

Expanding the Realm of the Possible

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THIS ISSUE OF *Innovations* begins a series of reports from a set of remarkable projects supported by Promoting Excellence in End-of-Life Care, a national program of The Robert Wood Johnson Foundation. Based on a belief that high-quality palliative care should be available for every terminally ill person regardless of diagnosis, ethnicity, age, or place of residence, Promoting Excellence was chartered to demonstrate that excellent care for dying people and their families is an attainable goal.

The overall goal of Promoting Excellence has been to expand access to services to patients and families who would not otherwise be able to benefit from palliative care, and to improve the quality of care received across a spectrum of conditions, phases of illness, and settings. The program had as its principal charge the identification and provision of financial support and technical assistance to innovative projects seeking to deliver palliative care to difficult-to-serve populations and in challenging contexts of care.

Team members of these innovative projects authored the papers in this series. The papers describe the development of and experience with initial program design and program evolution, including strategic responses to barriers encountered. A few articles similarly describe the creation or adaptation of specific clinical, educational, programmatic, and research products, such as curricula and novel decision-making procedures or tools that appear useful in palliative care.

A STRATEGIC INITIATIVE

The Promoting Excellence strategy was to respond to areas of identified need categorized by

discernible patient populations or by clinical settings in which hospice care was either unavailable or underutilized. The Promoting Excellence program did not seek to build alternatives to hospice care. Rather it sought to extend palliative care upstream in the course of illness, concurrent with ongoing life-extending care, and into contexts of care and patient populations that hospice has difficulty penetrating. In many of the projects, hospice programs were principals or collaborating partners and most projects developed a continuum of services that includes referral to hospice.

Demonstration projects were chosen as Promoting Excellence's means of exploring whether palliative care could be delivered in these new settings. Demonstration projects provide tangible examples of what is feasible—and what is not—in addition to how well it is valued. The innovative palliative care delivery models reported in this series represent applied research, the translation of theory and bench science into practice. The impact of successful demonstration projects can extend beyond local systems and communities, raising our collective expectations and challenging administrators, health planners, and public policy makers to aim higher than they otherwise might.

THE SELECTION PROCESS: IDENTIFYING LOCAL LEVERS OF NATIONAL CHANGE

The search for projects with the capacity to foster nationally significant long-term changes in care for dying people began with a call for proposals mailed to more than 30,000 health care clinicians, researchers, and administrators repre-

senting a broad range of disciplines. The call for proposals generated 678 initial letters of intent received from all 50 states and two U.S. territories. They represented children's hospitals, Veterans Administration sites, academic medical centers, managed care organizations, community health and social service organizations, and state governments. From this pool of proposals, Promoting Excellence staff and program officers from The Robert Wood Johnson Foundation selected 60 applicants to invite for full proposals. A National Advisory Committee, comprised of leaders in medicine, nursing, ethics, and allied fields, actively participated in subsequent phases of selection.

A consistent set of criteria was applied at each stage of the selection process. The criteria were designed to identify applications with the highest potential for local success, as well as for contributing nationally to efforts to expand access to services and quality of care.

CRITERIA FOR FUNDING

- Conceptual, operational, and financial feasibility of the proposed project;
- Degree of innovation of the intervention and strength of project design;
- Ability to leverage significant change nationally;
- Demonstration of best practices of comprehensive palliative care;
- Level of collaboration and/or partnerships;
- Prospects for sustainability, assimilation and/or implementation of; durable clinical or health system change; and
- Strength of institutional commitment and leadership.

The 22 projects awarded Promoting Excellence in End-of-Life Care grants represented a broad range of contexts of care. These included projects based in university cancer centers, tertiary care pediatric hospitals, hospice and home health agencies within highly penetrated managed care environments, dialysis clinics, nursing homes, dementia programs, penitentiaries, programs in rural and frontier communities, and inner city projects.

