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Promoting Excellence in End-of-Life Care: A Report on Innovative Models of Palliative Care

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ABSTRACT

Background: **Promoting Excellence in End-of Life Care, a national program of The Robert Wood Johnson Foundation, funded 22 demonstration projects representing a wide range of health care settings and patient populations to develop innovative models for delivering palliative care that addressed documented deficiencies in the care of patients and families facing the final stage of life.**

Objective: **To determine the practicality (feasibility of development and operation as well as acceptance by stakeholders) of new models of care and to determine the impact of the models on access to, quality of and financing for palliative care.**

Design: **The program cannot report scientifically rigorous outcomes, but the grant-funded projects used a variety of methods and measures to assess acceptance of new models and their impact from the perspectives of various stakeholders, including patients and their families, clinicians, administrators and payers. While it is not possible to aggregate data across projects, the data reported to the Promoting Excellence national program office were used to describe program impact with respect to the practicality of palliative care service integration into existing clinical care settings (feasibility and acceptance by stakeholders), the availability and use of palliative care services (access), quality of care (conformance to patient expectations and accepted clinical standards) and costs of care.**

Settings and subjects: **The 22 projects provided services in urban as well as rural settings, in integrated health systems, hospitals, outpatient clinics, cancer centers, nursing homes, renal dialysis clinics, inner city public health and safety net systems and prisons. Populations served included prison inmates, military veterans, renal dialysis patients, Native Americans, Native Alaskans, and African American patients, inner-city medically underserved patients, pediatric patients, and persons with serious mental illness patients.**

Results: **Hosting or adopting institutions sustained or expanded twenty of the 22 models, and feedback from all stakeholders was positive. Project sites developed and utilized new palliative care services and addressed quality through implementation of new standards and clinical protocols. Costs of care, where they could be assessed, were unaffected or decreased for project patients versus historical or concurrent controls.**

Conclusions: **The 22 Promoting Excellence in End-of Life Care projects demonstrated that by individualizing patient and family assessment, effectively employing existing resources**

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and aligning services with specific patient and family needs, it is possible to expand access to palliative services and improve quality of care in ways that are financially feasible and acceptable to patients, families, clinicians, administrators, and payers.

INTRODUCTION

The Robert Wood Johnson Foundation created the national program, Promoting Excellence in End-of Life Care, in 1997 to address demonstrated deficiencies in the way the health care system cares for patients in the final stages of their lives and to foster institutional change to improve palliative care for these patients and their families. From 1998 to 2004 the program provided approximately $9.2 million in grant funding and substantive technical assistance to a portfolio of 22 demonstration projects[a] developing innovative models for delivering palliative care (see Appendix A for project names and short descriptions). National program office staff, along with Foundation staff and a National Advisory Committee, selected projects representing a wide range of health care settings, patient populations and geographic areas to develop and test prototypical health service models. The selection group chose projects with potential national implications for improving the quality of end-of-life care by expanding availability of and access to palliative care for people with progressive, life-threatening conditions.[1]

Promoting Excellence projects directly served patients in urban, suburban, rural, and frontier locations, in a variety of health care settings (for example: integrated health systems; hospitals; outpatient clinics; cancer centers; nursing homes; renal dialysis clinics; inner city public health and safety net systems; and prisons). Targeted populations were unlikely to receive any specialized palliative care services or expertise through existing programs and within existing patterns of practice and health service delivery. Among the diverse populations of seriously ill individuals served by Promoting Excellence grant projects are children treated at tertiary care pediatric hospitals, persons with serious mental illness, frontier Native Alaskans, rural Native Americans, American military veterans and renal dialysis patients. Most of the projects introduced palliative care "upstream" in care delivery, providing palliative care concurrently with life-prolonging care.[2] While each project and delivery model was unique, they shared certain key features: comprehensive assessment encompassing physical, psychosocial and spiritual domains; interdisciplinary care; regular communication between and among providers, patients and families; coordinated care management; documented advance care planning; crisis prevention; ongoing monitoring and 24-hour access to a clinician who knew the patient; and patient and family education.[1]

Each project conducted its own evaluation using different measures and the specific methods and depth of evaluation varied widely. Details of individual project interventions and evaluation methods are available within published project descriptions (see Appendix A) and at ⟨www.promotingexcellence.org⟩.

It is not possible to aggregate data across projects or to report scientifically rigorous outcomes of the program as a whole because of the variation in measures and methods. However, data from many individual projects are instructive and illustrate trends observed by the clinician-researchers and by Promoting Excellence program staff through multi-faceted programmatic oversight. In this paper, we describe program impact with respect to the practicality of palliative care service integration into existing clinical care settings (feasibility and acceptance by stakeholders), the availability and use of palliative care services (access), quality of care (conformance to patient expectations and accepted clinical standards) and costs of care.

