

Crossing Organizational Boundaries in Palliative Care: The Promise and Reality of Community Partnerships

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Executive Summary

This report presents the first of a series of findings from the Community-Oriented Palliative Care Initiative (COPCI), an innovative program testing new approaches to caring for individuals with progressive, life-threatening illness. Developed and supported by the United Hospital Fund, the project was designed to initiate collaborations among health care and social service organizations, with the goal of reaching seriously ill individuals and their caregivers earlier in the course of illness and providing a broad range of coordinated services. Six such networks of diverse partners received a total of \$2.1 million in grants over the two-year period from mid-2000 into 2002.

The urgency to provide alternatives to current standard practice is underscored by the number of individuals affected: in New York City alone, in the year 2000, some 46,000 people died of diseases typically marked by a lengthy course from diagnosis to death. While many could have benefited from appropriate and timely palliative care services, most did not receive them.

The Fund reasoned that networks including not only hospitals and hospices but also social services agencies and other community resources could collectively respond, earlier and more fully, to the complex combination of medical, social, psychological, and spiritual needs that typify the months and years leading to death. Local expertise and resources should determine the structure of each network, the partners involved, and the specific model for service delivery. Drawing on the experiences of the six pioneering projects, this report focuses on the challenges of creating such new networks. Among the lessons to emerge were the following:

- **Incentives for joining a network must be clear and in alignment with the incentives of other partners.** Crossing organizational boundaries is a resource-intensive and time-consuming process that often challenges

long-held patterns and practices. Determining beforehand how network participation could benefit an organization, its strategic plans, current services, or clients is therefore essential. Anticipated prestige, or fear of missing out, is a weak underpinning for such an ambitious exercise. Incentives are diminished when a partner feels sidelined by the service delivery model chosen, lack of inclusion in decision-making, concern about burdens of participation, or lack of perceived relevance to its mission, resources, or clients.

- **Partners' resources and capacities must match the service delivery model.**

While there is no single way to structure palliative care networks, service delivery models must comprise practical, well defined means of identifying and referring patients; recruiting, training, and utilizing service providers; and coordinating services. Long-term care organizations may be particularly suited to leading networks, due to their familiarity with coordination and referrals, as well as access to staff and patients. At least one partner, not necessarily the lead agency, should be able to generate a large proportion of referrals, via its inpatient, clinic, or home-care services, or community-agency client roster; private-practice physicians are less likely to make referrals. Other important partner contributions include coordination of activities, access to community agencies and leaders, and medical expertise. Specific roles and responsibilities must be clearly defined to ensure that partners are fully utilized.

- **Capacity building must move beyond clinical expertise.** Partner organizations bring different levels and kinds of palliative care knowledge and experience to networks. Building understanding and key clinical skills is crucial but only one step. Initiating or expanding new services and modes of delivery also requires reviewing and modifying partners' programs, practices, and policies, and fitting new approaches and skills into the

framework of existing missions and resources. A third aspect of capacity building — the most challenging one when diverse organizations come together — concerns learning to work *as* a network, and developing an inter-organizational patient care coordination process. Finally, intensive community outreach may pay off down the road with enhanced community awareness, community leaders' and organizations' support for network goals and services, and increased volume of referrals.

- **Effective network leadership requires a broad repertoire of skills.** Clinical leadership is essential but must be matched with logistical, political, and management know-how, the ability to cross organizational boundaries to create new mechanisms for coordinated service delivery, and the skill to educate and inspire, build consensus, move the project through a developmental process, and forge a team. More successful leaders tested various strategies for reaching and serving patients, and kept an eye on the big picture in terms of productivity and sustain-

ability. They also realized that partners must be nurtured for collaboration to succeed. Building trust takes time, and the willingness to move beyond the rhetoric of collaboration to truly open communication, joint problem-solving, sharing of resources, and respect for each partner's strengths, contributions, and incentives. Projects were often well served by a blend of clinical expertise and programmatic and management skills spread across a number of individuals and/or partner organizations.

- **There are no guarantees of success, but viable networks share a number of specific traits.** Those characteristics include an effective, sustainable service delivery model; a good clinical team; a steady patient stream; nesting of services within a larger service entity such as a home-care organization or hospital; committed partners with services and resources that complement the lead organization's; and leadership with the ability to transcend professional and organizational lines, and solve problems creatively and collaboratively.

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Foreword

The United Hospital Fund's efforts to improve health care in New York are grounded in our three-pronged approach of health services research, independent policy analysis, and grant-supported program development. But equally essential to our mission are vision, commitment, and willingness to take risks. Nowhere has this been more evident than in the Community-Oriented Palliative Care Initiative established in 2000, the largest single financial commitment undertaken by the Fund thus far. This now-\$2.5 million grant-making program was designed to jump-start a new, more comprehensive approach to providing palliative care.

That goal has been made urgent by the health care advances that have increased lifespans at the cost, for most people, of those added years being spent with progressive, life-limiting illness. Long before the final months or weeks of life, these individuals and, often, their families, will need a complex, evolving mix of services. Yet with a compartmentalized and fragmented health care system that often has as much difficulty reaching patients in a timely manner as it does developing the services those patients need, no single organization can do it all.

Since its launch, in 1995, of the Hospital Palliative Care Initiative — developing the City's first clinical palliative care programs in acute care hospitals — the Fund has increasingly recognized the need for a more global, collaborative approach to palliative care. Community-based networks tailored to local needs and resources can, we believe, provide just that, reaching persons with life-threatening illness early enough and in a wide enough variety of settings to significantly improve how their final years are spent.

This report, the first of a series, presents early lessons from six pilot projects' efforts to forge such networks. While the results leave

us optimistic about the future of partnerships for community-oriented palliative care, these were not easy lessons to learn. Diverse organizations, each with potential for making valuable contributions to a network, typically had little experience in working together. Missions, resources, and operating styles were often at odds. Yet the grantees that were most successful learned to cross boundaries and work cooperatively to develop new models for palliative care.

Our efforts to move palliative care into the community would not have been possible without the generous support of the Project on Death in America of the Open Society Institute, and the Fan Fox and Leslie R. Samuels Foundation. We are grateful for their support, as well as that of the United Way of New York City.

I wish to acknowledge the leadership of project director and author Susan Shampaine Hopper and the contributions of staff members David A. Gould and Deborah E. Halper, who direct the Fund's grantmaking, and Phyllis Brooks and Andrea Lucas, whose editorial guidance helped shape this report.

I also wish to thank the staff at each of the organizations participating in the six networks for their enthusiasm, perseverance, and commitment to the project and their candor about the results. They continue, today, to learn, test, change, and rethink the relationships and strategies they developed, and we at the Fund learn with them. As the Community-Oriented Palliative Care Initiative moves through its third year, our high-risk venture has evolved into a viable new approach to meeting New Yorkers' needs.

JAMES R. TALLON, JR.
President
United Hospital Fund

Introduction

The sometimes years-long journey from diagnosis of a progressive, life-threatening illness to death calls for a broad range of intensive services. For individuals and their families, finding the needed medical, psychosocial, spiritual, and logistical aid can be overwhelming. For any single organization, providing all those services, over the full course of illness, is daunting as well.

Recognizing these dual challenges, the United Hospital Fund turned to the concept of provider networks as a way to deliver coordinated palliative care services. These networks of health and social service organizations would design service delivery models that would be practical, responsive to community needs, and potentially self-sustaining. Only by crossing traditional organizational boundaries, the Fund reasoned, could networks pool their individual strengths to deliver a diverse array of palliative care services in the community, with the resources and flexibility to meet changing needs over time.