COMMON PROGRAMMATIC THREADS

The Promoting Excellence projects that emerged from these proposals are each unique. Operational strategies and patterns of service respond to the needs of local stakeholders and, therefore, fit well within the particular health systems and communities in which they developed. Despite this uniqueness, common elements of care and service components are discernible across programs, including a focus on patients and families, state-of-the-art clinical practices, and respect for the cultural, ethnic, and religious values.

The programs all have explicit strategies for clear communication with patients and families, advanced care planning and ongoing care planning by a culturally competent interdisciplinary team that builds upon expressed values and preferences of patients and families. Case management is provided in every program, but in a variety of ways. Most often a specified nurse or social worker serves as a "care coordinator." Responsibilities of this key position include maintaining updated knowledge about the patient's and family's status, overseeing implementation of the plan of care, advocating for patients and families and assisting them in obtaining access to services, coordinating appointments and services, and maintaining communication among patients, families, and the health care team.

Crisis prevention and early crisis management are also important common elements of care planning. In every program, efforts are made to anticipate foreseeable problems. Specific measures to prevent and monitor for their occurrence are coupled with plans for responding rapidly to crises that do occur.

TYPICAL SERVICES OF PROMOTING EXCELLENCE IN END-OF-LIFE CARE PROJECTS

- Ongoing communication and review of goals;
- Advanced care planning;
- Formal symptom assessment and treatment;
- Care coordination;
- Spiritual care and attention to psychosocial needs;
- Anticipatory guidance related to adaptation to

illness and issues of life completion and life closure;

- Crisis prevention and early crisis management;
- Bereavement support; and
- 24/7 availability by a clinician knowledgeable about patient and family.

EVALUATION

Evaluation for these model-building projects focused on demonstrating the feasibility of the model and its level of acceptance among the full range of “stakeholders,” including patients and families, clinicians, and health system managers and administrators. Only a few of the projects that had previously conducted pilot phase studies were designed as randomized controlled trials. In most projects, data related to the therapeutic efficacy of the service delivery model await further analysis and, in many cases, will require a subsequent phase of research. A few projects will contribute preliminary comparison data on their project’s impact on resource utilization.

Pivotal data relevant to a project’s feasibility and acceptance include rates of referral and program census over time, lengths of service, and such basic facts as whether the program is being sustained by its parent health system after grant funds end.

FUTURE DIRECTIONS AND IMPLICATIONS

In writing for this series, authors were asked to conclude their reports by discussing potential future directions for their programs and for related efforts to expand access to services and improve quality of care. They were encouraged to provide a fuller context for their findings by reflecting on the implications their experience may hold for extending palliative care to similar patient populations and similar settings elsewhere. Their perspectives and insights into the practical and fiscal aspects of service delivery will advance national and international discussions of approaches for expanding access to and quality of palliative care.

OBSERVATIONS AND CONCLUSIONS

Without giving away the end of this story, it can be revealed that most of the programs described in this series are continuing beyond the period of grant support. They have proven their feasibility and efficiency within their local health systems and have been highly valued by patients, families, and providers alike.

What is most remarkable about this fact is that in virtually every instance, success was achieved amid serious, sometimes cataclysmic, shifts in the project’s operating environment. National instability in health care during this period included major downturns in managed care, the Balanced Budget Act of 1997, the near dissolution of physician-provider organizations, the rise and abrupt fall of Medicare + Choice, the Interim Payment System, and the Prospective Payment System. At the local level these changes were felt as health system mergers and dis-mergers, staff cutbacks, hiring freezes, changes in corporate leadership, and loss of key clinical champions. As will be apparent from reading the reports from the few programs that were not sustained, demise came from being scuttled by their health system amidst the gale winds and tides of health care in the 1990s. Each would likely have thrived in even slightly calmer circumstances.

The collective experience of these projects makes clear that palliative care is feasible to deliver and well accepted in a wide variety of health systems and settings, including those involving concurrent disease modifying and life-prolonging care.

As you will read, the history of the Promoting Excellence in End-of-Life Care program is not one story, but a rich anthology. We hope readers of this collection will be able to share some of the sense of adventure—that mixture of optimism and fear—with which the Promoting Excellence program and grantees approached this work.

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