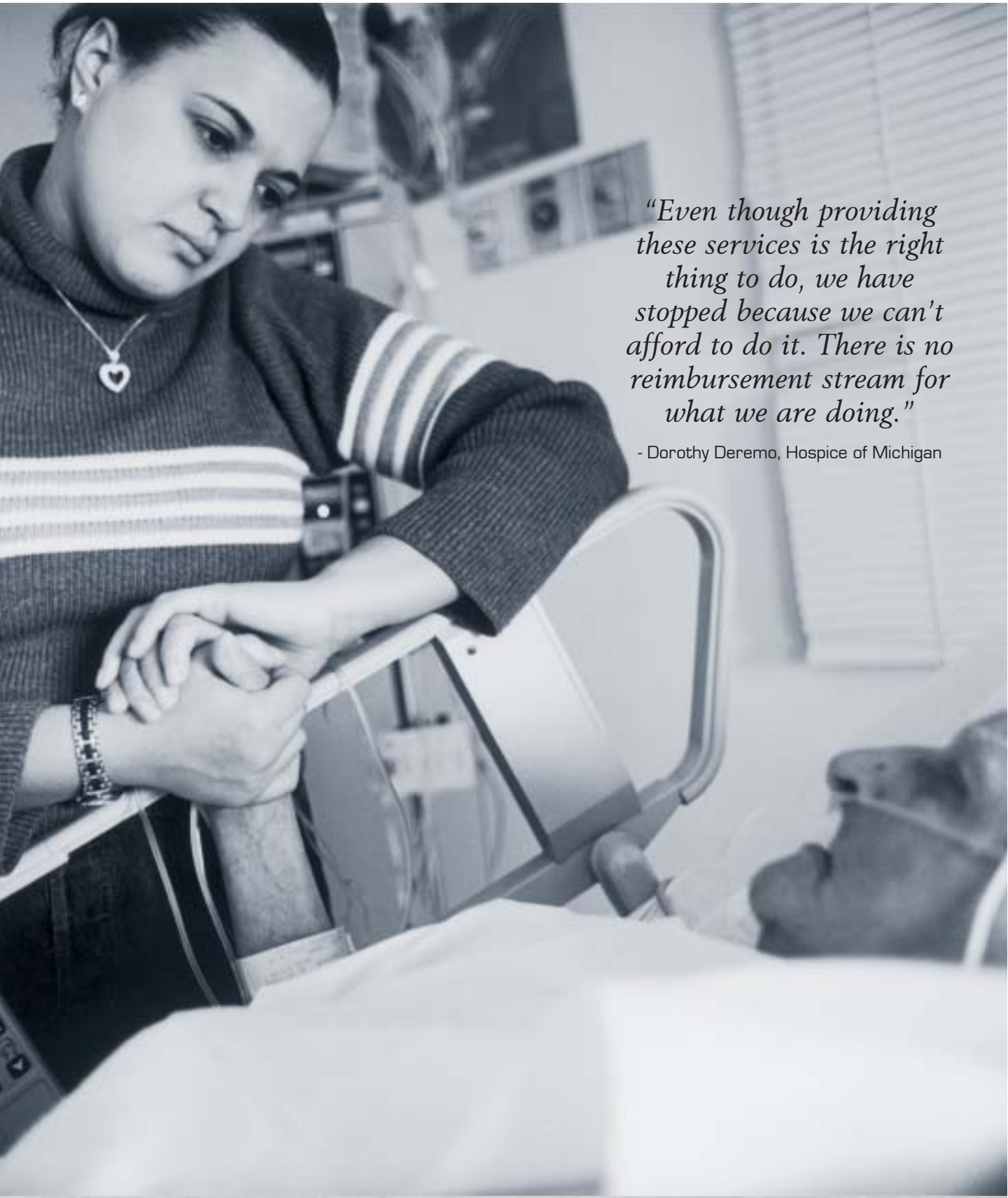
Meyers sees the significance of their findings not only for patients but also for the physicians and institution. “The bottom line lesson is that we confirmed our hypothesis that you can do palliative care and investigational therapy at the same time,”

Meyers said. “We changed the culture of the Cancer Center. The doctors not only embraced the intervention but they came to expect it. When the study stopped, they were all very disappointed.”