The Community-Oriented Palliative Care Initiative (COPCI) was conceived as an experiment to determine whether such networks could indeed be formed, what the right mix of organizations and leadership would be, and how expectations, roles, and service delivery model would influence the outcome. Now, some two years after the Fund awarded grants for development of six networks, this report analyzes how diverse organizations went about the business of forming a whole — how networks and partnerships emerged during their first stages of development, a period critical to setting the tone of each project and to creating a foundation for long-term success.

Overall, this is a story of many partial successes, and several more extensive ones in which networks started to ripen into genuine partnerships, capable of delivering palliative care in a new way. For others considering creation of similar networks to address complex health and social needs, we have distilled some of the lessons the Initiative yielded. A later report will analyze, in greater depth, networks' service delivery models, including enrollment, breadth and coordination of services, and effects on patients served. Here, we focus on several key questions related primarily to the first, formative stage of network development:

- How were networks structured?
- Why did organizations join? How well did partners' goals, and incentives for networking, mesh?
- How well did partners' skills, programs, and resources contribute to the model proposed by their network's lead organization?
- How were networks led and managed, communications and working relationships developed, and partnerships shaped?
- How timely and well sequenced were activities and decisions regarding partnerships and service delivery?

Why Community-Oriented Palliative Care?

With a lack of overarching management of care virtually the norm in progressive, life-threatening illness, patients and their family caregivers often find there is little attention to the complexity and evolving nature of their needs. Too often, they find a patchwork of unlinked programs, gaps in services, unresponsive providers, and significant financial barriers.

ers (Covinsky et al. 1994; Levine 1998). Too often, patients die in fear and discomfort, after long bouts of uncontrolled pain, without preparing end-of-life legal documents or having their wishes respected regarding how they die.*

While a pattern of unmet needs is all too typical, notable transformations in palliative care are taking place (Lynn 2000). Acute care hospital-based programs developed over the past decade have brought patient, family, and clinicians together to address pain and symptom management, advance planning, and a range of other needs (Pan et al. 2001; Billings and Pantilat 2001; Hopper 2000). Over 300 hospitals have palliative care programs, typically consultation services, and the number is growing (Pan et al. 2001).

Yet clinical activities in the hospital setting are usually crisis-oriented, the timeframe for discussion and actions highly condensed. As the United Hospital Fund's 1996-2000 Hospital Palliative Care Initiative revealed, the focus on urgent care and the likelihood of patients dying in the hospital or shortly after discharge also limits the scope of the response to their needs. For patients who *are* discharged, there are relatively few community resources for meeting the goals of care if hospice is, for whatever reason, not the next step (Hopper 2000).

Hospices nationwide, whose strengths over the past 25 years are well established, are currently employing strategies to expand the boundaries of their services, link with other organizations to generate more timely referrals, and overcome regulatory and reimbursement restrictions. The package of multidisciplinary services for which they are known serves as a model for emerging programs in other venues.

*The urgency to provide better alternatives is underscored by the number of individuals affected: in New York City alone, in the year 2000, some 46,000 people, over three-quarters of all those who died, succumbed to cancer, heart disease, chronic obstructive pulmonary diseases (including asthma, bronchitis, and emphysema), or AIDS, all diseases with a typically lengthy course from diagnosis to death (New York City Department of Health 2002).

Efforts to overcome the single-provider approach to palliative care include the National Hospice and Palliative Care Organization/Center to Advance Palliative Care project linking hospitals and hospices (National Hospice and Palliative Care Organization and the Center to Advance Palliative Care 2001), comprehensive programs such as those of the Cleveland Clinic and Northwestern Memorial Hospital (Arnold et al. 2000), and "bridge" programs such as the University of Pennsylvania Health System's for homebound cancer patients, staffed by hospice nurses (Casarett and Abraham 2001). Most of these efforts, however, have focused on individuals near the end of life. A clear need remains for multi-organizational partnerships that can provide coordinated services "upstream," or earlier in the course of illness, and enhance access to those services, including the option of blending palliative care with life-prolonging measures earlier on.

The Collaborative Process

Successful partnerships have been instrumental in a number of community health efforts, generally public health assessment and screening programs but occasionally the creation of more effective service delivery (Bazzoli et al. 1997; Roussos and Fawcett 2000). Indeed, the "unique advantage of collaboration" is its "power to combine the perspectives, resources, and skills of a group of people and organizations" to yield a whole greater than the sum of its parts (Fried and Rundell 1994; Lasker 2000; Lasker, Weiss, and Miller 2001).

But operationalizing such partnerships is no small challenge. "Collaboration requires relationships, procedures, and structures that are quite different from the ways many people and organizations have worked in the past" — a virtual rethinking of organizational operations and culture (Lasker, Weiss, and Miller 2001), requiring holistic and practical thinking, goals

that are understood and supported, and a voice for all stakeholders (Lasker 2000). Work is more likely to falter when partnerships are “forced,” i.e., initiated by funders without sufficient involvement of partners (Lewin Group 2000).

Moreover, for partnerships to be successful, whatever their ultimate goals, they must move through a “life cycle” “predicated on the notion of stages of development — i.e., emergence, transition, and maturity,” each presenting specific challenges and tasks (Weiner, Alexander, and Zuckerman 2000; Butterfoss, Goodman, and Wandersman 1996; Zuckerman, Kaluzny, and Ricketts 1995). Among the principle tasks of the emergence stage, for example, are “developing collaborative proficiency,” in part by defining roles and goals, and “building trust” through meetings and sharing of leadership and decision-making; for the transition stage, “making measurable progress” by confirming specific goals and recording advances toward them, and “managing cultural diversity,” including opportunities for cross-cultural dialogue; and for the maturity phase, maintaining partner commitment by educating administrators (or board members), “aligning management with partnership responsibilities,” “demonstrating results,” and committing enough staff and resources to accomplish tasks (Weiner, Alexander, and Zuckerman 2000). Leadership has the task of guiding that developmental process and keeping crucial partners committed to moving beyond professional and organizational priorities toward new broad, timely, and gap-free services.

Creating Networks for Community-Oriented Palliative Care

To tackle the challenges of delivering such services, the Fund launched COPCI with a request for proposals (RFP) in the spring of 1999. Sixteen groups of organizations in the

New York City area responded to the RFP, signifying widespread interest in addressing the issues described, despite the significant demands inevitable in that work. The RFP required that proposed networks include at least one hospital, plus a mix of other health and social service organizations, any of which could be designated the lead agency. Beyond an emphasis on early identification of patients and delivery of coordinated services, the Fund

What each lead organization sought to accomplish, and how it planned to do that, would essentially shape its roster of partners, how they related to each other, and what specific roles each played in the network’s service delivery model.

sought innovative approaches and strategies for community outreach, capacity building, and service delivery. Selecting six proposals for the Initiative, the Fund provided financial support, beginning in April 2000, of \$350,000 for each network over a two-year period.

Structuring Networks

For all grantees, the first step toward establishing cohesive community-oriented networks was development of guiding strategies consistent with local needs and resources. What each lead organization (and, ultimately, network) sought to accomplish, and how it planned to do that, would essentially shape the roster of partners, how they would relate to each other, and what specific roles each would play in the network’s service delivery model.

Each model included criteria and processes for such core functions as patient recruitment, coordination of defined services, integration of primary providers, incorporation of clinical expertise, and development of leadership and communications to move the model to reality.

Models varied greatly in how these elements were structured but tended to reflect the strengths, goals, and responsibilities of the lead agency, with other partners playing complementary roles. (In this report “network” refers to the structure linking participating organizations, while “partner” and “partnership” reflect the relationships among those components.)