PROJECT EVALUATION MEASURES AND METHODOLOGY

Because the projects were intended to build new health service delivery models, programmatic evaluation focused on practicality—whether it was fea-

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[a] The program office received 678 letters of intent in response to a broadly disseminated Call for Proposals, invited 60 to submit full proposals and awarded 22 grants.

sible in the context of resource constraints and competing priorities to create and run the new services, and whether the models were acceptable to clinicians, administrators, payers and patients and their families. Several projects also assessed use of services, as an indicator of increased availability of and access to palliative care, by tracking patient enrollment, length of service in the grant-supported program, days at home, and hospice length of service compared to concurrent controls or historical data. Public data sets provided additional comparative information. Projects that utilized education of professionals to increase capacity to deliver quality palliative care via professional education tracked the number of professionals trained, and educational outcomes were assessed via surveys of participants' knowledge and attitudes. Quality outcomes were measured using published instruments selected for relevance to specific care settings and patient populations. The instruments measured domains of symptom management, quality of life and perception or experience of care. Where relevant tools did not exist, investigators developed applicable measures. (For examples see Cohen et al.[3] and Foti[4] and view tools used by grantees at ⟨www.promotingexcellence.org⟩.)[3,17]

Financial outcomes were directly assessed in several projects, while in others units of health service, such as visits, hospitalizations and hospice days measured resource use as a proxy for costs. Overall impacts on costs to the participating health systems were also assessed through key informant interviews with leaders who held direct fiscal responsibility.

PROMISING RESULTS

Practicality: feasibility and acceptability

The practicality of these integrated health service delivery models is suggested by the fact that without exception projects designed to be continued (20 of 22) were sustained in some form by their home institutions beyond the conclusion of Promoting Excellence grant support[b] (Appendix A). Their continuance implies that the models were feasible to develop and manage and acceptable to clinicians, administrators and payers. Examples of positive responses to the models included: clinical providers who reported that the education and experience provided through the projects helped them to feel more confident and comfortable in caring for patients at the end of life[4–6]; clinicians who reported an improvement in their understanding of and comfort with hospice services and staff[7–9]; and both payers and administrators who demonstrated their acceptance and support by funding new service lines and in some cases by encouraging their expansion (see Appendix A). Several innovations were expanded within host health systems because of the success of the local Promoting Excellence demonstration project, and others were replicated at institutions not affiliated with the original grantee (Helping Hands, Balm of Gilead, and Project Safe Conduct).

Patients and families also appeared to find the new service models acceptable. Across all projects reporting enrollment data, only 4.6% of patients dropped out prior to death or completion of the project. Examples of patient and family responses include the following from projects that collected satisfaction data: patients responded positively to opportunities to discuss their concerns about serious illness[10]; families reported relief from fear and worry and feeling more prepared to deal with the patient's death (Helping Hands, Palliative Care Program, and Pediatric Palliative Care Project); and family members of Native Alaskans enrolled in the Helping Hands project reported that they wanted to have the same positive experience at the end of life as their loved ones, and that they would enroll in the care program "when their own time came."[5]

Access: availability and use of services

Access to health care typically refers to mechanisms that facilitate the process of obtaining care. Where core services do not exist, as is often the case for palliative care, increasing access requires development of new elements of the care system, increase in clinical capacity to deliver care and education of patients (and families) concerning the availability and benefits of the new services. Development and introduction of team-based palliative care "upstream" in the care continuum, concurrent with curative care, was the most common strategy of the Promoting Excellence projects for increasing access to special-

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[b] Two funded projects were exceptions and not designed to continue—one was a time-limited, randomized trial and one was a comprehensive community assessment.

Table 1. Lengths of Stay in Select *Promoting Excellence* Project Models of Care[a]

Settings	*Projects*	*Average length of stay*
Cancer centers	Project Safe Conduct	185 days
	Palliative Care Program	266 days
Prisons	GRACE Project	121 days
Rural	Helping Hands	> 365 days
Pediatric	Pediatric Palliative Care Project	71% > 180 days
Hospital/home-based	Pathways of Caring	> 120 days

[a] As reported to the Promoting Excellence in End-of-Life Care national program office.

ized palliative and end-of-life care.[7,11–16] Patients in most of the projects could receive team-based palliative care from the time of diagnosis or recognition of the advanced nature of their condition, whether or not they chose to continue disease-modifying treatment, including experimental treatments, such as phase 1 or 2 cancer clinical trials. As shown in Table 1, several Promoting Excellence projects delivered more days of palliative care per patient than the 50.6-day average reported for hospices nationally.[17]

Promoting Excellence projects reached broadly diverse populations—defined by a variety of diagnoses, ages, socioeconomic status, and location—including many people who would not have been served by existing local hospice programs or because of the constraints of prevailing Medicare or insurance hospice eligibility criteria.[17] For example, investigators at Seattle Children's Hospital, a pediatric tertiary care center, employed partnerships with local hospices and with local public health systems and collaborated to develop novel uses of existing insurance benefits to serve seriously ill children and their families, including those in rural communities. Promoting Excellence projects also served populations that would have had limited or no prior access to palliative care: prison inmates[18]; renal dialysis patients[19]; Native Americans and Native Alaskans[5,20]; African American patients in various settings; inner city medically underserved patients[14,15]; and persons with serious mental illness.[4] In addition, cancer patients on phase 1 or 2 clinical trials[7,14] who would have had difficulty accessing hospice care received palliative care from Promoting Excellence projects based in cancer centers.