The comprehensive services provided as part of Simultaneous Care required an investment on the part of the medical center. For each patient, the nurse visited two to four times a week and the social worker once or twice a week. Because the *Promoting Excellence* grant did not fund clinical activities, the Department of Internal Medicine had to cover the costs of these positions, which were approximately \$150,000.

But the hopeful lessons from Simultaneous Care have been well invested in the future. Meyers and his colleagues received a \$2.5 million, five-year grant from the National Cancer Institute to extend their work using a patient and family educational intervention with a randomized trial in three sites: UC Davis, The City of Hope Medical Center in Los Angeles and Johns Hopkins Medical Center in Baltimore.





*“Even though providing these services is the right thing to do, we have stopped because we can't afford to do it. There is no reimbursement stream for what we are doing.”*

- Dorothy Deremo, Hospice of Michigan

## University of Michigan's Comprehensive Cancer Center Palliative Care Program

The University of Michigan's Comprehensive Cancer Center's Palliative Care Program took the form of a Phase III clinical trial that compared advanced cancer patients receiving standard cancer care to those receiving standard cancer care *plus* hospice services. In addition to providing information on the impact on quality of care, this project is contributing much-needed data on the cost of providing concurrent hospice services and cutting-edge cancer treatment.

Preliminary data show that adding palliative services improves quality of care and reduces caregiver burden. Intriguing findings from this study also suggest that the hospice intervention may reduce the cost of care. Another exciting – and unexpected – finding is that patients who receive palliative care may actually live longer.

The Michigan experience also carries sobering implications that extend beyond the positive impacts of concurrent care. While it has shown what is possible, it also reveals how current reimbursement and regulatory policies present substantial barriers to realizing those gains.

The trial was a partnership of the NCI-designated University of Michigan Comprehensive Cancer Center and Hospice of Michigan (HOM). This Phase III trial built on an earlier pilot study at Wayne State University that found improvements in comfort and patient satisfaction among advanced prostate cancer patients who received concurrent palliative services. Phase III trials evaluate the effectiveness of a new treatment against existing treatments.

A total of 167 patients with advanced cancer of the prostate, breast, lung, colon, bladder or pancreas, or with metastatic melanoma, were enrolled. They came from multiple sites across the state, including private physician offices and community-based hospitals as well as the University of Michigan Comprehensive Cancer Center. All patients met hospice criteria of a life expectancy of six months or less, yet all were determined to continue life-extending treatment, including trials of experimental therapies.

Nurses trained as palliative care coordinators (PCCs) identified patients who met the study criteria and then approached the patient's oncologist to see if he or she would introduce the study to the patient. The PCCs obtained informed consent from patients wishing to participate. Patients were then randomized to receive either standard oncology care or standard care plus palliative services.

Eight palliative care coordinators worked closely with the study group patients. They served as liaisons to a hospice team from HOM that provided round-the-clock palliative services. Although similar to a case management approach, the coordinators were more closely involved with their patients, communicating frequently, monitoring their progress and attending physician appointments with them.

Because the trial involved patients with many types of cancer and involved many types of care settings and oncologists, the results were intended to be widely generalizable, according to Jeanne Parzuchowski, R.N., M.S., O.C.N., who was vice president for research at HOM during the trial and project director. Parzuchowski also ensured that the nurses who were trained to be palliative care coordinators represented a range of educational backgrounds to make the program easier to replicate in various settings.

Hospice of Michigan directly provided the palliative care services to the patients enrolled in the trial and covered all costs of the study group, billing Medicare or private insurers when possible. Therefore, HOM bore the greatest financial risk.

*“Oncologists were disappointed when their patients were randomized to the control arm because their perception was that care was so much better on the experimental arm. It was also easier for them to take care of the patients because there were far fewer phone calls, and emergency room visits in the middle of the night were rare.”*

-Dr. John Finn, Maggie Allesee Center for Quality of Life at Hospice of Michigan

## **Overcoming Barriers**

One of the early lessons of the program, especially for the hospice staff, was how many patients with incurable cancers hold out hope for cure or improvement. “We cannot underestimate patients’ and families’ desire for ongoing treatment despite the odds,” said Dr. John Finn, the program’s co-principal investigator and chief medical director of the Maggie Allesee Center for Quality of Life at HOM. This became clear early on when about two-thirds of eligible patients chose not to enroll in the study.