Lead agencies — which provided financial resources, management, and expertise in one or more areas critical to network operations — ranged from direct service providers to administrative bodies (see “The Networks at a Glance”). Two projects were led by departments within academic medical centers (Mount Sinai Medical Center’s Hertzberg

and followed by their own primary care practitioners.

Agencies with broad experience in long-term care led two other projects (the Visiting Nurse Service of New York for the Harlem network, and Metropolitan Jewish Health System for the Southern Brooklyn network). In Harlem, the Visiting Nurse Service supervised a nurse and social worker based at North General Hospital; the hospital, in turn, was to provide most of the referrals to the network. In Southern Brooklyn, a team of two social workers and a nurse, based at the lead agency, was to serve patients referred through all six partners, which included two hospitals and three community agencies.

The final two networks were led by providers of administrative services rather than direct patient care: in the Queens network the Department of Continuing Care, a coordinating program that supported service linkage within the North Shore-Long Island Jewish Health System, and in the Catholic network Clarion, a long-term care management agency within the Catholic Health Care System. Both networks’ models were predicated on the central role of private practice. In Queens, patients would be drawn from the practices of five area physicians, who would add palliative care to their professional activities; for the Catholic network, referrals to the network’s nurse staffer would come primarily from the independent practice association affiliated with the Catholic Health Care System, and from Catholic Charities.

While knowledge and capacities varied

Knowledge and capacities varied within and across networks, but each had at least one physician expert serving as educator, advisor, supervisor, and/or coordinator of services.

Palliative Care Institute for the Mount Sinai-NYU network, and Montefiore Medical Center’s Department of Family Medicine for the Bronx network). In both cases, the model targeted patients drawn from the lead institution, i.e., inpatients at Mount Sinai, who would be followed, upon discharge, by a nurse practitioner, and clinic patients in the Montefiore system, who would be enrolled

METHODS OF INVESTIGATION

Information for this report was obtained from analyses of site visits, meetings, informal communications, and grantees’ written reports. Additional information was gathered through interviews with network leaders, including lead-organization staff responsible for project management and finances, clinical experts, clinical and administrative staff working directly for the networks, and key staff of partner social service and community agencies. Semi-structured face-to-face interviews were conducted with five networks’ leaders by an external consultant and with the sixth’s by the COPCI director, initially between July and September 2001, and then at the completion of the project in April and May 2002.

THE NETWORKS AT A GLANCE

At the project's outset, the six networks comprising the Initiative had distinct configurations and philosophies, palliative care delivery models, and target populations, as outlined below.

THE BRONX COMMUNITY PALLIATIVE CARE NETWORK

Partners: Montefiore Medical Center Department of Family Medicine and Community Health, Beth Abraham Health Services, Aging in America/Morningside House

GOALS:

- Target a multi-ethnic, low-income community;
- Serve patients in Montefiore's family practice and geriatrics ambulatory care clinics;
- Serve patients in the nursing homes affiliated with other partners.

KEY STAFF: Led by the medical director of Montefiore's Department of Family Medicine and Community Health, with contributions from planning committees; a project coordinator focused on inter-partner activities, and a medical coordinator was responsible for palliative care training.

CARE COORDINATION: Palliative care services were provided by physicians and nurse practitioners located in outpatient clinics and by social workers in long-term care facilities.

PATIENTS: Persons diagnosed with congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), AIDS, cancer, and/or dementia, seen in family practice clinics; geriatric clinic patients over 75 years.

THE CATHOLIC HEALTH CARE SYSTEM (CHCS) NETWORK

Partners: Clarion Home Health Network, Calvary Hospital, Servitas (independent-practice physicians' association affiliated with CHCS), Terence Cardinal Cooke Health Care Center, Catholic Charities

GOAL:

- Work with physicians to manage complex medical and social services for patients with progressive, life-threatening illness.

CARE COORDINATION: Palliative care coordination provided by a nurse, supervised by Clarion; nurse case manager enrolled and maintained contact with patients, managed referrals.

PATIENTS: Manhattan and Bronx residents with one of several life-threatening illnesses, plus health insurance and a primary physician with membership in Servitas.

THE HARLEM PALLIATIVE CARE NETWORK

Partners: Visiting Nurse Service of New York (VNS), Memorial Sloan-Kettering Cancer Center, North General Hospital

GOALS:

- Address cultural and resource barriers to palliative care in the African-American community;
- Devise appropriate strategies for nurse-coordinated palliative care services;
- Create collaboration among physicians, community pharmacies, and religious organizations.

KEY STAFF: Lead agency (VNS) provided clinical management oversight; Memorial provided medical training and consultation; North General provided space for nurse coordinator and administration, and patient referrals from within its system.

CARE COORDINATION: Nurse interviewed and then followed up with patients, worked with families, made referrals to community agencies.

PATIENTS: Persons with CHF, COPD, end-stage renal disease, AIDS, and cancer were particularly targeted, but enrollment was open to any individual with progressive, life-threatening illness, referred by physician, agency, family, or self.

Continued

THE NETWORKS AT A GLANCE *(continued)*

THE MOUNT SINAI NYU HEALTH NETWORK

Partners: Hertzberg Palliative Care Institute of Mount Sinai Medical Center, New York University Medical Center Hospitals Palliative Care Program, Jewish Home and Hospital, Mount Sinai Home Health Agency, Mount Sinai Visiting Doctors, Cabrini Medical Center Hospice

GOALS:

- Integrate formal palliative care assessment, community-based care management, and promotion of primary physician involvement;
- Conduct formal analysis of project findings, beginning with a pre-intervention assessment of a patient sample;
- Demonstrate patient-care benefits and financial efficacy of providing palliative care within the Mount Sinai NYU system.

KEY STAFF: Led by a physician in the Hertzberg Palliative Care Institute; staffed by a nurse practitioner based in the Mount Sinai Visiting Doctors program, with clinical supervision by the program's physician director.

CARE COORDINATION: Nurse coordinator followed enrolled patients, using community referrals where appropriate.

PATIENTS: Persons with any of several specified illnesses — including lung disease, dementia, and cancer — enrolled before discharge from hospital.

THE QUEENS PALLIATIVE CARE NETWORK

Partners: North Shore-Long Island Jewish Health System, Hospice Care Network, Nerken Research Center at Parker Jewish Institute for Healthcare and Rehabilitation, Northern Queens Health Coalition (a group of more than 50 community-based organizations)

GOAL:

- Test a model of early patient identification and intensive service coordination using a small group of community physicians and a number of community service organizations.

KEY STAFF: Social work director from lead agency; nurse coordinator from the hospice partner; management committee of expert physicians and administrators, research director, and director of community coalition.

CARE COORDINATION: Small group of community physicians designated primary coordinators of palliative care; nurse coordinator provided support for assessment and referrals.

PATIENTS: Queens residents with cancer, cerebrovascular accident, COPD, or CHF.

THE SOUTHERN BROOKLYN PALLIATIVE CARE NETWORK

Partners: Metropolitan Jewish Health System, Lutheran Medical Center, Maimonides Medical Center, Bay Ridge Council on the Aging, Jewish Association for Services for the Aged, Park Terrace Interagency Council on the Aging

GOALS:

- Improve access to palliative care services for persons over the age of 65 from ethnically diverse neighborhoods of Borough Park, Sunset Park, and Bay Ridge;
- Work with community physicians to develop linkages, professional education, and training programs, and to coordinate patient care.

Continued

THE NETWORKS AT A GLANCE *(continued)*

KEY STAFF: Project director, manager, and evaluator based at lead agency; clinical team of two social workers and a nurse, also based at lead agency, to interact with primary physicians; advisory committee including expert physicians.

