## Financial Implications of Promoting Excellence in End-of-Life Care

PROMOTING EXCELLENCE IN END-OF-LIFE CARE A NATIONAL PROGRAM OFFICE 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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#### **About the Artist**

Deidre Scherer's fabric and thread images on aging have appeared in over one hundred individual and group shows throughout the United States and internationally, including her solo exhibition at The Baltimore Museum of Art. Her work has been featured extensively in publications and on covers including the best-selling, *When I Am an Old Woman I Shall Wear Purple.* 

With a Fine Arts Fellowship from the Open Society Institute's Project on Death in America, Scherer completed six life-size panels, *Surrounded by Family and Friends*. In this series, as in her past artwork, Scherer raises societal awareness concerning aging and dying. For more information, visit: www.dscherer.com.



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# 3

## Introduction

Too many Americans die badly. Despite the best in medical science and technology, many patients with advanced, life-limiting illnesses suffer needlessly in the final stages of their lives— and die in ways that leave their families with legacies of pain.

A number of national research initiatives, including the Institute of Medicine's report, *Approaching Death: Improving Care at the End of Life*, and the landmark SUPPORT project, have confirmed the serious, structural flaws in the way our health care system cares for those who are facing life's end. The aging population and growing numbers of people living with chronic, incurable illnesses highlight the urgency of developing better ways for providing highquality care—while avoiding unnecessary and unwanted care—during the waning phases of life.

A social and professional movement is underway in response to identified shortcomings in the way we die. Initiatives spearheaded by The Robert Wood Johnson Foundation and other prominent health care philanthropies, and advanced by leading health care professional associations, have confronted specific inadequacies in training and practice.

Change of the magnitude required is, however, rarely simple or quick. There are many challenges to achieving the goal of reliable, high-quality care for our loved ones, and eventually for ourselves, as we die. Longstanding deficiencies in clinical training, clinical protocols, and health service delivery, along with a paucity of tools and methodologies applicable to palliative end-of-life care, are among the reasons cited for the system's inertial resistance to improvement. Deeper still is our collective tendency, as a culture, to avoid thinking and talking about dying, death, and grief.

Psychology aside, one of the biggest factors underlying the current crisis involves financing. Barriers within the payment structures and mechanisms with which we pay for care for seriously ill Americans stand in the way of applying our finite health resources efficiently and effectively to maximize quality, value, and responsiveness to the needs of the ill individual and his or her family. Misaligned incentives in the twin currencies of reimbursement and provider time influence patterns of care, encouraging aggressive treatment as the path of least resistance. It is often easier for a busy doctor to hospitalize a patient or institute treatment than to have an always difficult and poignant discussion acknowledging the possibility that the patient is dying, and discussing alternatives such as home care and hospice.

Existing payment mechanisms drive health service utilization, especially acute care, but often in ways that are not consistent with established domains of quality in end-of-life care. Clearly, large-scale solutions will require health system reforms that better align financial incentives with high standards of care. Correspondingly, health systems need to redesign routine operations to make it easier for providers to do the right thing, consistent with clinical realities and patients' values and preferences. Major changes in policy and health care funding need to be based on evidence and solid programmatic experience.

#### THE RELATIONSHIP BETWEEN ACCESS, QUALITY AND COST

Promoting Excellence in End-of-Life Care, a national program of The Robert Wood Johnson Foundation based at the University of Montana, Missoula, has been a leading national initiative to improve the quality of care for dying Americans and their families. Through its grant funding for innovative demonstration projects, technical assistance and consultation, and the convening of national experts from diverse fields to advise on key themes of end-oflife care, *Promoting Excellence* has pushed innovation and experimentation in support of new and better models of clinical care and health service delivery.

In 1998, after winnowing through almost 700 proposals, *Promoting Excellence in End-of-Life Care* awarded three-year grants to more than 20 highly innovative demonstration projects targeting care in a variety of challenging settings and hard-to-reach patient populations. These demonstration projects rank among the most ambitious and innovative palliative and end-of-life care projects undertaken to date. Collectively, they shed light on practical and effective ways for improving quality and access to care for incurably ill patients and their families. No surprise, since the projects selected for funding were painstakingly chosen based on high expectations of what they could achieve in those areas.

What is surprising is the degree to which the projects have shown that introducing elements of palliative care "upstream" in the course of illness, concurrent with life-prolonging treatment, is associated with controlling costs. As a group, the experience of the *Promoting Excellence in End-of-Life Care* projects suggests that substantial improvements in access to palliative service and quality of care for patients with high burdens of illness may be achieved without increasing total health care costs.

As the Promoting Excellence projects strived to expand access and enhance quality, they were also improving their health systems' efficiency and health resource use. They achieved those results by coordinating care and facilitating communication between patients, families, and providers; by enhancing patients' autonomy and sense of personal control; and by assisting patients with advanced care planning and treatment decision-making that reflected their personal values and preferences. Through improved communication and coordination of services, the projects prevented medical crises or responded quickly and effectively to urgent problems when they arose, thereby diminishing emergency room visits, hospitals stays, and days of care in the intensive care unit.

In looking across these programs, discernable patterns have emerged from the preliminary results. To the extent that costs could be accounted for, the programmatic innovations have translated into enhanced efficiency, diminished use of resources, and savings in overall health care expenditures. Most of the available data needs to be viewed as preliminary; final cost accounting of the projects will require a year or more to complete.

The Promoting Excellence national initiative focused on "model-building." Project evaluation therefore emphasized assessment of the *feasibility* and acceptability of these new clinical and health service delivery models. Methodological challenges in documenting and quantifying actual costs-and potential cost savings—from the experimental models of palliative care have proven more daunting. In many instances, methods of cost accounting have not kept pace with the innovations. Palliative care often does not get "credit" for the systemic efficiencies it generates because of the compartmentalization of health care in distinct "silos" corresponding to reimbursement streams and direct budget line items. The projects often lacked capability to track total costs of their care or to compare those costs with costs in the baseline system.

However, as the cases described in this report make clear, despite the difficulties of accounting, the sites have amply demonstrated clinical value and costcontrolling potential worthy of subjecting their approaches to larger-scale national demonstrations. Despite the difficulties of delivering care within current reimbursement structures, service codes, and payment silos, the *Promoting Excellence* projects provide provocative evidence of their ability to streamline health service delivery to patients with the highest burden of illness, diminish utilization of more costly hospital and critical care settings, and relate health care interventions to patients' actual needs and desires.

#### CONCURRENT APPROACHES TO END-OF-LIFE CARE

The box on page 5 outlines a number of common elements of successful palliative care approaches found in many of the *Promoting Excellence* projects. One of the most important themes to emerge from the projects is the provision of concurrent care: palliative care focused on comfort and quality of life simultaneous with aggressive, life-extending or diseasemodifying treatment for patients with chronic, advanced, and life-limiting illnesses. The projects not only demonstrated the feasibility of this approach and its acceptability to patients and clinicians; they also showed its potential for containing costs.

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Hospice programs have been the primary drivers of improved end-of-life care in this country over the past 25 years, bringing national attention to the system's deficiencies and the needs of patients with life-threatening conditions. Comprehensive hospice care at its best is the gold standard for end-of-life care in America and it also provided a benchmark for the *Promoting Excellence* projects. The Medicare Hospice Benefit has supported the growth and maturation of hospice care—which now reaches about 700,000 patients and families every year. However, during the past three decades, medical treatment and patients' and their families' needs have changed.

In 1982, when Congress enacted the Medicare Hospice Benefit, political considerations demanded budget neutrality. Statutory provisions were added, first to require eligible recipients to give up lifeprolonging care in order to qualify for the support of hospice and second, to base eligibility on a prognosis of six months or less to live. The arbitrary six-month requirement has been shown to have no clinical basis. The either-or dilemma confronting patients has come to be known as "the terrible choice" and is regarded as the predominant barrier to hospice access currently. Because of advances in medical science, there is no longer-if there ever was-a clear distinction between living and dying. Correspondingly, distinctions between life-extending and palliative treatments have also been blurred.

As you will read in this report, new modes of delivering palliative services, in amounts and intensities that respond to patients' and families' actual, evolving needs, have emerged. They are innovative, designed to fit within existing systems and settings of care. They are less restrained by restrictions imposed by the Medicare Hospice Benefit, but many of them represent uncompensated care due to barriers in existing reimbursement structures and thus may not currently be financially supported in a sustainable manner.