One factor was that patients still fighting their disease were uncomfortable with the idea of getting care from hospice workers, said Finn. “Hospice doesn’t sell,” he said, “because it symbolizes dying and death to patients not wanting to face that.” According to Finn, many patients wanted palliative services, but they wanted to be identified as palliative care patients, not hospice patients.

Confronting death was a problem for physicians as well as patients. The first line of the consent form stated, “I have been told that I have an incurable disease,” and that forced a discussion about death that was difficult for many oncologists, said Parzuchowski.

Other cultural differences between oncologists and hospice staff also were apparent. “Even oncologists who we thought were hospice-friendly had a great deal of difficulty with notions of comprehensive palliative care,” said Finn. “Palliative care means different things to different people. When an oncologist thinks of palliative care, he thinks ‘if I can reduce some of the cancer cell burden, it will make the patient more comfortable.’”

All these issues complicated the way physicians introduced the trial to eligible patients and slowed recruitment into the trial. Another reason patients seemed reluctant, said oncologist Dr. Frank Worden, was that enrolling in this trial seemed like one more thing to deal with for worried and overwhelmed patients who were in other protocols that they hoped would be life-extending. To improve the recruitment process, project staff made a video of a physician skillfully talking with a potential trial participant. This video “role model” helped physicians introduce

patients to the study in a non-threatening manner. The team also provided other training and guidance in presenting the study. Recruitment improved following those interventions.

Although there were also other difficulties in bridging the cultures and operating the program, the positive effects of providing the services gradually won over participating physicians. “As the project progressed,” said Finn, “oncologists were disappointed when their patients were randomized to the control arm because their perception was that care was so much better on the experimental arm. It was also easier for them to take care of the patients because there were far fewer phone calls, and emergency room visits in the middle of the night were rare. The hospice nurse could usually handle problems at home.”

Dr. Finn said the program also appealed to oncologists because it affirmed their primary role in the patient’s care and eliminated the need for the doctor to effectively discharge patients from their practice in order for them to receive hospice services.

## **Intriguing Early Results**

Data from the Michigan trial are still being analyzed but preliminary data from 55 subjects suggest that the project has achieved impressive results in both the quality of care and cost arenas. Early data show that patients receiving palliative services had significantly less decline in quality of life compared to the group receiving standard care only. Caregivers of patients in the palliative care group also reported a lower degree of burden, especially in the first month. In addition, an unexpected finding is that patients in the palliative care group had a longer length of life – 266 days compared to 227 days.

Project staff are using the most sophisticated cost models available to compare the cost of caring for the patients in the study and control groups, said Dorothy Deremo, president and CEO of Hospice of Michigan. One challenge is developing standard costs for procedures being provided across the various settings. For example, a community hospital may charge less – or more – than a tertiary care center for a specific



procedure but traditional cost accounting methods will assign a single cost.

Preliminary data show striking cost savings for the patients receiving palliative care services. The average total cost per patient of the study group was \$12,682, compared to \$19,970 per patient for the control group receiving standard care only. Average cost of hospitalizations for the study group was \$8,974 per patient, compared to \$13,126 for the control group. These data do not include prescription drug costs for either group or some other costs. When those are added in, economists think the gap will close but there will still be a savings, said Deremo.

Some of the cost savings resulted from the reduced use of the emergency room and hospital by the palliative care group:

- *The rate of emergency room admissions was 0.8 for the study group over a 266-day period compared to 1.07 for control patients over a 227-day timeframe.*
- *Hospital admissions were 9.9 hospital days per patient over a 227-day timeframe for the control group while the study group had 7.7 during a 266-day period. This corresponds to an annualized rate of 15.9 hospital days per for control group patients compared to 10.6 hospital days for those receiving concurrent care.*

Deremo also cited national studies showing that caregiver stress increases morbidity and use of health services so the reductions in caregiver burden may well translate to additional cost savings.

“Our preliminary results indicate that providing palliative services is certainly improving quality, probably decreasing costs and possibly extending

lives,” said Demero. If the findings hold up, some staff wonder whether oncologists would feel ethically comfortable in enrolling patients in cancer trials in the future knowing that patients who simultaneously receive palliative care do so much better.