All grantees (except the community assessment project, Palliative Care Services for Urban African Americans) also developed routine procedures to assure and facilitate advance care planning conversations before crises or unplanned hospitalization. Table 2 provides examples of increased access to advance care planning in several projects. Three projects[6,13,19] evaluated patients' experiences with advance

Table 2. Examples of Advance Care Planning Initiative Outcomes

Enhancing Communication for Improved End-of-Life Care	A 3.5-fold increase in advance directives was the result of an electronic medical record prompt for physicians, 18 months after implementation.
PEACE project	65% of families of Alzheimer's patients in the project reported that hospice was discussed prior to death. (No data were provided on patients in the control group.)
Simultaneous Care	Chart reviews and patient surveys indicated that all patients in the project had in-depth discussions about advance care planning.
Comprehensive Care Team	Intervention patients were more likely to complete advance directive documents and funeral planning than control patients.
Renal Palliative Care Initiative	Chart reviews showed an increase in completed advance care planning documents from 6% of patients with any type of document in 1995 to 32% of patients with a health care proxy and 21% of patients with a living will in 2001.
End-of-Life Care for Persons with Serious Mental Illness	All 150 subjects in this study completed advance care planning interviews; there was a five-fold increase in advance directive documents completed by all outpatients in the project by the end of the study.

care planning services and reported data showing high satisfaction.

In addition to increasing availability of new palliative care services, over half of the projects provided education to patients and families, clinicians and the communities at large, thereby increasing recognition and demand for palliative care. Several projects also used clinician education as a critical mechanism for building clinical palliative care capacity within mainstream practice, and for increasing referrals to team-based palliative care programs. Many projects incorporated palliative care topics into required educational in-services, Grand Rounds and other "on-the-job" training for all clinical disciplines[8,19,21,27] and some offered lecture series and special training sessions on palliative care.[4,23,24] One project in New Mexico provided stipends to a nurse and a physician from each of seven rural communities for palliative care training leading to specialty certification.[20] Several of the demonstration projects also created new educational activities[5,13,14] and volunteer care resources[5,8,18,25] designed to help people become more active participants in decision making and care. Community outreach strategies were intended to raise awareness among those who might benefit from palliative care but do not know how or where to obtain it. For example, two projects based in comprehensive cancer centers used focus groups, community discussions and town meetings to understand community needs, raise awareness and provide practical information on access to services.[7,14]

Quality: standards, protocols, and quality of care

Using established quality improvement techniques, Promoting Excellence projects introduced new practices and procedures and then refined them in response to the observed impact on outcomes. Development and implementation of care standards, often as part of a care pathway or protocol, was the primary mechanism for clinical care improvement. The GRACE project modified the National Hospice and Palliative Care Organization (NHPCO) standards for hospice care to fit the prison setting.[18,26,27] Subsequently, the National Committee on Correctional Health Care adopted these new GRACE standards. Other projects that instituted standard protocols or care paths included Pathways of Caring,[15] Comprehensive Care Team,[12,13] Enhancing Communication for Improved End-of-Life Care,[6,28] PEACE,[29] and the pediatric Footprints[30] project.

New standards and protocols focused on assuring delivery of core palliative care services—pain and symptom management, psychosocial care, spiritual counseling and support, quality of life improvement and continuity of care. Several projects implemented pain and symptom management protocols that featured frequent assessment of symptom intensity along with questions about which symptoms were most bothersome and interfering most with daily life. The following are examples of the impact of these protocols:

- In Project Safe Conduct[7] the percentage of patients with lung cancer with documented pain assessments increased from 3% to 100% and the number of requests for pain consults also increased substantially.
- In the Comprehensive Care Team project, based in a general internal medicine service of an academic medical center,[12,13] 60% of patients were found to have untreated symptoms at the time of project enrollment. As one component of the multi-pronged intervention, 82% of patients received clinical pharmacist consults for symptom management.[12]
- Dementia patients in the PEACE project were less likely than control patients to report severe pain (23% versus 44%) following enrollment.[29]

Several Promoting Excellence grantees routinely offered psychosocial care by social workers, psychologists and, in some programs, by a psychiatrist.[4,19] The following are examples:

- In the PhoenixCare project,[16] 80% of patients received a formal social work evaluation and an average of four social work contacts, either by telephone or in person.
- In the Comprehensive Care Team project, all intervention patients underwent comprehensive psychosocial assessment by a social worker. Significant care needs were revealed for 74 percent of patients who then received in-home support services.[12,13]