The following program descriptions offer snapshots of a half dozen new models for delivering palliative care. They are typical of the other *Promoting Excellence* projects in terms of their creativity, persistence, and flexibility in responding to changes in their local environments. Each operates in a different setting for a distinct patient population, and each offers a unique set of experiences and insights. As a whole, they offer great promise in revealing viable, real-world models for aligning improvements in access, quality, and cost-containment. Their experience provides health policy-makers with important lessons. Together, they point toward effective strategies for addressing the current critical national challenges of caring for people who are nearing life's end.

Typical Features of Palliative Care in Promoting Excellence Projects

- 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
- An interdisciplinary team approach to care
- **10** 24/7 availability of a clinician knowledgable about the case

## Integrating Palliative Care and State-of-the-Art Cancer Care

Several National Cancer Institute-designated Comprehensive Cancer Centers received grants to test the simultaneous provision of active cancer treatment and supportive palliative care. The projects aimed to offer care consistent with cancer patients' actual needs and desires. Each sought to overcome the health policy-imposed dichotomy that currently requires patients to give up cancer treatment in order to receive palliative care directed toward improving comfort and quality of life.

The University of Michigan Comprehensive Cancer Center in Ann Arbor and Ireland Cancer Center in Cleveland, Ohio tested models of concurrent care, introducing palliative care and attention to comfort and quality of life "upstream" in the disease trajectory. Both projects were built on close collaboration between the cancer center and a leading hospice program. Both achieved strikingly hopeful results, demonstrating that improved access to palliative services and responsiveness to patient preference and comfort needs can be achieved cost-effectively—with at least budget neutrality—while measurably improving quality of care. At this point, data are still being analyzed and the projects can only report trends from their experience. But those trends are strongly encouraging.

University of Michigan Comprehensive Cancer Center, Ann Arbor, in conjunction with Hospice of Michigan, Detroit, Michigan Palliative Care Program Principal Investigator: Kenneth J. Pienta, MD Co-Principal Investigator: John Finn, MD Focus: A randomized controlled trial testing the quality and cost-effectiveness of concurrent cancer treatment and hospice care tied together by the services of a palliative care coordinator based on site in oncologists' offices. Ireland Cancer Center, in conjunction with Hospice of the Western Reserve, Cleveland, Ohio **Project Safe Conduct** Principal Investigator: James K.V. Willson, MD Focus: An integrated care path offering a seamless transition from curative to palliative care for dying lung cancer patients and their families using a hospice-like "Safe Conduct Team" to provide palliative care within a

cancer center.





#### THE ROLE OF PALLIATIVE CARE COORDINATOR The UNIVERSITY OF MICHIGAN

COMPREHENSIVE CANCER CENTER project

combined the services of a hospice team from Hospice of Michigan with a new role called Palliative Care Coordinator for cancer patients receiving anticancer treatment—including experimental Phase I-III cancer clinical trials. The model was tested through a rigorous, randomized controlled trial of conventional oncology care alone (control group) or in combination with the provision of hospice and palliative care coordination (intervention group). Intervention patients were immediately enrolled in hospice, while anti-cancer treatments, usually excluded from hospice care by Medicare regulations, continued.

The Palliative Care Coordinator's pivotal role enabled the project to blend essential elements of hospice care with cutting-edge cancer treatment. Functioning as communicator, educator, advocate, and integrator, the Palliative Care Coordinator was the "glue" that connected patients and families with clinical components of the project, making sure that the patients' needs and values were clearly reflected in the difficult treatment decisions they faced.

The Palliative Care Coordinator accompanied the patient to the doctor's office, made home visits, at times even meeting a patient in a restaurant or café, while maintaining persistent telephonic outreach. The goal was to guide patients and families through the health system's complexities. Although palliative services were directed at improving comfort and quality of life, the additional attention to communication, symptom control and the provision of emotional support enabled some patients to continue their experimental treatments longer than they otherwise might have done. For others, the expertise and time devoted to clarifying their values and preferences allowed them to identify alternatives to hospital-based care and let go of ineffective treatments sooner.

#### THE PROMISE AND PROBLEMS OF HOSPICE

"When I first entered the field of medical oncology, I thought, 'There has to be a better way of caring for dying people,'" relates Dr. John Finn, Chief Medical Director of Hospice of Michigan's Maggie Allesee Center for Quality of Life in Detroit. Finn's search led him to a career in hospice care. Over the past 13 years he has witnessed considerable progress in advancing the science and art of end-of-life care. Yet today, U.S. hospice programs are struggling to deliver state-of-the-art palliative care in the face of restrictive regulation, inadequate reimbursement, and precipitously short lengths of service. Additionally, the Medicare Hospice Benefit's regulatory requirement to give up life-extending treatment, known as the "terrible choice," has met with a cultural backlash against the hospice concept and its close association with death. Once again, Finn finds himself pondering: "There has to be a better way to care for dying patients."

The hospice model of care was developed primarily with cancer patients in mind, at a time when an admission requirement of six months or less to live better reflected the realities of medical treatment. Cancer treatment has advanced dramatically over the past 20 years. Today, clinical prognoses often are not black or white; indeed, it is ever more difficult to know when treatment has become futile. Many patients who need—and may qualify for—palliative care see hospice as giving up hope. This is especially true if they inhabit a gray zone of knowing that their cancer is considered incurable yet wanting to fight for a long-shot cure—or even just a few more months of life.

"To me, hospice is an elegant, high-quality, costeffective delivery model that should be provided throughout all of health care," says Hospice of Michigan's CEO, Dottie Deremo. "Our challenge is that hospice, too often, is perceived as 'selling death.' Nobody wants to admit they are dying. These services are needed much earlier in the course of a chronic illness, without getting caught in artificial barriers of curative treatment versus supportive care," she says.

"Could we provide what patients want and need, have it look and taste like hospice, and call it palliative care, transition services, or comfort care?" Deremo wonders. "If we relieve suffering at the same time that patients are receiving active cancer treatment, my firm belief is that it will be more cost-effective in total. Our palliative care study may be too small to prove that definitively, but it will give us some important indicators."

Adds the project's principal investigator, Dr. Kenneth Pienta of the University of Michigan Comprehensive Cancer Center, "We had a vision that we would bring hospice care into cancer patients' lives sooner, and that the extra support would improve their quality of life." The project has demonstrated that this can be achieved without generating net expense for the system.

## "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."

-MERI ARMOUR, MSN, VICE PRESIDENT, IRELAND CANCER CENTER

#### **POSITIVE PRELIMINARY RESULTS**

Michigan's Palliative Care Program is perhaps the first scientifically rigorous, randomly controlled Phase III clinical trial to examine the value of comprehensive palliative care. Analysis of data is still underway but preliminary results are starting to shed light on key issues in cancer care. The controlled trial enrolled 160 patients (81 control; 79 intervention). Accruals ended December 31, 2001, with a number of patients currently under treatment. Data from the first 55 patients who died, although too small to yield statistically definitive findings, provide an early glimpse at results in progress. Caregiver burden and patient quality-oflife measures are already showing positive results.

Another striking preliminary finding is that the "period of observation" from enrollment to death was actually longer for the intervention group (266 days) than for the control group (227 days). While that 39day difference also is not statistically significant because of the small number of subjects, the data are provocative in suggesting that the patients receiving palliative care through hospice actually lived longer than the control group.

Reflecting the challenges that have confronted other researchers who study the costs of end-of-life care, the Palliative Care Program struggled with numerous issues in trying to identify and allocate costs for the control and intervention groups within a fragmented health care system. Comprehensive cost analysis would need to include direct as well as indirect, societal, and out-of-pocket expenses, including lost workdays and stress-related health care costs incurred by family caregivers. Allocating the true costs of hospice care within the context of this study is another challenge, along with the cost of providing the overlay of the Palliative Care Coordinator.

With all of these caveats, the Palliative Care Program has begun to generate suggestive preliminary cost data. Early analysis of total Medicare-incurred costs (excluding prescription drugs) for the 55 decedents (30 control, 25 intervention) show total Medicare costs per patient for the intervention group of \$12,682 versus \$19,740 per patient for the control group, a net difference of \$7,058 per patient, adjusted for a mean enrollment duration of 250 days. The biggest difference between the two groups was for hospital care (intervention: \$8,974; control: \$13,126).

Final analysis, factoring in other components of total costs, has not yet been completed. Expenses on both sides of the ledger still need to be incorporated into the final cost comparison. The researchers suggest, based on current indications, that when complete, overall cost difference between intervention and control may be negligible. If so, the project will have achieved cost neutrality while improving quality of care and quality of life—*and possibly length of life*—for patients along with diminished burden for caregivers.