CARE COORDINATION: Clinical team enrolled and followed patients, made referrals, maintained contact with primary physicians.

PATIENTS: Individuals over age 65 residing within designated Brooklyn zip codes, with CHF, COPD, or stroke.

within and across networks, each project had at least one physician palliative care expert, whose role ranged from educator, advisor, clinical consultant, and/or supervisor to direct provider and coordinator of services.

Aligning Incentives

Partner organizations joined the networks for a variety of reasons. For many, the focus was on bolstering services: improving overall care and management of very sick patients and clients; expanding palliative care within the organization; increasing linkages among agencies serving the same clients; and smoothing transitions between services, such as hospital-nursing home transfers. There were organizational reasons as well: reaching diverse communities — often unaware of palliative care services, or otherwise previously unserved — in culturally appropriate ways; participating in a high-profile community effort; not wanting to be left out of a major grant; and real or perceived competition with other agencies that might participate.

For some networks, partners' incentives were clear and compelling, and in sync both with each other and with network goals. In Harlem, each organization could identify the benefits of an alliance: for the Visiting Nurse Service of New York, new inroads into the community for its overall services and its hospice; for the community hospital, North General, additional staff training and a palliative care focus that would dovetail with its

planned outpatient cancer center and positioning in the community; and for Memorial Sloan-Kettering, continuity of palliative care support for its Harlem-dwelling patients, increased local credibility, and a potential means of expanding minority participation in screening, clinical trials, and services.

Partners had a “shared vision and commitment — everyone put in more effort than the dollars rewarded, and brought resources to the table,” one leader commented. Administrators of the community hospital partner “never said no and always found a way,” even with very

There were numerous reasons for joining networks: improving care and management of very ill clients, expanding palliative services, increasing linkages among agencies, smoothing transitions between services, reaching diverse communities.

limited resources, to navigate the project through the hospital bureaucracy, said another.

Mount Sinai's network was nested in the medical center's geriatrics department, with its well-established hospital-based palliative care service and its physician home-visiting program. Other partners included a nursing home, a hospice, and New York University Hospitals, which had recently merged with Mount Sinai and which itself had an inpatient palliative care consultative service. For Mount

Sinai, the project was an opportunity to work on existing concerns — continuing care post-discharge, better use of resources, and expansion of the reach of services. Leaders planned to keep patients primarily within the Mount Sinai-NYU system by having the project’s nurse coordinator work through the medical center’s physician home-visiting program to organize services; where necessary, referrals would also be made to external agencies.

Long-term, Mount Sinai leaders wanted to position the nurse in the medical center’s home care agency, from which services could be coordinated for a broader base of patients. For partner Jewish Home and Hospital, that could potentially yield referrals of patients earlier in their illness, and opportunities to provide longer-term, less intensive care. But

were clear: a new awareness of palliative care in the community, and a cadre of physicians and nurse practitioners in its family practice and geriatrics clinics trained as palliative care case managers. What also became clear as the project unfolded was the conflict between the goals of clinic efficiency and provision of new, more time-intensive services (and, concomitantly, primary practitioners’ need for practical help with adding activities to already busy schedules). As a result, medical leadership initially resisted introducing clinic-based training and palliative care activities, significantly delaying the launch of services.

On occasion, it was the financial precariousness of organizations in combination with ill-defined incentives that significantly limited the time, personnel, and materials they could contribute. While many partners were grappling with budget challenges, some were frankly going under. The lead agency of the Catholic network, for example, had so weakened a financial base that it had been looking to grants to sustain its activities as it assumed its role within its parent Catholic Health Care System, a newly created affiliation of hospitals and long-term care organizations. For some of the System’s hospital partners, too, restructuring, extremely limited resources, and a fight for survival militated against participation in this unproven and unreimbursed venture — despite a network goal of demonstrating a 10 percent savings on Medicare costs through coordination of services for high-need patients.

Disincentives to participation — outweighing potential gains — were sometimes grounded in tensions between community-based organizations and hospitals and other large health care partners, reflecting real differences in vision and perceived differences in power or priorities. Smaller agencies tend to be highly pragmatic, strongly focused on meeting pressing client needs. They typically provide a narrow set of practical and social services (e.g., meal programs, case management) to

Agencies may see palliative care as having potential in their communities, but are often wary of time-intensive new ventures, particularly if they perceive a lack of immediate benefit to clients — or a lack of respect for and recognition of their expertise.

Mount Sinai’s internal focus made building links with community partners a secondary concern, and its research orientation, requiring matched patient groups for a controlled study, also limited partnership activities. Finally, negotiations to sell Mount Sinai’s home care agency — begun shortly after the network was initiated — increased the difficulty of carrying out the longer-range plan, and with it a second project goal of demonstrating financial, as well as clinical, benefit from coordinated care.

At times, one participant’s incentives, or expectations, proved to be disincentives for another, even within the same organization. In the Bronx network, the expected benefits for Montefiore Medical Center, the lead agency,

targeted clients, such as the elderly, within a specific neighborhood or catchment area. While rich in community information and established relationships with clients, they are also typically resource poor, understaffed, and constrained by city and/or state contracts. Agencies may see palliative care as having potential in their communities, but are often wary of time-intensive new ventures, particularly if they perceive a lack of immediate benefit to clients — or a lack of respect for and recognition of their expertise.

Indeed, more than a few organizations felt voiceless about network roles and resources. One leader perceived a lack of interest in collaboration, and pointed to “problems with the referral process — I could have helped if allowed to.” One network was described as “a real culture clash between ‘handmaiden work’ — performed by community-based social services organizations — and research design.” Another “looks like [something devised by] academics removed from the real world,” suggested a social services agency leader: “All that paper gets in the way.”

Participants in one network expressed frustration about the minimal sharing of responsibilities and resources, including dollars from the grant, and interagency interactions — not surprisingly, perhaps, given a lead-agency member’s comment that “we never really expected a program of equals.” Despite long-simmering negative feelings, however, time, persistence, and testing of interventions did bring hard-won improvements in the quality of partnerships, and the plan for accessing and serving patients, for at least several projects.

With time, too, incentives often became clearer and more compelling. Some initially reluctant partners became activists and supporters of their projects. In several cases, relationships improved once network service delivery began and organizations could see what the various partners contributed and how patients and families — and the partners themselves — benefited. Despite frustrations,

some partners ultimately expressed strong satisfaction with various elements of their networks, including greater access to clinical staff from other organizations, and opportunities to enrich their own programs.

Matching Resources and Capacity to Model

Although networks had proposals and work plans to guide them, the actual onset of collaboration required partners to change business as usual, develop common language and goals, and determine how to move beyond rhetoric to action. Regardless of network model, similar planning issues emerged, including the need for participants to “connect with other institutions” and learn more about their project goals, “figure out and define the product,” lay out roles and responsibilities and procedures for enacting them, and build capacity within organizations and collectively.

Networks differed significantly in how well and to what extent their diverse organizations drew upon each other’s skills and resources to create lasting, functional partnerships that could build capacity, engage in outreach, and deliver coordinated services. While there was an underlying assumption that networks would tackle each of those tasks in sequence, in reality those processes were often revisited or reinterpreted as the projects developed.

Goals and Roles

In several networks, particularly at the beginning, common goals were sometimes hard to visualize, much less achieve, and defining partner roles was an ongoing struggle. Partners weren’t “on the same wavelength,” noted one participant. “Responsibilities are unclear!” commented another, adding, “What are the outcomes desired?” Reflecting several project experts’ perceptions, one physician said he felt out of the loop, without a clear role except to “advise.”