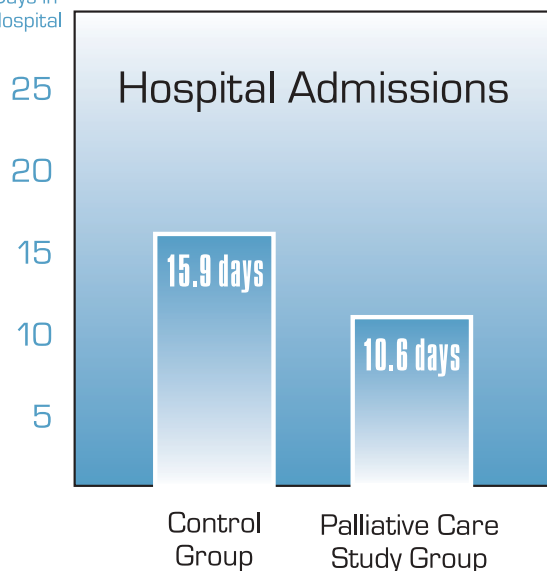
Ironically, despite these positive findings, including overall financial savings, access to concurrent hospice services ended when the *Promoting Excellence* grant was complete because of uncompensated costs of care. Medicare does not reimburse for hospice care while patients receive disease-modifying treatment. Although total health care costs for patients who received hospice care appear to be lower than for those who received standard care only, those savings went to Medicare and other payers and did not accrue to HOM, which assumed the costs for patients enrolled in the study arm. By the end of the trial, HOM had spent more than they expected – about \$1.5 million.

Parzuchowski worked with Medicare, insurers and managed care organizations to get them to share the costs for their patients in the study group. “It took tremendous effort with mixed results,” she said. She encountered restrictive payment caps and coverage gaps and questions about why patients who were dying were getting aggressive treatment.

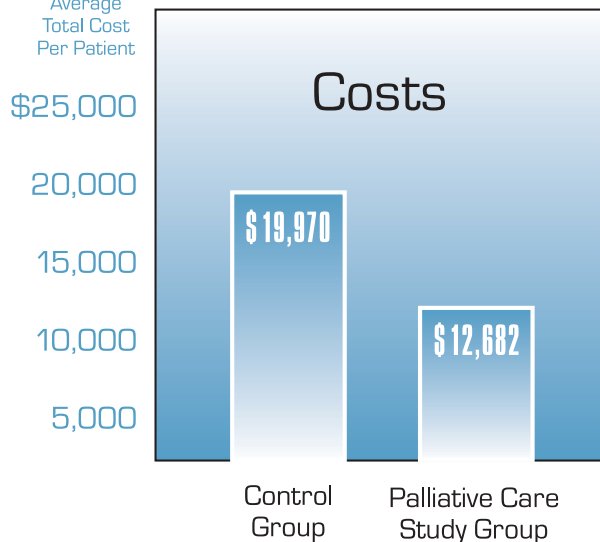
“Even though providing these services is the right thing to do, we have stopped because we can’t afford to do it,” said Deremo. “There is no reimbursement stream for what we are doing.”

It is regrettable, she adds, “We have let the reimbursement tail wag the dog and have not looked at the patient experience based on need.”

Annualized  
Days in  
Hospital



Average  
Total Cost  
Per Patient



*The “either-or” choice between disease-modifying cancer treatment and palliative care to enhance comfort and quality of life has been proven to be arbitrary and unnecessary.*



Photo by Amy Thompson, Valley News, Lebanon, N.H.

## Dartmouth's Norris Cotton Cancer Center's Project ENABLE

Project ENABLE (Educate, Nurture, Advise, Before Life Ends) brought palliative care to advanced cancer patients at a major cancer center, and it also showed that these services can be integrated into community-based oncology practices where most cancer patients receive their care. The program included workshops that gave patients and their caregivers tools to help manage their illness.

The project was a partnership of Dartmouth's Norris Cotton Cancer Center (NCCC), an NCI-designated Comprehensive Cancer Center that serves northern New England, and the Hospice of Vermont and New Hampshire (Hospice of VNH). NCCC treats about 2,000 new patients each year but, like many cancer centers, until recently offered few palliative care services. With a grant from the local Byrne Foundation, NCCC and Hospice of VNH formed an NCCC-based palliative care service with the long-term goal of expanding palliative care and hospice services to NCCC patients and others in the region. Project ENABLE was their first major effort to provide an integrated model of care.