Project partner Hospice of Michigan lost money providing services to intervention patients under the project, in part because of their greater drug costs per person, compared with usual hospice patients. Facing potential deficits in two of the past four years, the agency struggled to fulfill its commitment to absorb uncovered costs of the project and to communicate to staff why it was important—despite the financial challenges—but held firm to its commitment.

While celebrating the research project's success, Hospice of Michigan will not be able to sustain the clinical program unless there is a change in reimbursement structures to accommodate the earlier provision of palliative care in this setting. Ironically, uncompensated expenses are necessitating the end of this experiment, even though the provision of hospice and palliative care may represent cost savings for Medicare by reducing hospital utilization.

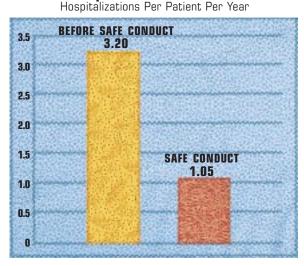
#### **PROVIDING SAFE CONDUCT**

Similar results are emerging from **PROJECT SAFE** 

**CONDUCT** (PSC) in Cleveland, Ohio, winner of the 2002 Circle of Life Award from the American Hospital Association. Project partners, Ireland Cancer Center and Hospice of the Western Reserve, successfully integrated a hospice team into oncology treatment provided by specialists at the cancer center for patients with advanced lung cancer. The project promoted an integrated, concurrent care model for these patients and their families, supplementing and enhancing traditional cancer care with all of the dimensions of hospice, focused on comfort and quality of life.

Rather than trying to build a bridge between the cancer center and hospice, the project merged the two

approaches by bringing hospice inside the cancer center's walls. A Safe Conduct Team comprised of a nurse practitioner, social worker, and spiritual counselor from Hospice of the Western Reserve was based at Ireland Cancer Center and carefully integrated into its normal operations. Research compared outcomes among patients receiving support from the Safe



**Hospital Admission Rates** 

Conduct Team with those of a similar group of lung cancer patients seen at the center in the year before the project began. Among the key results emerging from preliminary data:

- Unplanned Admissions/Emergency Room Visits: Counting the total number of unscheduled hospitalizations and/or emergency room visits per patient for the life of the project, there was a striking reduction from 6.3 per patient before PSC to 3.1 after the project was implemented.
- *Total Hospitalizations*: During the one year prior to implementing PSC, 274 lung cancer patients at Ireland incurred a total of 876 hospitalizations; by contrast, 233 patients seen by the Safe Conduct Team over a

two-to-three-year period had only 489 hospitalizations. This corresponds to at least a 67% reduction in the rate of hospital admissions, from 3.20 hospitalizations per patient per year before Safe Conduct to just 1.05 per patient per year thereafter.

- *Hospice Referrals*: The proportion of patients who were cared for by hospice rose from 13 percent pre-PSC to 80 percent under the Safe Conduct project. Median length of hospice care increased from just three days prior to Safe Conduct to 30 days, while mean length of service increased from 10 to 43 days.
- *Dying at Home*: Of 121 deaths recorded so far in PSC, 91 patients (75 percent) died at home

with the support of hospice or home care.

"Cost was never part of our specific aims. This was not a cost-benefit study," relates Ireland Cancer Center vice president Meri Armour, MSN. "Everyone says that, of course, it makes sense that palliative care could control costs." But in the current environment, it costs Ireland money to operate the program—even though palliative care potentially prevents emergency room visits and unplanned hospitalizations.

"I think we're making the case that hospice care should be extended across a greater time frame because the needs we're seeing here are very real. Patients and families are in great need of these services—there has to be a way to get their needs attended to," Armour says. "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. However, unless reimbursement changes, it could be a pretty hard sell to other academic hospitals."

## Special Attention to Children with Life-Threatening Illnesses

Tragic deficiencies in the treatment of dying children in this country have been well documented, most recently in the Institute of Medicine's July 2002 report, *When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*. Quite understandably, anxious parents resist acknowledging that their seriously ill child might succumb to disease. Young patients and their families face a host of difficult and complex medical and social challenges.

Too often, the health care system lacks the expertise and structures required to respond to the needs of seriously ill children, their siblings, and parents in a coordinated manner—or in a setting conducive to comfort, personal control, and quality of life. Because these children are often receiving curative treatment or experiencing an unpredictable trajectory, they do not meet requirements for either home health nursing or hospice care.

A palliative care project based at Seattle Children's Hospital has thought "outside the box," bringing together clinicians, payers, and hospice programs to implement a multi-faceted, collaborative, statewide initiative designed to improve continuity of service and quality of care for children with life-threatening illnesses and their families. The Pediatric Palliative Care Project (PPCP) succeeded in expanding access to home-based palliative care simultaneous with life-prolonging care while coordinating care across all settings, including the hospital. The project significantly improved the quality of medical decision-making as well as patients' and families' satisfaction. All of this was accomplished while achieving cost savings or, at least, budget neutrality for the collaborating partners.



Children's Hospital and Regional Medical Center, Seattle, Washington <u>The Pediatric Palliative Care Project</u> Principal Investigators: Ross Hays, MD, and Russell Geyer, MD Focus: Collaborative statewide project to promote family-centered pediatric palliative care, enhance insurance benefit administration, and create coordinated, home-based services for children with potentially life-limiting conditions and their families.

#### BUILDING FROM A BROAD Collaborative base

PPCP began by convening the key partners, Washington's Medicaid agency and Premera Blue Cross and Regence BlueShield, the state's two largest private insurers, along with 10 hospice and home care providers from around the state. Together, they agreed on new "co-case management" protocols for palliative care and an approach of flexible benefit management under which the health plans would remove barriers between existing insurance benefit categories, allowing services the children needed to be managed effectively in the appropriate environment.

The PPCP team at Children's identified potential clients and made initial home visits to assess patients and explain the program to them and their families. Eligible patients and families were then referred within the network of case managers at the hospice providers and insurance companies. From the beginning, the payers were full partners on the project team. Health plan pediatric case managers worked closely with their counterparts at the hospice agencies to develop and implement a patient- and family-centered plan of care to manage each child's care and needs. The hospice case manager made palliative care visits to the home, reimbursed by the health plan, to assess and monitor the child's care.

Many of the children served by the PPCP team were simultaneously receiving aggressive treatment for their potentially life-limiting conditions, while the home-based care coordination was provided by hospice nursing staff. Because the insurance companies allowed their case managers a more flexible approach of giving parents the care they wanted for their children without requiring a defined terminal prognosis, the project side-stepped much of the stigma that hospice holds for some parents.

#### FAMILY-CENTERED CARE PLANNING

Another key facet of the project was a *Decision-Making Tool* (DMT) developed by the Children's Hospital team based on a well-regarded construct of ethical decision-making. This deceptively simple tool

provides a guide for patients, families, and clinicians to work together during meetings in which critical medical decisions and pragmatic considerations are discussed. It allows patients and families to weigh the relevant factors and make decisions that are best for them and their particular situation.

The DMT proved to be a powerful aid for bringing together key parties to the child's care for a candid and respectful discussion of all aspects of the child's life and care needs, leading to a plan of care that they all could own and endorse. This process promoted autonomy for patients and families, and its success in this domain of quality was recognized and valued by the insurance companies.

"The DMT provided a framework for sorting out the most vexing problems," says Gerri Haynes, RN, the project's first co-director and a chief architect of the tool. "Families love it. They get information from the doctor, they get to correct inaccurate information on the DMT, and they get a printed copy to take home." However, Haynes emphasizes, proper use of the DMT requires time and experienced facilitation skills. These visits and clinical personnel time are not covered by insurance and must be subsidized by the hospital.

During the research phase of the project, 42 seriously ill children and their families were enrolled in the decision-making and co-case management process and its battery of research surveys. Follow-up surveys show clear improvements in patient/family satisfaction, health-related quality of life, functional wellbeing, and provider satisfaction with care.

Since completion of the *Promoting Excellence* grant, the partners have all advanced the work of pediatric palliative care, extending this more coordinated, personally satisfying way of meeting the quality-of-life needs of dying children and their families across all settings of care. Several of the participating hospices either added or expanded specialized pediatric services. Regence and Premera opted to continue their programs, based on high client satisfaction rates, improved quality of care, and at least budget neutrality. Children's Hospital is preserving its PPCP team in a new form as a palliative care consulting service. 11

## "THERE IS AT LEAST ANECDOTAL EVIDENCE TO PERSUADE THOSE OF US IN THE Administrative Ranks of this institution to open up the purse strings and continue to support this program."