Underlying those observations were the

nagging issues of whether there was real-world logic to each partner's planned contribution, whether the overall model of service delivery was coherent, and how participation would benefit each party. The grantees' proposals to the Fund had identified partners but someone, whether the project director or the coordinator, had to bring the group to consensus on network goals and assigned roles and responsibilities — and this did not always happen in a timely manner. A number of factors influenced how those roles would develop.

In some networks, partners' roles evolved or were consciously modified over time as the realities of capacity and commitment became clearer. The Queens network, for example, had set itself an ambitious long-range goal of integrating palliative care into the practices of primary physicians, skirting the need for special case managers. To do that it sought to teach palliative care precepts and procedures, and community referral tactics, to a small number of private-practice physicians who admitted patients to one of the constituent hospitals of the lead partner, the health system. Those physicians would, it was hoped, enroll appropriate current and future patients for network services, act as primary coordinators of those services, and ultimately serve as models for other physicians in the system. A simultaneous goal was expansion of palliative care into the ethnic and new-immigrant communities of Queens.

Early in the project, network partners shared common goals, even while advancing their own interests, and were largely successful in defining their roles in the network's community outreach efforts (e.g., a conference for clergy on end-of-life issues) and, to a lesser extent, capacity-building tasks. Staff from North Shore-Long Island Jewish Medical System provided operational oversight and medical expertise; Parker Jewish Geriatric Center, a long-term care facility affiliated with the health system, contributed a senior evaluator from its staff; Hospice Care Network

contributed, as project director, a palliative care nurse specialist; and the Northern Queens Health Coalition, an umbrella organization of over four dozen community agencies, brought to bear its cultural expertise and access to diverse populations, and offered practical assistance such as translation services.

Obstacles arose, however, in integrating each partner into the proposed service delivery model, as it allowed only the targeted physicians to identify and refer patients for network services. Compounding that structural problem were geographic, language, and ethnic differences between the targeted physicians and clients of the health coalition's community-based agencies, few of whom used those practitioners. Although the coalition could, theoretically, be instrumental in greater community outreach, member agencies were hesitant to participate in the network, feeling they would lose face in the community by promoting network services to clients whom they couldn't actually refer. Palliative care also seemed far removed from most agencies' primary missions — which ranged from insurance enrollment to mental health counseling — although less so for agencies serving the elderly. While the coalition did, ultimately, make significant contributions, its role in the network stopped short of what had been envisioned.

In the Catholic network it was the lead organization, Clarion, that played a weaker role than anticipated. Created to provide management services for six home health organizations, Clarion's visibility and clout proved limited. It was unable to win over Servitas, the recently formed independent practice association of system-affiliated physicians, which was supposed to be a major source of network patients. Indeed, Servitas initially requested a fee for every referral, and then avoided playing an active part in network development.

More active in the network was Catholic Charities, which contributed key staff with

expertise in services for the elderly, and promised social work coordination for network patients. Other partners, including Calvary Hospital, a well respected terminal-care facility for cancer patients, and Terence Cardinal Cooke Health Care Center, a large long-term care facility, contributed clinical expertise and leadership and expected to accept referrals from the network. Yet “there really never was a team,” noted one leader. Roles and goals of partners were not sufficiently in sync, diverse competencies remained underutilized and unblended, and resources were in short supply.

In the Southern Brooklyn network, despite well attended and intense partnership meetings, the vision of the lead agency remained just that for an extended time. Role development and, as a result, referrals were slow in coming, and partners, both hospitals and nearby community-based agencies, varied greatly in the extent of their contributions to the process. With persistence, frequent site visits, openness of the lead agency staff, and local “champions” in several partner organizations, some functional relationships did develop, however, generating referrals to the lead agency’s “Quality of Life Program” staff, and a new level of collaboration. Noting the successful example of one elderly-services agency in the network, the newly arrived director of another agency pointed to the “lost opportunity” in her own organization’s low level of participation, and agreed to formally specify agency contributions and goals for the future. In time, letters of agreement spelling out partner-specific goals and contributions would be initiated for all of the network’s partners.

In contrast to other networks’ experiences, what made partners’ roles relatively clear from the outset in the Harlem network was that each was already invested in palliative care and had resources and expertise that complemented that of the other partners. The Visiting Nurse Service would provide clinical supervision and expertise in data management and patient tracking. The medical director of

Memorial Sloan-Kettering’s well established pain and palliative care service lent not only his expertise but also his clout and personal commitment to raising the regard for palliative care among African Americans. He had already begun to work with North General to expand pain and palliative care training for the community hospital’s staff and to develop related services. North General, in turn, provided space and a base of operations, access to patients via existing services and staff, the expertise of a nurse practitioner and an oncologist, its standing in the community, and, over time, an interdisciplinary group of staff, links with local organizations, and supportive administration. Together, the partners also undertook one of the more elaborate community outreach and promotion efforts among the networks, seeing this as consistent with their common goal of serving the community.

Capacity Building

Underlying the initiative was the assumption that each partner had a potential contribution

Partners’ roles evolved or were consciously modified as the realities of capacity and commitment became clearer. In contrast, roles were relatively clear from the outset where partners were already invested in palliative care and had complementary resources.

to make, whether medical, social, psychological, spiritual, or logistical. To turn that potential into actuality, networks were urged to build capacity and competency during the first 12 months of the grant, to be ready to deliver services at the beginning of year two.

How networks interpreted that directive speaks directly to the challenges involved in creating the elements of a more integrated system. At least four aspects of building capacity and competence emerged as the projects progressed:

- Building key clinicians' and leaders' understanding of palliative care, practical skills, and confidence;
- Reviewing and modifying partner organizations' programs, practices, and policies, with the goal of initiating or expanding palliative care services;
- Creating an inter-organizational coordination process; and
- Promoting community understanding and support for the goals and services of palliative care.

Depending upon partners' sophistication in palliative care and the directions taken by project leadership, capacity-building activities varied. All networks engaged in the first of the

For all the networks, creating an interorganizational coordination process — a structure for working *as* networks — proved the most complex and challenging aspect of building capacity and competence as the projects progressed.

tasks above. The second — fitting a new approach and skills set into the framework of existing organizational mission, services, and resources — was particularly difficult for social service agencies, but some medical systems also found it problematic. And the third, the task of creating the structure for working *as* networks, proved the most complex challenge to all the projects. The fourth task, building understanding and support in the community, was tackled by several networks, with efforts sometimes but not always meshing with the strategy chosen to deliver services.

Bolstering clinical skills and understanding. Networks varied in whom they chose to educate — typically clinicians directly responsible for patient care, but in some cases staff

of partner organizations as well. Over the first 18 months, clinicians in several networks attended the American Medical Association's Educating Physicians in End-of-Life Care (EPEC) training or similar intensive programs. More often, training was closer to home, with staff from partner organizations well versed in palliative care — usually physician and nurse experts from hospitals, outpatient clinics, and hospices — playing a significant role in training network colleagues.

In the Southern Brooklyn network, for example, meetings hosted by the lead agency included teaching by invited experts on clinical and programmatic aspects of palliative care. The lead agency's Quality of Life staff met with the network's three medical experts to discuss admission and care criteria; they also met with the health system's hospice staff, to learn both its comprehensive approach and specifics such as how to run case conferences. At Mount Sinai, the Palliative Care Service already had a tradition of weekly case review conferences covering current inpatients and discharged patients being followed by the network's nurse practitioner.

For the Queens Palliative Care Network, building capacity among the private-practice physicians who had agreed to participate in intensive training was, on paper, a relatively straightforward task. Through regular meetings with the network's project and medical directors, the clinicians were to learn how to integrate a palliative care approach into their practices, use assessment tools, and make referrals to community agencies for additional services. (For the time they spent in this training, the five targeted physicians would receive financial compensation.) The longer-term goal was training for a broad range of physicians affiliated with the medical system's hospitals, in part as a cost-effective way of providing palliative care.