Promoting Excellence projects that incorporated formal spiritual care into their project interventions demonstrated that clinical providers, patients and families were "won over" to its value. In the cancer center-based Project Safe Conduct,[7] physician follow-up questionnaires cited satisfaction with the project's spiritual care component, and the spiritual care provider was retained by the cancer center as a member of the now established and organization-supported Project Safe Conduct team. In the Renal Palliative Care Initiative,[19] patients and families reported that the staff was sensitive to spiritual and religious concerns, and families of decedents rated spiritual care as "excellent" on after-death surveys. All patients enrolled in the Comprehensive Care Team project received a chaplaincy consult, and 42% requested additional chaplain support. Intervention patients scored higher on the Spiritual Well-Being Scale and improved more over the course of the project than control group patients.[12,13]

A number of the Promoting Excellence projects addressed patient and family quality of life, including aspects of life completion. Projects typically used quality of life assessment tools[31–34] to uncover domains of patient or family-reported quality of life to focus therapeutic attention. Clinicians used life review, values-based care and targeted psychosocial and spiritual interventions in efforts to enhance quality of life. The Helping Hands project developed and gave each person served a beautifully crafted, culturally relevant journal in which patients with their families and friends in these frontier Native Alaskan villages could tell stories, record memories and share wisdom.[5] Two projects, Integrating Community Case Management and Palliative Care[22] and the Pediatric Palliative Care Project,[35] documented increases in quality-of-life scores and patient and family well-being in data reported to the Promoting Excellence office. Although no direct clinical outcome measures of grief were used by the projects, a number of project sites addressed bereavement by conducting patient memorial services.[7,8,14,19] At the Renal Palliative Care Initiative,[19] more than 100 family members attended the yearly memorial service and the physician evaluation questionnaires cited the services as "very useful" for meeting staff and family needs.

Perhaps the most important Promoting Excellence project elements for improving quality were those designed to improve coordination and continuity of care. According to an unpublished survey conducted by the Promoting Excellence office in the spring of 2001, 12 of the 18 projects that provided direct patient care designated an individual responsible for knowing where and when care was being provided for each patient, managing transfers between settings and/or provider agencies, coordinating clinical visits (sometimes extending to accompanying patients to visits), facilitating communication among caregivers and/or co-managing services with a health plan case manager.[2] The following are examples of benefits referable to improved care coordination:

- Families of patients in the Helping Hands project[5] reported satisfaction with having one place to call for any of their care needs.
- Pediatric specialists at Children's Hospital and Regional Medical Center in Seattle[35] reported better relationships between themselves and hospice providers.
- The Comprehensive Care Team was alerted when project patients were admitted to the hospital, enabling the team to talk with nonproject clinicians about the patients' preferences for care (documented for 90% of project patients.)[12,13]

Financial impact: health care utilization and costs

Several Promoting Excellence projects documented changes in utilization and patterns of use, occurring coincidently with access to new palliative care services and heightened attention to coordination of care. As shown in Table 3, there was less utilization of routine hospital bed days, emergency room services, intensive care bed days, ventilator care, primary care visits, and urgent care clinic services as patients accessed inpatient palliative care units and consult services.[2,36,37]

Complexities of health care billing and pricing make it difficult to account for actual costs and obscure distinctions between cost reduction and cost shifting.[38] Several Promoting Excellence projects reported data suggesting that provision of palliative care concurrent with life-prolonging treatment was financially neutral or associated with measurable savings.[36]

- In the Palliative Care Program at the University of Michigan, preliminary data showed total Medicare costs per patient for the project intervention group of $12,682, versus $19,740 per patient for the nonproject control group, a net difference of $7,058 per patient, adjusted for a mean enrollment duration of 250 days. The two groups in this project also showed a significant difference for hospital care—with costs for the intervention group at $8,974 and the control group at $13,126.[36]
- In the Pediatric Palliative Care Project an analysis of six high-cost children participating in the program revealed an average savings of $3,652 per client per month.[36]

TABLE 3. EXAMPLES OF CHANGES IN HOSPITAL UTILIZATION AND PLACE OF DEATH

Project	*Intervention patients*	*Control patients*
Palliative Care Program	10.6 average hospital days 3 emergency department admissions per 1000 patient–days of care	15.9 average hospital days 5 emergency department admissions per 1000 patient–days of care
PEACE	62% died at home	55% died at home
Pathways of Caring	43% died at home	75% died at home

- Franklin Health, Inc., a collaborator in the Integrating Community Case Management and Palliative Care demonstration project, reported a positive return on investment resulting from reductions in average numbers of hospital inpatient days, admissions and readmissions per claimant ($2.7 million in savings on $0.8 million in care management costs—or $22,000 per managed case—in the second year of implementation, and $55.4 million in savings on $1.3 million in costs—or $33,000 per managed case—in the third year of implementation).[36]

PROGRAMMATIC LESSONS

Routine communication and technical assistance activities, such as semiyearly progress reports, yearly onsite visits and focused site visits for evaluation technical assistance, presented opportunities for the Promoting Excellence program staff to glean information about the experience of grant-supported projects. Analysis across the various Promoting Excellence models yielded essential ingredients for building successful palliative care programs (Table 4). Project clinicians and investigators observed that patient, family and clinician resistance to palliative care is often steeped in misunderstandings about hospice. They found that confidence could be earned through skillful symptom management, clear communication and decision making, and continuity of care.