PATRICK HAGAN, SEATTLE CHILDREN'S HOSPITAL AND REGIONAL MEDICAL CENTER

#### PAYER CHANGES IN THE WAKE OF PPCP

**REGENCE BLUESHIELD** formalized its "Palliative Care Option" for beneficiaries of all ages as an administrative benefit in July 2001. Regence is also giving strong consideration to including palliative care as part of its standard benefits packages. "The Palliative Care Option is based on the assumption that regular visits by a hospice case manager will reduce the need for emergency room visits and hospitalizations for preventable causes, thus increasing the patient's quality of life," says Dr. Mark Rattray, vice president of the company's Health Care Services Division. "Considering all recipients of palliative care in the aggregate, it is anticipated that the cost will be, if not an overall saving, at least cost-neutral."

Cost savings were never the motivation for the initiative, adds project administrator Patricia Emerick, MSW. "We're doing this because it's the right thing to do for our members at a difficult time in their lives, when coverage limitations are no longer serving a useful purpose," she explains. "I think it's looking at members' needs; it's helpful to members while being costeffective. It breaks down barriers to care, and it's good patient care."

BlueShield actuaries and epidemiologists took a look at claims data comparing the handful of children enrolled in the palliative care demonstration with similar patients receiving standard care. Essentially, cost differences were negligible, Emerick says, while family satisfaction surveys showed dramatic improvements for the palliative care group. Regence's administration is "very enthusiastic about the whole thing" and has submitted the project to a national Blue Cross/Blue Shield association "Best of Blue in Medical and Pharmacy Management" quality award competition.

**PREMERA BLUE CROSS**, the state's other major private insurer, is making co-case management and its flexible benefit administration system standard operating procedure for children identified by the PPCP team, says Premera medical director Dr. Peter West. Since the project began, Blue Cross has enhanced its "care facilitation" function, named for its focus on facilitating the best standard of care. For Premera, it is not a question of quality versus costs. "We assume that the best standard of medical practice is also less costly care—along with making for a pleased and a healthier consumer," West explains. "We would expect the return to be both economic and in higher quality of life."

Premera has not conducted a formal cost analysis of the children involved in the palliative care demonstration project. Based on the company's experience with case management services overall, "We were convinced that palliative care was the right thing to do. We don't have any reason to believe case management and care facilitation would be less effective for this population," West says. The company's internal estimates suggest a six-to-one return on investment—six dollars in reduced health care costs for every dollar spent on case management and related case finding. Blue Cross actuaries might quibble with that total, West adds, but they agree that it achieves at least a four-to-one return.

What makes the extrapolated cost savings even more attractive to the company is that palliative care "is well-received by our members. Case management is a very positive experience for everyone. It facilitates access to the right kind of services and gives the case manager the ability to adjust services as needed," West says. "In end-of-life care for children, the complexity of care is great. When you apply case management to these kids, it achieves more appropriate service settings, and you get better satisfied customers."

WASHINGTON DEPARTMENT OF SOCIAL AND HEALTH SERVICES' Medical Assistance Administration (MAA) is also continuing what it calls its "pre-hospice" service agreement with hospice agencies under authority of the Early and Periodic Screening, Diagnosis and Treatment services program (EPSDT), a federal Medicaid mandate designed to deliver accessible and comprehensive health care to children. Eligible patients are under age 21, covered under Medicaid fee-for-service, and reviewed by the PPCP team at Seattle Children's Hospital. "This program is for the sickest kids, not those with stable chronic illness," says MAA's Phyllis Coolen.

"When we go into a project like this, we try to look at all facets," Coolen says. "In Medicaid, our funding is limited and shrinking. Hospitalization continues to be our top expenditure, so any time we're looking at alternatives to hospitalization, we're interested especially if the case is complex and the client is going in and out of the hospital," she relates. Based on a recent analysis of six high-cost children participating in the program, DSHS concluded it saved an average of \$3,652 *per client per month*. Although the number of cases is small, palliative care offers great potential for cost-effectiveness for this difficult and complex population.

**CHILDREN'S HOSPITAL** preserved the nucleus of its PPCP team by absorbing the staff's salaries and incorporating the positions into a multi-disciplinary palliative care consulting service launched in October 2001 to continue coordination, assessment, and educational activities throughout the medical center. The new consulting service has already experienced greater demand than expected, with 60 referrals for consultations in the first six months—quadruple the projection.

According to executive vice president Patrick Hagan, Seattle Children's Hospital entered the palliative care project "predisposed to be supportive of it." The *Promoting Excellence* grant thus pushed the facility in a direction it was already inclined to go, becoming more family-centered and patient-focused. The project was an opportunity "to see if our predisposition was correct—that this approach would provide a better experience for patients and maybe a cost-effective one, as well." The potential for cost-effectiveness, Hagan says, comes from helping families transition away from treatments that are becoming ineffective, wasteful, painful, and unnecessary while maintaining intensive care focused on comfort and quality of life.

"The data so far have demonstrated much greater satisfaction with this approach. Can we go to the next step and say we have evidence of savings?" he asks. "There is at least anecdotal evidence to persuade those of us in the administrative ranks of this institution to open up the purse strings and continue to support this program." The hospital will continue to track satisfaction and cost data on the program, but the palliative care staff positions have been approved for a second year. The next challenge, Hagan adds, will be to spread PPCP's influence throughout the institution so that the palliative approach becomes more standardized.

"Palliative care is just good care," observes Children's Hospital palliative care social worker Bonnie Shultz. "All of us have talked about the barriers to hospice referral long enough. Now we need to stop talking about the barriers," she says. "Hospices do great work—we need to join with them so that they can do what we need them to do, and we need to find a way to support them and pay them to do it—breaking them out of the box and becoming their partners."



## Improving Comfort and Quality of Life within a Safety-Net Health System

In a public health system "safety net" setting in New Orleans, Louisiana, a demonstration project called PalCare set out to create a new model blending and integrating palliative care and aggressive treatment for people with advanced HIV disease. By bridging gaps in service, PalCare built trust among a distrustful, disenfranchised, stigmatized patient population, even prompting earlier hospice referrals. Over the past four years, the PalCare project has evolved to meet a variety of patient and system needs. With each step it has become ever more valuable to the HIV Outpatient Program (HOP) at Medical Center of Louisiana at New Orleans (MCLNO) and Louisiana State University (LSU) Health Sciences Center.

The *Promoting Excellence* grant is now completed. But HOP's administration has incorporated PalCare staff positions into the outpatient clinic's budget, preserving the program's value to the LSU system as a source of expertise on pain and symptom management, psychosocial/spiritual support, and existential or life-transition counseling for the most difficult cases seen at the clinic, says Dr. Lynn Besch, HIV Division Director at LSU and the administrator responsible for HOP's budget.

"We would fight for this program even if it never was 'cost-effective' in money terms because it is so effective in clinical terms," Besch says. "The reason we supported the continued existence of PalCare is that this program allows us—clinicians, social workers, nurses, in other words, the 'clinic'—to do a better job of taking care of our patients."

PalCare focuses on multiply diagnosed patients with advanced HIV disease who "aren't doing well" and may be refractory to anti-viral therapies. Such patients tend to fall through the system's cracks because they present a host of symptoms, secondary infections, psychiatric diagnoses, and social problems but often aren't ready to consider a hospice referral that might help to manage their care. "Truthfully, 'hospice' sometimes does tend to be a dirty word for both patients and health care providers," reflecting widespread misconceptions about the concept, says PalCare team physician, Dr. Jim Zachary. "We have improved referrals to hospice—but it's very difficult to do."

Louisiana State University Health Sciences Center, New Orleans, Louisiana <u>PalCare: A Palliative Care Program for People with</u>

## Advanced HIV/AIDS

Deidre Scherer, 2000 from the series Surrounded by Family and Friends, 36" x 30" fabric and thread

0

Other"

Each

Bigger Than

Principal Investigator: Harlee S. Kutzen, MN, ACRN Focus: A team approach based in an outpatient HIV clinic, offering comprehensive palliative care and support for patients living with advanced HIV disease and their families as well as support for other clinicians in dealing with the challenges of this high-risk, high-need, multiply diagnosed population. PalCare

a palliative care program for people with advanced HIV/AIDS



"YOU HAVE TO ASSUME THAT THIS PROGRAM Results in COST Savings from Decreased Stress for Staff, Better Care for Patients, Enhanced Continuity of Care, and Better Utilization of Home Care and Hospice."