Project ENABLE was integrated into NCCC and two community sites:

- New Hampshire Oncology-Hematology Associates (NHOH), a six-physician practice with a main clinic in Hookset, New Hampshire and satellite offices in other New Hampshire towns, and
- Androscoggin Hospital in Berlin, NH, a rural community hospital in an isolated region on the northern border of New Hampshire.

Project ENABLE was so successful in the physician practice and at the cancer center that those sites continued to provide concurrent care after the demonstration project ended. The rural hospital site encountered unanticipated obstacles, including the departure of the CEO, conflicting time demands on the palliative care coordinator and an economic downturn in the area, that kept the program from becoming well established there. Because of these difficulties, the question of whether such a program can work at a rural site, where there are relatively few patients with advanced cancer, remains unanswered.

### A New Model of Care Emerges

Project ENABLE targeted patients with the most common cancers and poor prognoses. Patients participating in the project had been newly diagnosed with advanced lung cancer, metastatic gastrointestinal cancer or metastatic breast cancer. All were expected to die from their disease, probably within two years.

These patients and their caregivers were given access to a broad range of education and palliative care, including services related to life completion, from the time of their diagnosis. Specifically, the program had three major components. First, it placed a palliative care coordinator (PCC) at each of the three sites to provide case management-like services. The PCCs were experienced advanced practice oncology nurses with training in palliative care who had ties to their practice site. Second, Project ENABLE aggressively addressed pain and symptom control with a baseline assessment and ongoing monitoring of all patients. Third, the project offered patients and caregivers a series of seminars, four in one month, called "Charting Your Course." The seminars were tailored to each site and aimed to enable participants to take charge of their illness, helping them navigate the health system, make decisions and better manage symptoms and emotional stress.

During a four-month pilot study preceding implementation of the program, staff tested proposed study procedures and made presentations to oncologists and oncology practice staff. They held nine focus groups, one each with patients, families and clinical providers at the three sites. They also collected data on 91 patients to serve as historical controls, according to Marie Bakitas, M.S., A.R.N.P., C.H.P.N., a PCC who was also on the management team of Project ENABLE.

Throughout the planning process and the project, the PCCs, who came from acute care cancer settings, and the hospice staff worked closely together to effectively integrate the hospice services at the sites. They learned from each other. For example, hospice staff helped the PCCs become more comfortable communicating about difficult topics, including fears of the future, loss and grief. In

turn, the PCCs helped hospice staff become better informed about intensive cancer care. Bakitas recalls that some hospice staff initially thought radiation and chemotherapy were always aggressive treatment and questioned their use. Through “symptom of the month” seminars and a variety of teaching formats the PCCs explained that these treatments are often used to alleviate symptoms – a form of palliative care – so the goals for the oncologists and hospice staff were well aligned.

Palliative care coordinators identified potential patients for the project by attending tumor board meetings and disease management groups, reviewing daily appointment lists and asking physicians and nurses for referrals. The coordinators contacted patients by phone, at a clinic appointment or in the hospital within two weeks of identification to ask if they would like to participate, according to Bakitas. In all, the coordinators recruited 253 patients for the intervention.

Early on, the PCCs helped Project ENABLE patients identify their health care team, which included their oncologist, primary care provider and nurse practitioner as well as community resources, including social workers, spiritual support, hospice and home care and friends. By establishing a team at the beginning, project staff hoped to smooth the transition from one stage of illness to another. The PCCs maintained close contact with patients and their families. They assessed their needs and wishes and shepherded them through the complexities of their cancer care, including hospice and home care. The PCCs assessed not only for physical symptoms, but also for the patient’s and family’s psychological, emotional and spiritual issues. They attended oncology appointments with the patients and followed up with phone calls.

### **“Charting Your Course”**

The “Charting Your Course” workshops were an important part of Project ENABLE. This self-care course helped patients and their families take charge of their illness and make choices reflecting their values and preferences. Staff modeled the workshops on childbirth classes, which over the last few decades have transformed the childbirth experience by enabling families to take control of the birthing process and by better preparing future parents. Most cancer patients have spent little time thinking about death and the practical steps they need to take, such as preparing a living will and signing a durable power of attorney, said Tim Ahles, Ph.D., one of the project’s directors. “Prior to their diagnosis, patients haven’t been thinking about how they’re going to deal with advanced stage cancer,” Ahles said. “Rather, they were thinking about their next vacation or retirement.” The

seminars helped people become prepared for the difficult new reality they faced.