Other lessons emerged from observations of common experiences within Promoting Excellence projects, including the following:

- Palliative care programs have an increased chance of succeeding when housed in stable institutions. Palliative care is not often seen as a basic service and is highly susceptible during any period of funding cutbacks. Even successful Promoting Excellence projects suffered when the host institution or health system experienced severe financial stress, or substantially changed its infrastructure.
- Education can increase quality and access to care, but it is only effective when clinicians perceive a "need to know" and desire to learn. If they do not perceive a need and have little interest in expanding their knowledge or skills in this area, physicians, particularly, can be difficult to reach through education sessions or courses. Incorporating physician education into existing "teachable moments," such as morning rounds, regular noon conferences or morbidity and mortality sessions, was well accepted in several projects (Balm of Gilead, Enhancing Communication for Improved End-of-Life Care, and Renal Palliative Care Initiative). These forums affirmed the value of peer-to-peer teaching.
- Collecting process and outcome data proved to be difficult in busy clinical settings. Although collection of clinical data used in care planning can be incorporated into existing care processes, busy clinicians often do not have time to administer lengthy surveys.
- Collecting patient and family satisfaction data also proved to be very difficult. Patients were typically very ill, many with cognitive deficits that precluded reliable reporting. During care delivery, families were often overwhelmed by the illness and decision making, and after death, families were grieving and vulnerable and needed time to recover before responding to a survey. In many instances it was not possible to survey or interview family members, either because the ill person did not have or was estranged from family or, after the person's death, a spouse or other close family member relocated.
- Specific lessons from rural demonstration projects—Existing models of care delivery and reimbursement do not work well within the geographic and logistical realities rural communities face. Successful programs formed partnerships between the academic medical

TABLE 4. ESSENTIAL INGREDIENTS FOR BUILDING SUCCESSFUL PALLIATIVE CARE PROGRAMS

- A well-defined vision that:
  - Advances the institution’s mission &
  - Encompasses a comprehensive definition of palliative care
- A well-planned implementation strategy that is:
  - Manageable in scope &
  - Consistent with available human and financial resources
- Unwavering support from clinical and administrative leaders willing to:
  - Champion the program &
  - Help secure operational resources
- 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
- A focus on making “the right way the easy way” by:
  - Responding to workday needs of time-pressured clinicians and management &
  - Redesigning operations to embed and trigger palliative practices in daily routines
- Ongoing education, support, and attention to team building for clinicians and system personnel to:
  - Ease adoption of innovation &
  - Strengthen clinical interventions
- An assurance that palliative care teams have:
  - Authority to carry out their clinical recommendations and interventions for patient care &
  - “Safe havens” for the discussion of problems and ideas
- 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
- Targeted data collection focusing on:
  - Increased access to palliative care
  - Improved quality of care
  - Resource utilization and cost
  - Patient/family/clinician satisfaction
- A communications strategy for succinctly presenting relevant data to stakeholders

center, local providers and the community, marked by co-ownership and collaboration. Needs assessments helped local providers identify areas of education and services and the corresponding training, resources and technical assistance required to improve and expand palliative care services in their communities.

- Lessons from urban demonstrations projects—In inner-city projects, even seasoned clinicians were surprised at the depth and breadth of unmet needs among patients with advanced, life-limiting illnesses. Successful projects established working partnerships with local city, county or federal programs providing a safety net for the uninsured and underinsured. They worked with established volunteer programs, and/or extended services by using volunteer professionals.
- Lessons from cancer centers—Concurrent cancer treatments and palliative care was practical and valued by all stakeholder groups in each of four projects. Patients in phase 1 and 2 clinical trials were successfully included. Clinical trial patients and their families were highly satisfied with the concomitant comprehensive focus on improving their comfort and quality of life. Clinical program designs that build palliative care expertise within oncology teams and include screening and referral to palliative services in standard operating procedures were consistently well accepted.[37,39]
- Lessons from payers—Flexibility of insurance benefits, or the lack of flexibility, can have major implications on care. Some projects worked with insurers who helped devise creative uses of benefits within established guidelines. Some Promoting Excellence projects found that loosening the specific restrictions on insurance benefits led to more effective care that was highly satisfactory to patients and families, and financially accepted by the institution.[36]

DISCUSSION

Implications of findings

The Promoting Excellence in End-of-Life Care grant-supported projects demonstrate the practicality and broad acceptance of palliative care, often concurrent with life-prolonging care, in a wide variety of settings and patient populations. Available data and collective project experience demonstrated that expanding availability of and access to palliative services for patients with progressive, life-limiting illness can improve quality of care. Costs did not increase in these projects, although costs of health care in the last 6 to 12 months of life remained high, commensurate with the complex needs of people who are seriously ill. In fact, in the projects able to track resource use or expenditures, total health care costs were moderately reduced, even with the provision of concurrent palliative and curative care. The experience of these prototypical service delivery models suggests that creative, careful realignment of existing health system resources can improve the ability to meet patient and family needs without increasing costs.