But network leaders greatly overestimated the influence of the medical-system lead agency on the target physicians. "We had great

expectations,” one leader said. “We spent one year working with them, discussing palliative care precepts and developing clinical criteria for enrollment.” Yet, in the end, they all continued to resist “giving bad news,” making referrals, and completing time-consuming assessment and tracking tools, especially for psychological assessments. As a result, only two of the physicians regularly attended training sessions, identified patients earlier in the illness process, or initiated discussions with patients on palliative care issues.

Revising established practice. Modifying organizational capacity depended on partners’ having both an interest in change and the resources to create it. Some partner organizations fared better than others. In the Bronx, for example, Montefiore’s ambivalence about adding new palliative care communication and practice duties to busy clinicians’ already tight schedules led to an overly long focus on educational activities and significant delays in implementing changes in practice patterns.

The medical center’s focus on its “captive audience” of clinic patients also left little room for its two long-term care partners, Beth Abraham Health Services and Aging in America, to play a meaningful part in the network and in delivering coordinated services. Yet those organizations — each comprising both large nursing homes and programs for the elderly living in their own homes — were determined to move beyond their limited roles.

Meetings on clinical and policy aspects of palliative care, led by Montefiore staff, were valuable first steps toward enhancing their programs. Staff of the two agencies also overcame their historical rivalry to work together through committees on the broader issue of enhancing palliative care throughout the Bronx. And individual organizational efforts mobilized internal change as well. At Beth Abraham, for example, a stronger focus on staff training, and a host of new programs and policies, allowed the system to identify, assess,

and serve palliative care patients among its nursing home residents. New monthly on-site consultations with the medical director of Montefiore’s inpatient palliative care service further enhanced the nursing home’s capacity to care for critically ill patients, rather than hospitalizing them.

These efforts yielded an “internal success story,” as one leader commented. Yet having little direct functional relationship with delivery of care through Montefiore’s outpatient clinics meant there “was never clearly a shared referral network of patients,” noted a leader of one of the programs for home-based frail elderly.

In Queens, with private-practice physicians not fulfilling their expected role, leaders looked elsewhere for a health system partner with the capacity to refer sufficient numbers of patients. An effort to work with a managed-care physician group practice affiliated with the medical system encountered barriers as well, such as administrative limits on referrals and physician reluctance to spend the extended time necessary to complete a referral.

The network eventually found the partner it needed in one of the system’s own outpatient oncology clinics, located at an affiliated teaching hospital. This arrangement — with its steady stream of eligible patients, interested clinicians, and a staff social worker — required intervention by the project’s nurse director only in the most complex cases. To some degree this was a retreat from the community-based capacity that had been anticipated. Leaders concluded that the scant resources, relative newness to the health system, and other organizational issues of the small community hospital originally selected as the locus for physician recruitment — a choice based more on geography and demographics than on capacity — reduced the potential resources that the extended medical system might have brought to bear.

A number of factors made building capacity especially challenging for the Queens net-

work's community health coalition partner: the "fit" of palliative care-related activities within ongoing services, agencies' not being allowed to make referrals, and a need to prioritize limited resources. Their greatest potential contributions — translations, for example, and educating and mediating with clients about the benefits of palliative care — were also largely sidelined by the failure of community palliative care services to materialize on a network level.

Yet the coalition, too, was ultimately able to contribute to and benefit from the network. Training by the project director helped some of the coalition's agencies themselves better assist clients with palliative care needs, as those agencies expanded their goals regarding services for the elderly. With time, the network nurse director's provision of information on additional palliative care resources for agencies' clients also increased coalition members' satisfaction with the project.

Creating inter-organizational coordination. What networks chose to label capacity building was not always closely linked to actual delivery of timely, coordinated palliative care services in the community. Some partners became frustrated at the lack of focus on developing a "product," a set of services and functional relationships to enhance referrals across the entire network. In one network, planning retreats focused on "community-building" and discussing death and dying but, as one participant noted, project leaders never spearheaded efforts to develop clear objectives and a network-wide strategic plan regarding how partners would jointly provide coordinated services.

In several networks, non-lead partners had no real role in providing care, due to the choice of service delivery model, poor partnership relationships, mismatch between their services and patient needs, or geographical restrictions. While partners theoretically served the same clients, many agencies were not prepared or equipped to partner in the

care of the very ill patients who were the focus of palliative services. Truly collaborative care management by medical centers and community-based organizations was frequently a long time coming.

Such collaboration did, at times, develop, however. As Montefiore's clinic staff gained experience and increasingly incorporated palliative care interventions into their practices, they increased interactions with their community-based partners as well. The lead clinic-based palliative care coordinator referred patients to Aging in America's case management program, a practice to be followed by other clinic staff in the future. The agency's social workers also added palliative care services to their other home visiting activities — a move one administrator lauded as cost effective, as staff was already in place. Of her advocacy of closer relations between her long-term care organization and the medical clinics, she observed, "We are just getting into what we should have been doing." As network leaders looked to a third year for the initiative, they began planning specific strategies to increase such referrals for patients with significant social needs.

Formal and informal meetings among various partners' key staff members were also important elements of capacity building. In the Southern Brooklyn network, Metropolitan Jewish Health System's Quality of Life staff, which made a number of visits to its hospital and agency partners to discuss the program, began to meet regularly with the staff of a particularly receptive community agency, the Bay Ridge Center; in time, the two groups collaboratively identified potential enrollees and managed cases.

The network's staff offered elderly clients "frequent contact with social workers, and follow-up that our case managers [on their own] can't provide," said the Bay Ridge Center's project leader. "If the patient is hospitalized, our case workers [normally] have to 'close' the case and reopen it after discharge. But the network social workers call and go to

the hospital, eliminating gaps in service. Now clients feel they have an advocate [during their hospitalization].”

When Harlem network staff arrived at the community-hospital partner, North General, they were drawn into existing pain and palliative care capacity-building activities, including multidisciplinary staff training, grand rounds, and case conferences, all part of a recently established joint venture between the hospital and the director of the pain and palliative care service at Memorial Sloan-Kettering. Weekly case conferences provided a forum for discussion of individual patients’ medical, social, and practical needs, generated referrals to the network, and promoted interdependency among hospital and network staff. With hospital administration encouraging integration of all these efforts, internal service boundaries were frequently reduced. Project leaders also developed an extensive database of resources — over 50 community-based organizations, pharmacies, nursing homes, home care agencies, physicians, outpatient clinics, and clergy — that could supplement hospital services. Such cooperative activities, generating a steady stream of patients from the hospital and increasing the likelihood of community referrals, afforded an opportunity for case-based learning and forged stronger alliances.

Promoting community support. Several networks carried out activities to build community understanding and gain a broader base of support among laypersons and professionals, additional resources — such as agencies or other experts — for enrolled patients, and referrals to the network, if the enrollment model permitted. Networks used a variety of media to publicize themselves. The Catholic Network, for example, distributed flyers and other information through religious and social service networks and parish newsletters, garnering patient referrals from parish nurses as well as from social service agencies within Catholic Charities.