The “Charting Your Course” workshops provided information and practical tools for dealing with the health care system in a supportive, interactive environment, said Bakitas. “For example, in our session on symptoms, I asked patients and their families to talk about symptoms they experienced or were fearful of having and then asked them ‘are you heard when you bring these to the doctor’s office?’” She said the workshops taught patients strategies for communicating with their health care providers about their symptoms. All participants received diaries to monitor symptoms and learned ways to rate discomfort and language to use in reporting symptoms that would be heard by their providers. “Our message was that you need to communicate to your providers that this is important to you and get the resources to deal with it,” said Bakitas.

“Charting Your Course” participants enthusiastically endorsed the workshops, giving them an average score of 1.5 on a scale of 1-5, with 1 being “excellent.” When asked in a separate evaluation if they were likely to use the information they acquired, most answered, “Yes, definitely.” Comments were also positive. One participant wrote, “Keep those workshops going. They made us talk about things we never would have touched. They really helped.”

Not all patients were reached by the workshops. Only about a third – or 90 – of the eligible patients and families participated. A few patients were too ill to attend, and because New Hampshire is a rural state, many lived far away from the workshop sites. The PCCs were able to provide the material one-to-one to some people who could not attend. Project staff also created a CD-Rom with material from the workshop and put it on the Web to make the information accessible to more patients and caregivers.

### **Integrating Palliative Care Within Community-Based Oncology Practice**

Although most cancer patients receive their treatment from oncologists in the community rather than at comprehensive cancer centers, community oncologists traditionally are not able to offer comprehensive palliative care. Therefore, the results of Project ENABLE’s community oncology practice site provide especially important and heartening news.

The Project ENABLE palliative care coordinator at the six-physician practice based in southern New Hampshire – NHOH – was familiar with the practice and quickly became an integral part of the oncology staff. “This integration of care was really innovative for a private practice,” Bakitas said. “Patients and families



communicated about what a benefit it was to have a person who could spend more time with them, and someone who could follow up even after the last chemo treatment when patients weren't coming to the office much anymore."

Dr. Danny Sims, an oncologist at NHOH and medical director of a hospice in Manchester also observed the project's positive effects on patients. "People who have a great deal of anxiety around certain issues could get help either through the coordinator or the workshops. Patients really need this type of support. If we don't provide it, it can interfere with their care." He said it also helped him do his job. "In many ways, it made my life easier. Ultimately, it helps us as oncologists because patients can be more focused on their treatment, and we aren't also dealing at the same time with all of the other outstanding issues."

Sims and his colleagues were so impressed by the project that they continued to pay the salary of the palliative care coordinator after the *Promoting Excellence* grant ended. The coordinator recently left for another position, but the practice plans to maintain the position. Since the physicians feel they have capacity to address pain and related symptom management using clinicians in their practice, Sims said they may try filling the position with a social worker who can bring needed expertise in psychosocial issues. Project ENABLE staff feel that the professional discipline of a palliative care coordinator, such as whether the person comes from a nursing or social work background, must be matched to the particular circumstances and practice setting.

### Integrated Care at the Cancer Center

The intervention was also well received at the Norris Cotton Cancer Center. A key factor there, too, was employing familiar, experienced, respected ENABLE staff, Bakitas said. "These were people the doctors had worked with and trusted so there was credibility when we approached doctors."

Some clinicians had reservations at the start of the study, Ahles said. "Some staff were concerned that talking about end-of-life issues with patients would upset and depress them because they're not thinking about dying. In reality they are thinking about it. One of the most important things we learned is that patients do know what's going on, and they can be realistic. They want treatment for their cancer and also want to plan ahead for themselves and their families."

Project ENABLE patients told their providers that they valued the interventions. "Our best press was the patients," Ahles said. "Most liked the program and many went back to their doctors and thanked them for getting them involved."

Palliative care services have found a place at the NCCC. Cancer center providers and administrators expanded the program from the palliative care coordinators to a new palliative care consultation service that has a team of two full-time nurse practitioners and six part-time physicians. The care team provides inpatient and outpatient consultation and palliative home and hospice care – 24 hours a day, seven days a week – to patients with life-limiting cancer at NCCC and throughout the Dartmouth-Hitchcock Medical Center. The palliative care consult service is supported primarily by the grant from the Byrne Foundation with 10% of its revenues coming from third-party reimbursements.