The experience of Promoting Excellence projects is relevant to public health and health policy. At present, many patients and families who would benefit from palliative expertise and specialized services are effectively denied access, either because providers and services do not exist or because they are excluded by the eligibility requirements of Medicare, Medicaid or private insurers. The data and collective impressions of clinical teams of Promoting Excellence projects strongly suggests that good outpatient palliative care can prevent or manage crises that would otherwise require hospitalization.

If the success of these prototypical models is an indication of the future, health care utilization patterns will shift as increased numbers of patients have access to high quality palliative care. Costs, and therefore reimbursement streams, will also shift. Organizations that bear financial risk must participate in developing palliative care health service delivery so that financial resources can be allocated effectively and efficiently. New programs are more likely to succeed if they represent authentic partnerships in which the fiscal well-being of each partner is considered.

By focusing on comfort and quality of life Promoting Excellence projects advanced the institutional missions of their health systems and, not surprisingly, raised patient and family ("customer") satisfaction. Many institutional stakeholders mentioned within routine written reports, in correspondence or during onsite visits that the project had fostered cultural change in the institution marked by openness and interest in pain management and the social needs of all patients. The experience of Promoting Excellence projects suggest that health systems would benefit in terms of quality, efficiency, and costs by implementing mechanisms to identify patients in need of comprehensive palliative care, and developing the capacity to deliver it.

The Promoting Excellence in End-of-Life Care program was intended to test the theory of earlier and concurrent palliative and life-prolonging care in practice. Promoting Excellence projects provide the real-world programmatic experience needed to develop and refine new models of clinical care and health service delivery. The value of these 22 palliative care projects extends beyond the patients they directly served. Large-scale regional demonstration projects that track resource utilization, quality of care and satisfaction could test the findings from Promoting Excellence projects on a population basis and investigate the potential value of these approaches to national health care systems. At present the Promoting Excellence projects offer adaptable models that health care professionals, administrators and payers striving to care well for increasing numbers of seriously ill individuals and their families can draw on.

For more information on the Promoting Excellence in End-of-Life Care models, visit ⟨www.promotingexcellence.org⟩. Published descriptions of most of the demonstration projects appear in a special series of the Journal of Palliative Medicine in 2003 and 2004 (Appendix A and references).

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Appendix A. Promoting Excellence in End-of-Life Care Demonstration Projects

Grantee site	*Project name*	*Project description*[a]	*Status*	*Articles describing project*
Baystate Medical Center, Springfield, MA	Renal Palliative Care Initiative	Developed palliative care program for patients in eight dialysis centers in western Massachusetts to guide patients through advance care planning and help them confront issues, including the possibility of eventually discontinuing dialysis.	Sustained through adoption of policies and practices into routine care; additional grants have been secured to continue affiliated research.	The renal palliative initiative. JPM[b] 2003;6:321–326.
Bristol Bay Area Health Corporation, Dillingham, AK	Helping Hands	Developed end-of-life care services for 32 Alaskan Native villages throughout a 47,000-square-mile area of Bristol Bay, building on existing networks.	Skeletal program sustained in Bristol Bay; Replication underway via recent award of five-year $1.6m NCI grant to ANTHC to establish a palliative care training program for health care providers of Alaska Natives.	Establishing a culturally sensitive palliative care program in rural Alaska Native American Communities. JPM 2003; 6:501–510.
Children's Hospital and Regional Medical Center, Seattle, WA	Pediatric Palliative Care Project	Created a system of support and decision making for families who have children with life-threatening illnesses, through co-case management involving hospice and payers.	Sustained as formal program with hospital operating funds; expanded to include inpatient consult service, a formal palliative care residency training program, and additional partnerships with providers and payers.	Enhancing the quality of life for dying children. Children's Hospitals Today, Fall 2001.
Comprehensive Cancer Center, University of Michigan, Ann Arbor, MI	Palliative Care Program	Worked in collaboration with Hospice of Michigan to bring palliative care to community-based cancer patients while they are undergoing disease-modifying treatment.	Randomized control trial designed to conclude at grant's end; data continuing to be analyzed for future dissemination; formal program discontinued at grant's end.	
Cooper Green Hospital, Birmingham, AL	Balm of Gilead	Established a comprehensive palliative care program, including a 10-bed inpatient palliative care unit, training for medical residents, interns, and medical students on rotation, and coordinated care in area nursing homes.	Sustained as a formal program at Cooper Green Hospital. Replication of aspects of the program is underway in the VA system.	The Balm of Gilead Project: A demonstration project on end-of-life care for safety-net populations. JPM 2004; 7:486–493.
Dartmouth-Hitchcock Medical Center, Norris Cotton Cancer Center, Lebanon, NH	Project ENABLE	Provided palliative care throughout the course of cancer treatment in New Hampshire's regional cancer center, a community-based oncology practice and in a rural community, emphasizing patient education and empowerment.	Sustained in the regional cancer center; modified some program components, expanding into a clinical service, continuing its educational component, and receiving NIH funding for a clinical trial to further test ENABLE.	Project ENABLE: A palliative care demonstration project for advanced cancer patients in three settings. JPM 2004; 7:363–372.