DR. LYNN BESCH, HIV DIVISION, LSU HEALTH SCIENCES CENTER

#### MULTIPLE DIAGNOSES, COMPLEX NEEDS

For many patients with HIV disease, current treatment regimens include Highly Aggressive Anti-Retroviral Therapies (HAART) that have revolutionized treatment over the past five years. HAART can be extremely complicated and burdensome and cause significant side effects. Often patients need considerable support to remain on the therapies.

The patients served by PalCare may have intractable physical symptoms, dementias, intergenerational and family infection issues, multiple losses, and co-factors such as poverty, homelessness, mental illness, incarceration, and addiction. The public health system often is ill-equipped to handle such multiple needs. Since there is, as yet, no cure for HIV, it is possible to view *all* HIV treatments as essentially palliative in seeking to forestall opportunistic infections and their consequences while improving comfort and quality—as well as duration—of life.

#### HIV CARE IS NOT BLACK AND WHITE

PalCare helped organize and standardize HOP's approach to this gray zone between (or straddling) aggressive and comfort-oriented treatment approaches, "allowing us to do a better job of taking care of our patients," Besch explains. "The project provided a common language to start identifying these issues and a place to go" to discuss and learn more about a subject that other providers had tended to avoid. Thanks to PalCare's services and resources, clinical and support staff's stress has diminished and efficiency has increased. The project also helped to change the medical culture at HOP, fostering recognition of the importance of end-of-life care. "I don't think any of us had any idea how valuable PalCare would be," Besch says.

"Clinicians were spending enormous time and resources on these patients but it wasn't a coordinated approach," she adds. For example, primary care providers often struggled to treat patients' reported pain while dealing with their histories of addiction and the real potential for drug diversion. PalCare staff worked to establish trusting relationships with patients while simultaneously setting clear boundaries and negotiating contracts for compliance.

The project's demonstrated value to patients and providers has earned the system's financial support. The PalCare director's position is now being covered through the clinic's administrative services contract with MCLNO while the social worker's position has been picked up with the help of federal Ryan White Act Title I funds. Part-time physician, advanced practice nurse, mental health nurse, nutritionist, and epidemiologist positions, funded by in-kind allocations from HOP, are also continuing.

Originally planned as a modified case management model, PalCare quickly evolved in response to other needs within the local health system. It has emphasized proactive, comprehensive, interdisciplinary palliative care and support, patient advocacy and lifetransition counseling, and education and support for other health professionals in the HOP clinic and beyond. "Although we designed the project around end-of-life care, we really focus on life and life-planning issues," including patient-defined life goals that can encompass their eventual deaths, says PalCare director Harlee Kutzen, MN.

HOP struggles with the challenges common to most inner city, safety net systems—along with the fiscal and political vicissitudes of public health funding in Louisiana. PalCare's real value to this system lies in identifying and filling a wide variety of needs and creatively adapting services to plug the gaps. Examples of this penchant for solving system problems, creating new resources, supporting and extending primary care services, reducing stresses and burdens on the system, and thereby enhancing overall efficiency, include:

- Onsite availability of PalCare staff in each primary care clinic at HOP;
- A special palliative care clinic offering urgent appointments to PalCare's medically complex patients;
- Pain management and drug monitoring, including a process for streamlining the filling of pain prescriptions;
- Pain and symptom management consultations with other clinical staff, both formally and in casual conversations;
- Development of standardized procedures and approaches for treating symptoms;
- Development of an inpatient pain and symptom management consultation service for the HIV Inpatient Unit at MCLNO; and
- Education for inpatient and outpatient staff, role modeling of palliative care skills, and formal and informal clinical mentoring.

As the clinical program evolved and expanded, research aspects of PalCare lagged. Because of PalCare's popularity and clinical success, staff's time has been captured by increased requests for service, while data-gathering efforts had to be scaled back. Only a small proportion of the hundreds of patients served by PalCare was formally enrolled in the grant's research program, because of their marginalized circumstances. Many more benefited from its clinic visits, pain consultations, and case management.

#### POTENTIAL FOR COST EFFICIENCIES

Although data on health service utilization and overall costs have not been formally tracked, aspects of the PalCare project that may impact on system efficiency or resource use include:

- Improvements in outpatient HIV primary care, including improved symptom management, which decreases crises and unplanned, urgent, and emergency medical services;
- Management of difficult pain problems, freeing primary care practitioners to concentrate on other issues;
- Facilitated communication between patients, families, and primary care providers to better reflect patients' goals and enhance the effectiveness of treatment;
- The potential for earlier hospital discharges because of PalCare's inpatient pain and symptom management consultation and participation in discharge planning rounds at MCLNO; and

 Increased hospice referrals, made possible by non-threatening explanations and alliance building by PalCare staff.

The story is not straightforward. PalCare clinicians emphasize that it is often difficult to decrease hospital length of stay for this complex, needy population in this setting. In fact, when necessary for managing a patient's disease and urgent complications, PalCare staff may send the person to the emergency room or advocate for a hospital admission.

Actual savings in hospital days, emergency room visits, other unnecessary health care utilization, or overall costs will require further study. But the program's value has been noticed all the way to the top of the system's organizational charts. Dr. David Martin, chief of LSU's Infectious Disease Section, which oversees all infectious disease programs within the Health Sciences Center, notes, "From an administrative point of view, a program like this helps to create a team approach to a common and very serious disease that has significant end-of-life issues. If those issues aren't properly dealt with, it puts a lot of stress on the whole system."

Besch, who administers HOP, is unequivocal about PalCare's value. "It wouldn't matter how much it costs to keep this program here—we would do it. It wouldn't matter if it saved a dime or not." It helps, she adds, that the post-grant funding required to continue PalCare was not excessive. Even though some other clinic positions had to be cut when HOP's Ryan White funding was recently reduced by 25 percent, Besch found ways to include key PalCare positions in Ryan White allocations or administrative contracts.

"We were prepared to defend PalCare's budget, but it was just approved as part of the administrative contract," she says. Of course, as HIV division head, Besch answers to the health center's administration which "is extremely pleased" with PalCare and its success. PalCare focuses on those patients "who cost the system the most—both financially and in terms of wear and tear. You have to assume that this program results in cost savings from decreased stress for staff, better care for patients, enhanced continuity of care, and better utilization of home care and hospice."

Challenges continue. The impact of Louisiana's system of health care financing, with its potentially severe dislocations from year to year, has posed intermittent threats for the project. The HOP clinic currently has fairly stable funding and has been able to respond to the needs of even medically indigent patients, but it remains in a precarious position. All of that makes the system's vote of confidence in PalCare and its continued funding even more remarkable.

## Palliative Care's Contribution to a Globally Budgeted VA Health System

At the Veterans Affairs (VA) medical center in Los Angeles, California, global budgeting for medical services has helped to illuminate palliative care's potential to increase both the quality and the efficiency of health care delivery—even within a system struggling against financial uncertainty. The VA, which in recent years has pursued a national agenda of improving end-of-life care, often provides a clearer setting to demonstrate the benefits of palliative care than does fee-for-service health care. Each VA medical center is an integrated health system, with an overall or "global" budget under which it assumes financial risk and responsibility for the health care needs of enrolled veterans—and thus for the prevention of unwanted and costly treatments and hospitalizations at the end of life.

The **PATHWAYS OF CARING** demonstration project at the VA's Greater Los Angeles (GLA) Healthcare System has posted impressive results in improving quality of care while reducing hospitalizations and overall costs of care for veterans with advanced lung cancer, congestive heart failure, and chronic obstructive pulmonary disease while dramatically increasing the proportion of those patients enrolled in hospice and achieving high rates of completed advanced directives and documented goals of care.

Based on the program's demonstrated efficiency of health care utilization, the medical center's administration has opted to continue the project beyond the duration of its *Promoting Excellence* grant, supplemented by a new Inter-Professional Palliative Care Fellowship Program awarded to the program starting in academic year 2002–03. The planned institutional expansion of the Pathways program (renamed the Veterans Integrated Palliative Program or VIP) to poor-prognosis patients regardless of diagnosis has been delayed by organizational instability.

Such instability has included three changes in CEO in the past four years, hiring freezes and "reductions in force" actions, reorganizations, budgetary cuts, and the loss of key departmental physician champions of palliative care. While the delay underscores the fact that even successful palliative programs are at the mercy of organizational problems within their parent systems, GLA VA's leadership remains committed to continuing and, ultimately, expanding VIP.

Department of Veterans Affairs, Greater Los Angeles Healthcare System, Los Angeles, CA Palliative Care Management: A VA Demonstration Project Principal Investigator: Kenneth Rosenfeld, MD Focus: Case management, interdisciplinary symptom management, patient education, and empowerment for

poor-prognosis patients at a VA medical center.