NCCC received a follow-up five-year \$1.8 million National Cancer Institute grant in January 2003 to continue their work in providing concurrent care.

"This project was part of a very important mix that got Dartmouth off the mark to decide to sustain and carry the cost of a palliative care program for the whole institution," said Dr. E. Robert Greenberg, principal investigator and former director of the Norris Cotton Cancer Center. "Now the institution is committed to funding this long term. There is recognition that it is not going to make money, but it is something that we need to do to provide good care."

*The four Charting Your Course workshops address such issues as:*

- Symptom Management
- Sense of Personal Control
- Identification of Support Networks
- Financial Issues
- Community Resources
- Spiritual Issues
- Decision Making and Planning
- Communication with Health Care Providers
- Stages of Grief
- Listening Skills
- Complementary Therapies
- Impact of Illness on Family and Friends



*"Patients really need this type of support. If we don't provide it, it can interfere with their care."*

- Dr. Danny Sims, New Hampshire Oncology-Hematology Associates

## What Have We Learned?

The success of these projects summons us to a new era in cancer care. It is a future in which attention to comfort, quality of life and family support is simply part of comprehensive cancer treatment. This vision of a seamless continuum of care has been elaborated by the Institute of Medicine and leading professional organizations, such as the American Society of Clinical Oncology. These innovative demonstration projects, supported by The Robert Wood Johnson Foundation's *Promoting Excellence in End-of-Life Care* program, have now shown that this bright vision is achievable and well within reach.

The four *Promoting Excellence* projects featured in this report were conducted in state-of-the-art academic cancer centers and included community oncologists and local home health and hospice providers. They integrated key services of palliative care within busy oncology practices. Although the project designs varied across sites and were matched to the needs of local partners, they had important elements in common: At each site an expanded interdisciplinary team of clinicians attended to physical symptoms and psychosocial distress and helped develop a plan of care consistent with the patient's and family's values and treatment preferences. Plans of care included a crisis prevention and early crisis management plan, and a team member was available 24 hours a day to respond to questions or problems and provide support to family caregivers. Cancer patients and their families were offered spiritual support and counseling with issues of life completion and life closure and families were extended bereavement support.

Differences between these two modes of care were not insurmountable, as some may have suspected. Indeed, the clinician-researchers found that palliative care and oncology treatment are more effective together than either is alone. Providing psychosocial and spiritual support, including discussions of issues pertaining to the end of life, did not detract from patient compliance with ongoing anti-tumor treatments. On the contrary, several clinicians observed that intervention group patients seemed better able to tolerate the rigors of both therapeutic and cancer research protocols.

Concerns that the expanded menu of services of these integrated models would prove too costly also were not borne out. Instead, although the results are all preliminary, they have consistently been in the direction of cost savings, largely corresponding to diminished use of hospitalizations.

Referrals to hospice and length of hospice service rose at all sites. This is a positive outcome, reflecting expanded access to an array of palliative services for which patients and their families are eligible.

### Conclusions

These projects each built new delivery models that proved to be feasible, well accepted and clinically effective. Although results are still emerging, an important conclusion can be drawn. The "either-or" choice between disease-modifying cancer treatment and palliative care to enhance comfort and quality of life has been proven to be arbitrary and unnecessary.

"These results demonstrate that concurrent palliative care and treatment are possible, are desirable, are implementable and they work," said Dr. Kathleen M. Foley, Professor of Neurology at Cornell University and attending Neurologist at Memorial Sloan Kettering Cancer Center, who is a member of the Institute of Medicine and co-author of the NCPB report.

The message from the *Promoting Excellence* cancer projects is hopeful, and it is clear. As Ellen Stovall, President and CEO of the National Coalition for Cancer Survivorship, states: "The simplicity of these lessons poses a question about providing care any differently."

*“These results demonstrate that concurrent palliative care and treatment are possible, are desirable, are implementable and they work.”*

- Dr. Kathleen M. Foley, Memorial Sloan Kettering Cancer Center

### **Where Do We Go From Here?**

These projects build on a foundation of clinical best practices and a vision defined by leading voices in American health care. In turn, the success of these projects provides a foundation of experience from which to expand. These institution-based demonstrations form a springboard for larger, population-based studies into the clinical and health service delivery impact of concurrent oncology treatment and palliative care.