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Appendix A. Promoting Excellence in End-of-Life Care Demonstrations Projects (*Continued*)

Grantee site	*Project name*	*Project description*	*Status*	*Articles describing project*
Department of Veterans Affairs, West Los Angeles Medical Center, Los Angeles, CA	Pathways of Caring	Integrated palliative care into its continuum of services for veterans with lung cancer, advanced congestive heart failure, chronic obstructive pulmonary disease, and cirrhosis.	Sustained; expanded to include patients with all poor prognosis diagnoses with expanded staff & space; received funding for a 4-year randomized control trial based on Pathways program that is anticipated to serve as basis for national dissemination.	Palliative care management: A Veterans Administration demonstration project. JPM 2003;6:831–839.
Henry Ford Health System, Detroit, MI	Enhancing Communication for Improved End-of-Life Care	Expanded its state-of-the-art computerized record system to include patients' preferences and end-of-life plans; collaborated with Michigan State University to develop an interactive CD-ROM to assist with advance care planning.	Sustained through adoption of products and protocols into electronic record system, institutional policies and into institutional educational resources.	Enhancing communication for end-of-life care: An electronic advance directive process. JPM 2003;6:511–519. Completing a life: development of an interactive multimedia CD-ROM for patient and family education in end-of-life care. JPM 2003;6:841–850.
Ireland Cancer Center: University Hospitals & Case Western Reserve University, Cleveland, OH	Project Safe Conduct	Established a palliative team within the cancer center in conjunction with the Hospice of the Western Reserve to provide symptom management, psychosocial and spiritual support for lung cancer patients—even those receiving life prolonging care, including experimental therapy protocols.	Sustained as formal program; expanded to include additional diagnoses.	Project Safe Conduct integrates palliative goals into comprehensive cancer care. JPM 2003;6:645–655.
Louisiana State University Medical Center, New Orleans, LA	PalCare	Created a palliative care service for people with HIV/AIDS—often with additional diagnoses—that treats symptoms, coordinates care and assists with clarification of treatment goals.	Sustained and expanded as a formal service providing consults and case management.	The positive outcomes of HIV palliative care consultations: Five meaningful cases. HIV Clin 2003;15:1–5.
Massachusetts Department of Mental Health, Metro Suburban Area, Medfield MA	End-of-Life Care for Persons with Serious Mental Illness	Created a bridge between hospice and mental health providers to improve care for dying people with long standing severe psychiatric illness, and developed tools for evaluating the competency of these patients to make decisions and to complete advance directives.	Research portion of project completed; palliative care practices sustained via adoption of policies and practices and continuing education; expanded via adoption of statewide policies on end-of-life care and advance directives.	Do it your way: a demonstration project on end-of-life care for persons with serious mental illness. JPM 2003;6:661–669.