#### VA GREATER LOS ANGELES HEALTHCARE SYSTEM



A Division of VA Desert Pacific Healthcare Network

#### INTRODUCING PALLIATIVE CARE AT THE EARLIEST OPPORTUNITY

Clinician-researchers at GLA knew that barriers to improving quality of life for patients with advanced. incurable illnesses included late identification of dying patients, inadequate management of symptoms, and discontinuities of care. The Pathways team aimed to address those barriers by implementing a generalized palliative care model with disease condition-specific elements. The program centered around a nurse case manager who educated enrolled patients and families regarding decision-making and symptom self-management, provided continuity and coordination of care, and served as the "hub" of an interdisciplinary palliative care support team that helped to manage patients' psycho-social and spiritual needs. Team members, in addition to the nurse, included a psychologist, chaplain, dietician, pharmacist, physician, and advanced care planning expert.

"A key component of the program design was our decision to introduce palliative care at the first possible opportunity after a poor prognosis is given— offering frank discussion of illness and advanced care planning farther upstream," says the project's principal investigator and medical consultant, Dr. Kenneth Rosenfeld. Key to achieving that goal was early identification of eligible patients through active case-finding in clinics, tumor board meetings, and other locations with information on newly diagnosed patients. This proactive approach proved far more effective than relying on primary care physicians for referrals.

In another setting, the program's assertiveness in recruiting patients and then encouraging them to con-

sider their own treatment goals and preferences might have been viewed as intrusive and an infringement on physicians' professional prerogatives, Rosenfeld notes. The Pathways project was able to pursue such an assertive approach, he adds, because the historical lack of continuity of care within the GLA VA system left a vacuum for palliative care to fill. A 1996 chart audit of patients diagnosed with incurable lung cancer confirmed the extent of discontinuity faced by GLA patients and providers. None of those patients ever had a return visit to their primary care physician following diagnosis, and a quarter of them were completely lost to follow-up.

"We recognized this as an opportunity, but also a mandate to try to bridge those gaps and reconnect doctors to patients, based on our understanding of this system and how it works." Still, Rosenfeld notes, there was ongoing tension with primary care providers and some resistance to the program's emphasis on facilitating open discussions about prognosis and goals of care. Enrolled patients and their families almost universally reported that these honest discussions were among the most beneficial services offered by Pathways.

Ultimately, Rosenfeld explains, the program tried to orchestrate the provision of two markedly different approaches to care: disease-modifying treatment for advanced, life-limiting conditions and palliative care focused on improving comfort and quality of life. Providing what at times seemed like contradictory approaches side-by-side proved to be a complex balancing act. For the Pathways team, it required carefully negotiating the nuances of concurrent life-prolonging and palliative care.

#### **Cost Per Patient in the Final Month of Life**

P		Pathways of Caring 54		Control Group 28	
Nursing home care unit costs, mean	\$	2,428	\$	1,424	
ICU costs, mean	\$	250	\$	4,871	
Outpatient costs, mean	\$	3,069	\$	1,923	
Total costs, mean	\$	10,248	\$	18,853	

Source: Department of Veterans Affairs, Greater Los Angeles Healthcare System \*Does not include long-term care facility costs listed separately.

## "AREAS OF TENSION BETWEEN THE PALLIATIVE Model and Standard Care Need to be Discussed Openly and Productively. You Can't Pretend That They Don't Exist."

#### - DR. KENNETH ROSENFELD

"Areas of tension between the palliative model and standard care need to be discussed openly and productively. You can't pretend that they don't exist," he relates. "But it was important to us that patients had an understanding of their prognosis. We are not willing to sacrifice fundamental principles of palliative care just to make the program more acceptable to physicians—for example, allowing patients to receive chemotherapy thinking it would cure them, when it won't."

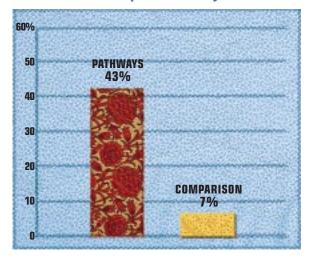
In addition to early case identification, care coordination, communication, and holistic symptom management, other key components of the Pathways program include:

• Patient education, particularly regarding prognosis, condition, what to expect from disease progression, symptom management, and how to prevent exacerbations;

- An emphasis on goal setting to shape end-oflife care;
- A biweekly outpatient palliative care clinic that offered multidisciplinary team assessment and care planning;
- Intensive telephonic case management by an advanced practice nurse;
- Coordination of home-based services; and
- 24-hour availability of the team's medical consultant.

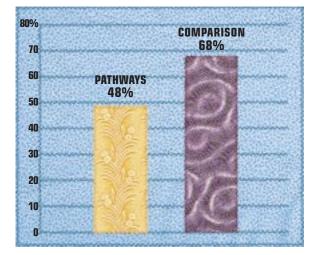
#### **POSITIVE OUTCOMES FROM PATHWAYS**

Preliminary data on 54 participants who died while enrolled in the Pathways of Caring program, compared with a retrospectively matched control group of patients who did not receive the palliative intervention, show dramatic differences. Forty-three percent of Pathways patients were able to die at home, compared to just 7



#### **Patients Who Spent Last Days at Home**

#### **Patients Who Died in Hospital**



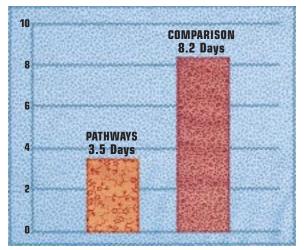
percent of matched control patients. Forty-five percent of Pathways patients died in a hospital or long-term care facility, compared to 68 percent of controls.

The Pathways program averaged 3.5 hospital days per patient during the final month of life, compared with 8.2 days for the control group. More striking still, the group of patients who died while served by Pathways spent an average of just 0.4 days in an intensive care unit during the last month of life, compared with 4.5 days for those in the group not served. Intervention patients also spent far less time on mechanical ventilators, 0.1 days per patient in the final month versus 3.5 days in the control group.

Expressed in financial terms, the program's ability to better manage its patients with life-threatening illnesses in more appropriate and cost-effective settings breaks down as presented in the chart below, with overall savings of 45 percent on the cost of care in the final month of life. Rosenfeld and colleagues are now seeking additional grant funding to expand the project as a randomized controlled trial with more extensive and rigorous data-gathering capacity.

Patient resistance to lengthy and cumbersome quality-of-life assessment tools has limited the project's ability to gather clinical efficacy data. However, available evidence indicates improvements in the proportion of cases with documented goals of care (69 percent) and completed advance directives (72 per-

#### Number of Days Spent in Hospital During Last Month of Life



cent). Medical records also revealed that 55 percent of Pathways patients indicated that they favored some limitations in life-sustaining treatments.

## EASING THE TRANSITION TO HOSPICE

"The transition to hospice care can be a tough issue," Rosenfeld notes. The Pathways of Caring project addressed this challenge first by establishing a collaborating relationship with Trinity Home Health and Hospice, a Medicare-certified community hospice program based in nearby Torrance. The hospice assigned a liaison nurse to attend Pathways team meetings and work closely with the project's case managers and agreed to a more flexible approach to care planning. The VA system permitted hospiceenrolled patients to continue receiving chemotherapy and other disease-modifying treatments, if that is what they wanted, without having to confront the "terrible choice." Patients enjoyed greater flexibility of care goals and more innovative side-by-side care planning than is customary in hospice care.

The flexibility and coordination between the VA and Trinity Home Health and Hospice proved effective. Fully 50 percent of Pathways patients who died were enrolled in hospice care before their deaths, compared with only 4 percent for the control group, with a median length of stay in hospice care of 29 days. That figure is higher than current national averages and, Rosenfeld believes, may be "about right" for this patient population.

Overall, the Pathways project identified "incredible unmet needs" within the GLA VA health system. "What we found in doing this project confirmed our understanding of what was missing from the status quo." At times the Pathways program was oversubscribed and had to turn patients away. Although the project's evaluative data may be hard to generalize to other settings, he notes, "We showed that within this care system and its structure, using this particular way of doing business, we could be successful."

## Aligning Palliative Care with Capitation

A project of Sutter Visiting Nurse Association and Hospice of Emeryville, California, focuses on patients in capitated Medicare risk plans. Comprehensive Home-based Options for Informed Consent about End-stage Services, or CHOICES, for short, is designed to care for chronically ill, medically unstable, high-risk elders in their own homes. By reducing the incidence of medical crises, emergency room visits, and hospitalizations, CHOICES has successfully demonstrated its value and cost-effectiveness.