In Queens, one of the network’s first out-

reach activities was to hold a well attended town meeting for local clergy and physicians, and network staff. This was the first time, some of the clergy commented, they had spoken about end-of-life issues and palliative

What networks chose to label capacity building was not always closely linked to actual delivery of timely coordinated care. Partners were frustrated by the lack of focus on developing a network-wide strategy, set of services, and functional relationships.

care with health care providers. In turn, the project drew on the health coalition’s knowledge of the area’s various communities, and held focus groups on end-of-life issues, and discussions about the philosophy and services of palliative care, with members of the African-American, Chinese, Hispanic, Korean, and Russian communities. These sessions elicited a wealth of information on gaps in health care delivery for ethnic populations in Queens, including inadequate translation services, benefits assistance, and transportation; a lack of culturally competent and ethnically diverse clinical staff, support groups, and home care services; and a lack of venues for discussion of advance directives. The result, largely through the work of the community coalition, was a resource manual for physicians, other providers, and the lead-agency health system, documenting key cultural beliefs and practices of many of the area’s immigrant and ethnic communities, and listing area agencies serving those communities.

The Harlem Network saw educational outreach in the community as integral to its basic mission *and* its service delivery plan. The network’s goal of promoting palliative care services and overcoming resistance to palliative care among African Americans (Crawley et al. 2000; Payne, Payne, and Heller 2002) was later expanded to address needs of Harlem’s

growing Hispanic community as well. The network's highly inclusive service model was consistent with this approach. While it had targeted for enrollment individuals with any of five common diseases, its policy was that no one with a progressive, life-threatening diagnosis would be turned away, if willing to sign an enrollment agreement. By 20 months into the project, the team had conducted over 150 group and one-on-one meetings, presentations, and clinical grand rounds, reaching approximately 4,350 health care professionals, clergy, community-based organizations, and lay persons. The network later initiated a telephone survey of family caregivers whose network-patient relatives had died, to assess

required a broader repertoire of skills than those used within leaders' "home" organizations. To succeed as trans-organizational leaders, individuals had to have the ability not only to inspire and educate would-be partners but also to focus pragmatically on managing a process and forging a team.

Clinical leadership was crucial, given the services that networks were to provide. To be most effective, however, it had to be matched with logistical and political agility, strong management skills, and the ability to generate referrals from colleagues, address turf issues, cross disciplinary boundaries to address social as well as medical needs, and otherwise guide these novel and sometimes misunderstood projects. More skilled leaders considered how partners could build consensus, how the pieces of the service model fit together, and how capacity could be developed, or resources best accessed, among all partners.

Procrastination, avoidance of thorny decisions, or lack of interest in or understanding of all partners' goals and incentives at times got in the way of leaders moving a network forward or forging working partnerships. But some individual leaders grew, over the course of the project, in their capacity to think and plan outside the confines of their own organizations and build collaborative proficiency, sometimes with prodding from other partners.

In some cases, along with the designated project leader, other significant leaders were identified early on or emerged over time. Projects were often well served by a blend of clinical expertise and programmatic skills spread across several individuals (and sometimes agencies) able to work as a team.

Organizations as Leaders

By itself, the type of work an organization performs, and the setting it does it in, is unlikely to make or break the success of a community palliative care program. But the mission and orientation of a network's lead agency is likely to influence, at least, how the project is conceptualized and implemented.

In the Initiative, lead agencies' varying

Long-term care agencies may have some advantage in devising a community-oriented approach, given their experience with coordination and interagency collaboration, provision of care in clients' homes, and patients' extended time in their systems.

satisfaction with services. These efforts garnered a growing number of referrals — approximately 20 percent of all referrals to the network — from interested community agencies, physicians, and clergy, and reached community residents with much-needed information and support.

Network Leadership

In analyzing and assessing network leadership, several key elements emerge as important, notably the skills and styles of individual project directors, the qualities that make for successful lead agencies, and the role of the leadership team in bringing networks through their stages of growth.

Individual Leaders

Leading partnerships, inventing and reinforcing new alliances, and responding creatively to the many and varied challenges of networks

reward and management structures, resources, and skills sometimes significantly affected how projects were operationalized and supported. Context mattered, as well, with evidence of benefits to nesting new services within existing ones; in itself, however, this was no guarantee of success.

While two academic medical centers — Mount Sinai and Montefiore — brought well developed core palliative care expertise and inpatient services to leading their networks, they had first conceived of their projects as primarily medical, with little social service content. Both were only marginally oriented to community partnerships, and focused instead on internal alliances. By project's end, however, there was appreciation for a broader approach. At Mount Sinai, one leader noted his belief that long-term care organizations might be the best suited to lead such endeavors in the future, a strategy in step with the network's original longer-term plan. At Montefiore, faced with complex social needs beyond the boundaries of family practice, leaders planned to introduce an expanded role for clinic-based social workers, and make more referrals to a long-term care partner that could provide intensive case management and home visiting.

Long-term care agencies may indeed have some advantage in devising a community-oriented approach because of their prior experience with coordination, referrals, and interagency collaboration, their systematic provision of care in clients' homes, and patients' extended tenure within their systems. Nevertheless, those agencies, too, had much work to do on building collaborative efforts, addressing the issue, for example, of how to bring hospital-based physician and nurse experts into the loop for referrals and consultation. The Harlem Network's Visiting Nurse Service, for example, was able to focus on refining its procedures and upgrading capacities, rather than on patient recruitment, largely because of its working relationship with its community hospital partner, which provided three-quarters of the network's referrals.

Conversely, non-service components of larger organizations may be at a disadvantage when taking the lead in such initiatives, because of their lack of a clearly defined space — figuratively and literally — in the organization's caregiving structure. It was, perhaps, this lack of involvement of a direct service component within their hospitals that led the Queens and Catholic networks to adopt the models that they did — working directly with physicians in private practice, relying on them for referrals and, in one case, coordination.

This approach to enrollment proved the most demanding, and frustrating, of any attempted by the networks.

Although the Queens project was able to use the freedom of its “flexible positioning” to cross boundaries and address a myriad of issues creatively, its leaders ultimately determined that clinic-based primary care was a more viable option than relying on private-practice physicians. Moving from their initial approach, they suspended network services and instead brought their observations and experience to a newly formed North Shore-Long Island Jewish Health System committee examining opportunities for system-wide approaches to palliative care.

Moving through the Developmental Process

For both individual and institutional leadership, the task that encompassed all others was moving partners through a developmental sequence, in a timely manner, to the level of true partnership. In planning, building capacity, and preparing to deliver coordinated services, the six networks all addressed, if not always successfully, some of the benchmark activities of at least the emergence and transition — if not maturity — stages of organizational development. Nevertheless, the developmental process varied from network to network, as well as from traditional research schemata.

Two hallmarks of the emergence phase — developing collaborative proficiency and build-

ing trust — actually continued throughout the project, in response to the demands of service implementation. Leaders encouraged formal and informal meetings among key staff, which, particularly in a few projects, eased conflicts among partners and led to increased sharing of decision-making, ultimately enhancing trust. Lead agencies and their partners began conducting realistic inventories of “assets, skills, and knowledge” at this point, but this process also continued throughout the project. Networks continued with capacity-building activities (e.g., partner and provider education, revision of policies and procedures, and improved linkage of services during transitions between providers) as well, which contributed, in varying degrees, to collaborative proficiency. During this first phase, for example, the Harlem network’s medical director and lead-agency staff spearheaded community outreach work that appeared to have benefits further down the road.

Leadership was crucial in melding partners’ incentives and the project’s operational goals. Networks that had difficulty moving through the steps of the emergence phase tended to get stuck at building consensus, establishing roles, or realistically assessing skills and knowledge related to partnering per se. That sometimes reflected the “set-up-to-fail syndrome,” which begins “when partners lack a clear, shared understanding of the partnership’s purpose, and may have joined for political, funding, or convenience reasons. Partners often rally around broad, abstract statements of purpose that assure high levels of initial buy-in but also permit varying interpretations or simply confusion about the partnership’s focus” (Weiner, Alexander, and Zuckerman 2000; Phillips and Springer 1997). Critical as primary-agency leadership was, though, in some cases when things bogged down “boundary-spanning” leadership (Alter and Hage 1993) emerged, instead, from other partner organizations, helping nudge the collaborative process along.