Medical University of South Carolina, Charleston, SC	Palliative Care Services for Urban African Americans	Investigated end-of-life attitudes, beliefs and needs of African-Americans in an economically disadvantaged urban area.	Community assessment concluded at end of planning grant.	End-of-Life care for African Americans: Voices from the community, JPM (in press)
Mount Sinai School of Medicine, New York, NY	Integrating Community Case Management and Palliative Care	Partnered with Franklin Health, Inc. and Blue Cross/Blue Shield of South Carolina to infuse palliative care into the comprehensive case management provided to high-rsk homebound commercially insured patients with life-limiting illnesses.	Maintained and extended to all clients of Franklin Health (now "Paradigm Health") and is implemented in health plans and self-insured plans covering five million lives.	Integrating case management and palliative care. JPM 2004; 7:119–134.
PhoenixCare at Hospice of the Valley, Phoenix, AZ	PhoenixCare	Collaborated with several large managed-care organizations to bring key components of hospice care to patients with cancer, congestive heart failure, and chronic obstructive pulmonary disease, and at an earlier stage than traditional hospice.	Sustained via a five-year Medicare Demonstration Project grant, with similar PhoenixCare service package offered to nonmanaged high-risk Medicare recipients.	The PhoenixCare Program. JPM 2003;6:1001–10012.
SSM Cardinal Glennon Children's Hospital, St. Louis, MO	FOOTPRINTS	Developed a statewide network of health care providers to care for children dying at home by: providing inpatient palliative care at the tertiary pediatric hospital; educating pediatricians, the staffs of community hospitals and area hospices; and creating educational modules.	Sustained with expanded staffing and additional venues; received federal grant to export Footprints to five sites in Missouri.	The FOOTPRINTS$^{(SM)}$ model of pediatric palliative care. JPM 2003;6:989–1000.
Sutter VNA and Hospice, Emeryville, CA	CHOICES	Offered palliative care to home-based patients receiving life-extending care with emphasis on advance care planning and individualized plans of care that include preparations for potential crises.	Sustained, with CHOICES becoming AIM (Advanced Illness Management); expanded from Emeryville throughout the Bay Area and expanding to include inpatients at two hospitals.	CHOICES: Promoting early access to end-of-life care through home-based transition management. JPM 2003; 6:671–683.
University of California Davis, School of Medicine, Sacramento, CA	Simultaneous Care	Extended palliative care to patients and families pursuing life-prolonging treatment; used satellite telecommunications to link the teaching physicians at the university with their rural colleagues; and introduced palliative care services to women in prison in collaboration with the California Department of Corrections.	Simultaneous Care program sustained via federal grant for 5-year multi-site randomized control trial. Rural component's telemedicine conferencing replicated for other diagnoses. Prison component skeletally sustained, with designated hospice beds in women's prisons.	Widening the circle for palliative care: Bringing palliative care home to patients engaged in clinical trials. An interview with Joan Blais. Innovations in End-of-Life Care, 5 (4): July–August 2003

(*continued*)

Appendix A. Promoting Excellence in End-of-Life Care Demonstrations Projects (*Continued*)

Grantee site	*Project name*	*Project description*	*Status*	*Articles describing project*
University of California, San Francisco, San Francisco, CA	Comprehensive Care Team	Collaborated with Hospice by the Bay to offer palliative care to patients receiving concurrent curative care in an outpatient clinic, using a social worker-led case management model, and included volunteer support services, faith communities and social agencies.	Isolated portions of the original project were sustained; project is currently being adapted for the GYN-oncology outpatient practice at UCSF's Comprehensive Cancer Center.	The comprehensive care team: A description of a controlled trial of care at the beginning of the end of life. JPM 2003;6:489–498.
University of Chicago Medical Center, Chicago, IL	PEACE	Extended palliative care to people with Alzheimer's disease and their families. In Chicago, PEACE is centered within in an academic primary care geriatric practice. In Greater Detroit, the PEACE team provides care for patients with dementia in nursing homes through Hospice of Michigan.	U of Chicago: Sustained as formal program, with protocols embedded into practice, expanded to include frail elderly patients with diagnoses other than dementia. Michigan Program: Sustained through incorporation of anticipatory care planning and treatment policies and procedures into nursing homes.	Palliative Excellence in Alzheimer Care Efforts (PEACE): A program description. JPM 2003; 6:315–320.
University of New Mexico, Health Sciences Center, Albuquerque, NM	When Cure is No Longer Possible	Created a palliative care network in seven rural communities within three distinct subcultures in collaboration with hospices, and assisted the Zuni Home Health Agency in establishing a Native American palliative care program.	Sustained as Palliative Care Information, Referral and Training (PERT) office and with ongoing availability of palliative care in rural settings, including Zuni pueblo; expanded to include palliative care section in department of geriatrics, palliative care fellowship program, and telemedicine program for family practice residents.	Palliative care in the Pueblo of Zuni. JPM 2004;7:135–143.

University of Pennsylvania, School of Nursing, Philadelphia, PA	Palliative Care in Nursing Homes	Worked with Genesis ElderCare to develop palliative care teams in several Maryland nursing homes; developed a training program for nursing home staff on the spiritual, psychosocial, and bereavement aspects of care, and developed techniques to embed palliative care in daily routines.	Sustained via integration of palliative care policies and procedures into nursing home policies; the program has expanded to four additional nursing homes.	Integrating palliative care into nursing homes. JPM 2003; 6:297–309.
Volunteers of America, Inc., Alexandria, VA	GRACE Project	Worked in four states to integrate palliative care into care for seriously ill prisoners, and convened a national workgroup of wardens, clinicians, pastors, attorneys, and inmate advocates to assess the changes needed in correctional end-of-life care and develop standards for hospice and palliative care prison programs.	Sustained through formal transfer of resource center to NHPCO and through adoption of end-of-life care standards by National Commission on Correctional Health Care.	The GRACE Project: guiding end-of-life care in corrections 1998–2001. JPM 2004;7:373–379.

[a] Detailed descriptions of all projects can be found at <www.promotingexcellence.org>

[b] *Journal of Palliative Medicine*

HIV/AIDS, human immunodeficiency virus/acquired immune deficiency syndrome; NIH, National Institutes of Health.