The patients targeted by CHOICES are at high risk of falling through the cracks of existing regulations and service delivery programs. They don't meet the Medicare Hospice Benefit's definition of "terminally ill" because they lack a clear prognosis of six months or less to live. And they are understandably unwilling to forgo life-extending treatment in order to enroll in hospice care. Yet such patients may also be excluded from home health coverage because they are only intermittently homebound or because they lack defined skilled nursing needs. CHOICES' eligibility criteria were more clinically meaningful and realistic for such chronically ill elderly patients. A diagnosis of an incurable illness and the treating medical professionals' statement that they "would not be surprised" if the patient were to die within two years sufficed for patients to receive an array of palliative and supportive services from the CHOICES team.

What CHOICES patients need, says co-principal investigator Dr. Brad Stuart, is care coordination, health education, support for advanced care planning, and careful management of their medications and symptoms. If they don't get such support, many of them run into avoidable exacerbations and crises that can land them in an emergency room or an unplanned hospitalization. "This is a project about preventing bad, and costly, outcomes for seriously ill elders, especially hospitalizations. Such crises are common for people this sick, especially under routine and customary—which is to say fragmented—health care," Stuart says.

The CHOICES team includes a geriatric nurse practitioner, home care nurse, social worker, and physician (Stuart). The team offers "transition management," working with patients living at home, managing their care, and building trusting relationships. Over time it becomes possible to clarify patients' care preferences and start a meaningful dialogue about what lies ahead. But it is not always easy, Stuart says, noting that such clarity often has been more difficult and time-consuming to achieve than anticipated.

The name CHOICES was apt. Patients found its concurrent care valuable by helping them to explore a full range of care options and preferences, often impossible during time-pressured physician's office visits under managed care. Health plans found that patient and family appreciation for CHOICES' coordination added value to benefits. Clinicians working in the medical groups appreciated the program's ability to prevent unnecessary utilization while improving the quality of symptom management, coordination, and care planning.

However, the unstable financial terrain of the region's health care economy, along with shifts in key corporate leadership, mergers, and dissolutions among project partners, made it difficult to document CHOICES' positive fiscal impact—or even to capture the attention of corporate financial officers at the partnering agencies.



Sutter Visiting Nurse Association and Hospice, Emeryville, California CHOICES: (Comprehensive Home-based Options for Informed Consent about End-stage Services)

Principal Investigators: Brad Stuart, MD, and Carol D'Onofrio, DrPH Focus: A program of care coordination, patient/family education, advanced care planning, and home-based medical, psychosocial, and end-of-life care for high-risk, medically unstable patients enrolled in Medicare risk plans who otherwise might fall between the cracks of home health or hospice care.

#### INCENTIVES UNDER CAPITATION

Sutter VNA and Hospice is a large, established home health and hospice provider in San Francisco's East Bay within the regional, multi-site, nonprofit Sutter Health system. Under the CHOICES project, Sutter VNA collaborated with North American Medical Management (NAMM), a nationwide physician management group that has many doctor members in the East Bay caring for seniors enrolled on managed health plans.

The cornerstone of capitated managed care is set in holding providers financially responsible for specified health services needed by a defined group of beneficiaries. Avoiding over-utilization is essential for provider organizations to thrive—or even survive—on the permember-per-month capitated rate that managed care companies pay. For a senior population with multiple chronic health conditions, that means supporting patients to make treatment choices reflecting their values and preferences while preventing or responding quickly to medical crises.

"CHOICES was based in a Medicare+Choice HMO setting. That was a fruitful place to innovate, particularly in end-of-life care, because capitated payment means that financing incentives are aligned with better care management to keep people out of the hospital," Stuart reports. "Unfortunately, the future of Medicare+Choice itself is uncertain. The health care market has definitely changed." Most of the managed care organizations offering Medicare risk plans in the Bay Area have since dropped Medicare+Choice. NAMM's enrollment of such patients for medical services under capitation shrank—choking CHOICES in the process.

"The challenge for creative palliative care projects is to shake loose enough savings from preventing hospitalizations and then persuade whomever is paying for those hospitalizations to pay for the preventive coordination, instead," Stuart says. "The program could pay for itself by saving even a few hospitalizations." However, amid mergers, changes of leadership, and incompatible information systems, cost accounting has proven difficult. The project's experience underscores the need to collect actual health utilization data, rather than just claims data.

CHOICES' creators have consolidated their experience in a proposed new endeavor called AIM (Advanced Illness Management) to offer a similar package of staffing and services within a different health care context—home health care under its recently implemented prospective payment system (PPS). "In CHOICES, we provided what the patients needed. We could do that and ignore some of the 'silos' or artificial, bureaucratic separations between different categories of service and coverage," because of capitated financing, Stuart says. "CHOICES made it easy to operate outside of the silos, but in AIM we'll be consciously operating within the silo of home health care." AIM is being designed to provide palliative care coordination in the home at a time when recent changes in home health regulations have thrown the entire industry into turmoil. Stuart is exploring a Medicare waiver or demonstration status to ease some of the home health regulations that don't exactly fit AIM, including language related to skilled nursing needs, evaluation, and homebound status. He hopes to launch the project by the end of 2002, with or without a waiver.

#### **LESSONS LEARNED**

*Palliating Upstream:* The CHOICES program tried to move palliative and end-of-life care upstream, offering it concurrently with active treatment—and succeeded. It was able to serve a broader population than typically enrolled in hospice, including more cardiac patients and others with uncertain prognoses. CHOICES served patients for a median of 260 days, much longer than the local median hospice length of service of 21 days. Therefore, even those CHOICES patients who ended up in hospice with short lengths of stay already had the advantage of earlier palliative care. Pain was being addressed and advanced care plans were in place. Crises and related hospitalizations were uncommon.

*Dying at Home:* Fifty-nine percent of all patients enrolled in CHOICES who died were at home. Compare that figure with national home death rates of only 22 percent—26 percent for the Northern California region—to see the program's ability to prevent the crises that lead to terminal hospitalizations. In a capitated health care environment, the rate of deaths at home likely represents substantial cost savings.

The CHOICES approach could be expanded through better coordination with hospitals and especially with emergency room staff, Stuart notes. An integrated health care system potentially could view programs like CHOICES and AIM as a worthwhile investment because home-based transition management and palliative care prevent unnecessary hospitalizations. For example, on average, elderly patients who die at one of the nearest hospitals in the Sutter system do so after 16 days in the hospital—and their Medicare DRG payments on average cover only about a third of the hospital's costs.

Identifying appropriate patients—while not bringing on too many too soon—is key to the success of this approach. The cost of managing and monitoring chronically ill but stable patients, such as those who suffer from dementias or debilities for years, could become prohibitively expensive. Stuart stresses that the financial viability of programs like CHOICES and AIM depends on identifying and enrolling the highestrisk patients with complex needs. "Transition management is for people who are really sick," he explains.



## State of the Art in Palliative Care Management

A collaborative demonstration project focused on highly advanced care management brought together the Hertzberg Palliative Care Institute at Mount Sinai School of Medicine in New York City, for its expertise and training skills in palliative pain and symptom management; Franklin Health, Inc. (FHI) of Saddle River, New Jersey, for its industry-standard complex care management program; and Blue Cross/Blue Shield of South Carolina, which supplied patients with complex illnesses who could benefit from palliative care and care management.

FHI, one of the country's leading disease management firms, has established the gold standard for the effective coordination and management of difficult, costly, high-utilization cases. Managed care organizations across the country contract with FHI to identify such patients from utilization data, provide on-site care coordination, and work with health plan officials and primary care physicians to optimize coordination of care and prevent medical complications that lead to costly hospitalizations.

Mount Sinai School of Medicine, New York, New York, and Franklin Health, Inc., Upper Saddle River, New Jersey Improving End-of-Life Care: Integrating Community Case Management and Palliative Care Principal Investigators: Diane E. Meier, MD, and William Thar, MD, MPH Focus: A partnership between an academic medical center and a private disease management firm to integrate patient-centered palliative care for community-dwelling adults with serious and life-threatening illnesses into an existing care management system through development of palliative care training and treatment protocols.



MOUNT SINAI SCHOOL OF MEDICINE

## "MOST HOSPITALIZATIONS OCCUR IN A CRISIS, When the whole care system falls apart and the patient ends up in the emergency room—the place of last resort and a highly inefficient setting to manage this patient population."