Of course, regulatory and reimbursement change will also be required in order to realize the potential revealed by these demonstrations. As the NCPB report *Improving Palliative Care for Cancer* recommended, the Centers for Medicare and Medicaid Services can now support larger demonstration projects aimed at identifying reimbursement structures that support integrated care.

The findings from these four demonstration projects also add fuel to other recommendations of NCPB's seminal report that called on the National Cancer Institute to assume a central role in advancing palliative care. Many cancer care providers say they would like to integrate palliative services into their cancer care but need the kind of support and training that NCI can provide. The National Cancer Institute has shown a new openness to support research into palliative domains of care, as reflected in the recent NCI grants awarded to the project teams reported here. Much more is needed, and the NCPB report offers a roadmap for work ahead.

As critically important as research and changes in

regulations and reimbursement are, the principal challenges and core changes required are cultural. Oncology and palliative care have been assumed to be diametrically opposite approaches for so long that many professionals in both fields assume they are incompatible. We know now that apparent clinical or service delivery barriers to comprehensive palliative and oncology care are all surmountable. A vision of integrated whole person and family care must guide future work in clinical care, in health service delivery, in quality improvement, in research, in policy work and in public education and consumer advocacy.

“We worked hard to build a platform for future population-based research and policy initiatives to expand access to services and improve quality of care,” said Dr. Ira Byock, Director of *Promoting Excellence in End-of-Life Care*. “This base of programmatic experience and early evidence presents both challenges and opportunities that are broadly shared,” he added. “Barriers can be overcome with creative, collaborative efforts.”

These demonstration projects offer an enticing glimpse of truly comprehensive cancer care – care that offers cutting-edge anti-cancer treatment while addressing with equal intensity patients' comfort and well-being. The hopeful results from these models encourage us to collaborate in creating a future in which oncology care encompasses and routinely provides a continuum of palliative services. By expanding and refining the work reported here, we can advance along this high road and realize this bright future.

*“The simplicity of these lessons poses a question about providing care any differently.”*

- Ellen Stovall, National Coalition for Cancer Survivorship



## 10 Essential Ingredients for Building Successful Palliative Care Programs



- 1** A well-defined vision that
  - Advances the institution's mission
  - Encompasses a comprehensive definition of palliative care
- 2** A well-planned implementation strategy that is
  - Manageable in scope
  - Consistent with available human and financial resources
- 3** Unwavering support from clinical and administrative leaders willing to
  - Champion the program
  - Help secure operational resources
- 4** Ongoing efforts to bridge the differences between palliative and acute care clinical cultures that
  - Entail learning on both sides
  - Integrate experienced staff with diverse expertise, including psychosocial and spiritual care
- 5** A focus on making "the right way the easy way"
  - Responding to workday needs of time-pressured clinicians and management
  - Redesigning operations to embed and trigger palliative practices in daily routines
- 6** Ongoing education, support and attention to team building for clinicians and system personnel to
  - Ease adoption of innovation
  - Strengthen clinical interventions
- 7** An assurance that palliative care teams have authority to carry out their clinical recommendations and interventions for patient care and have safe havens to discuss problems and ideas
- 8** Attention to diverse ethnic and religious cultures of individual patients and families through
  - Sensitivity to the uniqueness of individuals and their preferences
  - Careful selection of language to convey program elements
- 9** Targeted data collection focusing on
  - Increased access to palliative care
  - Improved quality of care
  - Resource utilization and cost
  - Patient/family/clinician satisfaction
- 10** A communications strategy for succinctly presenting relevant data to stakeholders

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## Contacts

For more information on the demonstration projects profiled in this report, contact the following:

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For information about the financial implications of integrating palliative care with curative care, see the recent *Promoting Excellence in End-of-Life Care* monograph, "Financial Implications of Promoting Excellence in End-of-Life Care," available at [www.promotingexcellence.org](http://www.promotingexcellence.org)

Visit the comprehensive Web site of *Promoting Excellence in End-of-Life Care* for more information on these and other innovative demonstration projects dedicated to long-term changes to improve health care for dying persons and their families: <http://www.promotingexcellence.org> or contact:

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