Early on networks had their share of

critical, make-or-break moments; both the sensitivities and logistics of introducing change could be major stumbling blocks, requiring tough decisions from leadership. The Mount Sinai network had to compete with other hospital projects for patients, faced the rigorous demands of two institutional review boards, and lost the expected resource of the hospital’s home care agency. In the Bronx network, leaders had to address the loss of two coordinators over the course of the project, and, after delays in implementation, push through issues of clinic staff time and patient load in order to roll out services. For the Queens and Brooklyn projects, an inadequate number of patient referrals stimulated new partner roles and alignments, and strategies for recruiting providers who would refer sufficient numbers of patients. Following a regulatory challenge that drew leadership’s attention away from network development, the Harlem project had to transfer management responsibilities from the lead agency’s hospice to its business-development division, a move that proved successful because of the division’s experience with start-up projects and access to a wide range of expertise within the agency.

As networks moved into the transition phase, the initiation of service delivery was a loud wake-up call for leadership and partners alike. The processes of enrolling and serving patients tested each network’s model; the need to make and measure progress loomed large. It was shortly after initiating services — when the *lack* of progress became clear — that the Catholic network’s leadership decided to terminate their project, some 15 months into it. For other networks, revision and fine-tuning of the service delivery model continued until nearly the end of the funding period.

The transition phase also brought into the open whether agencies were really in their partnerships or out of them, and how leadership would manage sometimes difficult relationships to move networks forward. Those relationships were continually changing. In some cases, leadership shifted: physician

palliative care experts who had played a major educational role during the first phase of development often found they had no role as consultants once primary physicians began delivering services, either because the network model made that difficult or the primary physicians weren't receptive. Clinical teams, in contrast, took on a greater leadership role, as they observed and modified how the model actually worked. And leaders from some marginalized partners, such as the long-term care organizations in the Bronx network, used this transition phase to demonstrate how integral they could be to the process.

In short, the developmental process was messier than the literature has described, involving ongoing dialogue and multiple adjustments among partners. While no network escaped major challenges, leaders in some of them, particularly those with adequate access to patients and resources, were able to take timely steps to promote their networks' forward movement.

Conclusions

In exploring networks' strategies for creating effective partnerships, we found that the promise of community palliative care was often difficult to translate into reality: for some partners, burdens outweighed benefits. Networks varied in their overall strength, capacity, effectiveness of service delivery model, and ability to work productively with community partners. Yet by the end of the two funding years, the Community-Oriented Palliative Care Initiative had evolved from a high-risk venture to a program with genuine potential.

Some networks were better than others at attacking necessary developmental tasks in a timely manner, or responding to unexpected crises. Several had significant achievements that nevertheless stopped short of a viable strategy for delivering coordinated services with partners' full support. And some lasted through the funding period but ultimately

determined that the time and resources needed to continue their efforts were not there. Overall, the five surviving networks had demonstrated, with varying degrees of depth and practicality, that if they could enroll patients they could provide them, and sometimes their caregivers, with coordinated palliative care services. In some, health and social service organizations had learned how to work together, and partnerships had become a valuable tool for expanding their range of services and options for coordination.

Three of the networks, Harlem, Southern Brooklyn, and the Bronx, had passed through the emergence phase and were actively engaged in "transition." Each had developed and was refining a delivery and coordination

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system, and was testing strategies for sustainability. None, however, had yet reached "maturity," i.e., consistent replication of coordinated care for a significant number of clients — not surprising, given the complexity of the task. Most networks had significant accomplishments in at least some areas. The Bronx and Mount Sinai projects had both established practice patterns that could deliver palliative care services outside their inpatient units, and the Bronx network was expanding its efforts to improve coordination with its partners. The Southern Brooklyn network had effectively deployed an interdisciplinary team to provide coordinated care for enrolled patients; while continuing to boost collaborative services and referrals from partners, it ultimately chose to better integrate itself into the varied services of its lead agency.

to establish a network against institutional criteria for promotion and tenure, such as the need to conduct publishable research. For community agencies, which must often focus on generating and fulfilling contracts by providing predetermined services to a specific number of clients, palliative care networks may not appear relevant or viable.

Similarly, the competitive advantage that does sometimes accrue from linking network services to a current program, such as a hospital's home health agency, can easily evaporate if that component is sold or reconfigured. Indeed, networks and their associated partnerships took strongest hold where needed resources served more than one component of a system — justifying expenditures by spreading them over several departments, divisions, or partners — or where the project dovetailed with other initiatives.

Based on COPCI's early findings, networks seem to hold promise for bringing community residents with life-threatening illness appropriate palliative care services, earlier and more effectively than has been achieved thus far. What is also clear is the extent of the work ahead: strengthening services and programs, refining collaborative relationships among network and partners' staffs, and enhancing strategies for sustaining these programs. To continue that work, in 2002 the Fund invited the five remaining networks to apply for a third year of funding. Two, the Mount Sinai-NYU and Queens projects, chose not to request that, instead continuing to apply their own resources toward integrating coordinated palliative care into ongoing services. The Bronx, Harlem, and Southern Brooklyn networks were each awarded third-year grants of between \$125,000 and \$150,000.

RECOMMENDATIONS

- Draw upon the strengths of the lead organization in developing the network's service delivery model, and then identify complementary partners that can meet patients' medical and social needs, or otherwise enhance the model.
- Bring into the network at least one partner, not necessarily the lead partner, with a clinical setting in which to nest services, for optimal access to patients, opportunities to link with providers, and administrative support and staff training.
- Identify goals and measurable outcomes for the network as a whole and for individual partners early in network development, to set the tone and provide a base for the hard work to come.
- Match roles to partners' goals, services, resources, and strengths. Create a plan that incorporates each partner's potential contributions and specifies how services will be integrated across partners.
- Practice trans-organizational leadership, stepping beyond the boundaries of leaders' own organizations and professional disciplines to recognize and use the expertise of other, often smaller partners. Share authority, solicit advice, and give partners responsibility and decision-making power for project components; distribute financial and other resources equitably as well.
- Elicit partners' commitment, early on, to their assigned roles, although those roles may be modified, or expanded, over time. Commitment to the *idea* of partnerships is also essential.
- Anticipate partners' differing expectations, and make explicit efforts to address them. Partnerships benefit from an early exploration of what each organization wants and expects to achieve, for itself and the network as a whole.

Continued

RECOMMENDATIONS *(continued)*

- Don't assume that partner meetings per se will lead to trust and buy-in. Meetings must incorporate joint decision-making, airing of differences, and sharing of resources; failing to address conflicting needs and approaches can exacerbate conflicts and weaken the partnership.
- Extend capacity building beyond clinical issues to include strategic skills for individual partners and the network as a whole. Strengthen abilities to communicate, make referrals, overcome barriers to collaboration, expand and pool knowledge, and incorporate new tools and approaches into ongoing practice.
- Focus on hospital- or clinic-based *staff* physicians and nurse practitioners for the majority of patient referrals and promotion of services. Be realistic about the ability of medical systems to influence private-practice clinical and management patterns, in the absence of strong support, leadership, and incentives for participation.
- Once service delivery has begun, keep partners interested by promoting ongoing dialogue, collaborative case management, and demonstration of successes.
- Be prepared to assume risk to reap long-term benefits.

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