DR. DIANE E. MEIER, MOUNT SINAI SCHOOL OF MEDICINE

FHI, which bases its highly trained and closely supervised nurse care managers in the communities where the health plan's members live, does not assume fiduciary responsibility for patient care or for coverage decisions. The care managers do not make treatment decisions for either the patient or the doctor. Instead, they provide information and recommendations, based on their established relationship with the patient, home-based assessment of the patient's needs, and ongoing monitoring of the patient's condition. They are viewed as patient advocates, rather than as functionaries of the insurance company trying to save money. Yet this coordinating, educating, and empowering service typically generates a return on investment averaging three or four to one for the insurer.

The Promoting Excellence grant project's enhancement of this successful care management product involved a series of treatment protocols on pain and symptom management, advanced care planning, and physician communication, accessible to the care managers via computer. It was supported by training in palliative care, symptom management, use of the protocols, and communication skills for the care managers, taught by experts from Mount Sinai. Using these tools, the care managers were better able to identify patients' needs for symptom management, end-of-life care, and support, and then recommend action plans to their physicians."The palliative care protocols are more specific than before," says FHI's director of research, Dr. William Thar. "Instead of saying to the doctor: 'Can you do something about your patient's pain?' the care manager is able to say: 'Here's what the treatment guidelines would recommend to treat this patient's pain." Thus, the palliative care protocols represent a refinement or a strengthening of a powerful and successful care management product. and a natural step in the ongoing improvement of an

approach that FHI has effectively employed for a decade, he explains. It gives the nurses new tools and builds on an already existing and well-functioning system.

The company recently decided to roll out the palliative care protocols nationwide and to train all of its care managers from coast to coast in their use. "I think it's very positive that a complex care management company of the quality and reputation of Franklin has adopted this program," attesting to its success, notes Dr. Diane Meier of Mount Sinai School of Medicine, project co-principal investigator. The company's preliminary data also shed light on other measurable results from the palliative care initiative, including:

- Significant reduction in perceived burden of symptoms by seriously ill patients and improved symptom management scores eight weeks following admission in a number of key areas;
- Increase in the number of advanced directives completed and used in clinical decision making;
- Very high acceptance and patient satisfaction rates, as well as high acceptability rates from clinicians;
- Increase in the number of identified domains of care that the nurse care manager identified as problems to be addressed; and
- Increase in the number of new prescriptions ordered to treat specific symptoms (from 28 percent per patient in the control group to 64 percent in the palliative care intervention group).

"Patients in the intervention group received more prescription drugs aimed at symptomatic distress, including pain medications, which means the care manager has successfully contacted busy primary care doctors in their offices and, when indicated, gotten them to prescribe controlled substances," Meier explains. "That's incredible. The doctor still has to sign the order for the prescription, but I thought that would prove to be one of the biggest barriers to the project."

The power of the palliative care intervention, she says, lies in empowering the nurse case managers not only to assess patients' needs, but also to actually do something about what they find. "They were given the clear expectation that when a symptom was identified, they had to do something about it. Nurses do not want to be in the position of assessing things for which they are helpless to intervene—so they don't do it," Meier says. The palliative care protocols included very specific recommendations to share with the doctor, which was an important ingredient in the project's success. FHI case managers trained in the protocols also report increased sense of empowerment and professional competence.

#### **RETURN ON INVESTMENT**

FHI has worked long and hard on the challenge of identifying patients who really need this kind of intensive care coordination while being careful not to enroll too many patients whose care needs and complexities are not as severe. The company tracks overall cost savings generated by its complex care management program—as well as the extremely high rates of acceptance, patient satisfaction, likelihood to recommend the program to others, and positive contributions to quality of life. All are at an 80 percent level or above.

Although the palliative care protocols have clearly enhanced the company's product, the company's leaders emphasize that FHI was already in the palliative care business. "I would say that our complex care management program is an intensive example of palliative care," says FHI's medical director, Dr. Jeff Gruen. "Look at what our nurses do. The majority of their time has to do with supporting patients, not about a specific treatment but about assessing their social support system, improving their knowledge, making sure they have a safe environment and can identify their providers and coordinators of services. We also advocate for patients when they need flexibility in extra-contractual benefits and we usually have a formal mechanism for submitting such recommendations," Gruen asserts.

In recent data from a partnering insurance plan, FHI calculated a return on investment of 3.2 (\$2.7

million in savings on \$0.8 million in care management costs—or \$22,000 per managed case) for the second year after implementing complex care management. The company posted an even higher return on investment of 4.3—equating to \$5.4 million in savings on \$1.3 million in costs or \$33,000 per managed case—in the third year of implementation. These positive impacts on costs principally result from reductions in average numbers of hospital inpatient days, admissions, and readmissions per claimant.

This is where the potential for cost savings resides, Meier notes. "Most hospitalizations occur in a crisis, when the whole care system falls apart and the patient ends up in the emergency room—the place of last resort and a highly inefficient setting to manage this patient population. The hospital avoidance occurs not because somebody says, 'You can't go because we won't pay for it,' but because the need is averted which is also good for the patient." When patients feel safe at home because they know they have a care coordinator who knows them and can help them at a moment's notice, they are much less likely to take their problems to the emergency room. "It's the ones who don't feel safe at home, who feel abandoned, who end up in the hospital," she notes.

For FHI's complex care management in South Carolina, bolstered by the palliative care protocols, "it probably does save money, although our actuaries sometimes roll their eyes when they hear claims of cost avoidance," says Dr. Ashby Jordan, medical director of Blue Cross/Blue Shield of South Carolina. "We view it primarily as an empowering process, and our experience is that patients really do like it. I'm convinced that patients go to the emergency room less often, based on the activities I hear the nurses doing. Our senior management is pleased enough that the program would be worth doing even if it only broke even," he relates.

"We are a mutual company—not a for-profit—but we are exquisitely market driven," Jordan says. "This product is not a hard sell in this market." He adds that the medical system typically does not do a very good job of educating patients with complex care needs about their medical condition and treatment options. "A relatively simple, straightforward intervention can make a huge difference in giving people what they want in their final days. And people do make difficult decisions once they have the information."

## Looking Forward

Demonstration projects funded by*Promoting Excellence in End-of-Life Care* strived to expand access to palliative services and improve comfort and quality of life for people with the highest burden of chronic, incurable diseases. Collectively, they focused on those in hard-to-serve and previously underserved populations whether or not they were pursuing curative or diseasemodifying treatment. As the projects described here illustrate, they succeeded in those primary objectives. They proved to be feasible and heartily accepted by clinicians, health system managers, payers, and, most importantly, patients and families.

At the same time that patient and family satisfaction with care received and provider satisfaction with care delivered both increased, there was yet another important and hopeful trend. Improved access to services and quality of care seem to be well-aligned with system efficiency and cost containment. Particularly striking is the impact on decreased hospitalizations during the last year of life, resulting from enhanced coordination, advanced care planning, and crisis prevention—along with increased hospice referrals and enhanced opportunities to be cared for and to die at home.

While these programs have achieved impressive outcomes in a wide variety of settings, sustaining them has proven difficult in the current health care environment. That is especially true for programs operating in a fee-for-service setting where incentives tend to encourage utilization over continuity and efficiency. Those in safety net settings or other contexts with global budgeting more readily recognize that incentives for improving access and quality are in line with preventing hospitalizations and better managing limited resources. Programs in systems such as the VA medical center described on page 18 had an easier time making the case to their parent organizations that palliative care returns dividends to the system far beyond the required investment because they can more clearly see the results in reduced hospital expenditures.

These results hold important lessons and potential implications for health policymakers. Foremost is the need for large demonstration projects of concurrent palliative and life-prolonging care that incorporate coordinated services to improve comfort and quality of life for patients with advanced illnesses and their families. Further research is needed to examine potentials for improved system operations, decreased service utilization, prevention of caregivers' burden and secondary health costs, and, most tantalizingly, positive impact on survival.

Preliminary results from the projects profiled in this report suggest that the savings, particularly in unplanned hospitalizations, will exceed the invested costs of care coordination, symptom control, crisis management, and other elements of palliative care. That is what now needs to be tested. Leading clinicianresearchers among the *Promoting Excellence* projects agree on the need for larger-scale research. They call for population-based or multi-site studies of patients with multiple life-limiting diagnoses, accompanied by rigorous evaluation of quality and costs.

This is only the beginning—but it is a solid beginning. While the findings are preliminary, they are positive and hopeful. Well-designed, large-scale studies may enable our national health care system to remove the artificial distinctions between living with serious illness and dying and, in the process, to remove unnecessary impediments to improving comfort, ensuring family support, and enhancing the quality of life's end for all Americans.

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Visit the comprehensive website 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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