The PATHWAYS Hospital Project

by M.C. Sullivan

In 1995, the Hospital Ethics Committee Consortium organized by Midwest Bioethics Center created the PATHWAYS to Patient-Centered Palliative Care: A Community Approach *— a guideline document, or "how to" manual for hospitals that want to improve care of the seriously ill and dying. Following the publication and wide dissemination of this manual, the Center began to implement strategies to produce positive change in the way hospitals respond to dying persons and their families. Spurred by the same desire to alter hospital culture through improved care of the dying, eleven hospitals collaborated with the Center to form the* PATHWAYS *Hospital Project.*

As the PATHWAYS project gradually took shape, two basic premises became apparent. First, we planned to use SUPPORT (SUPPORT Principal Investigators 1995) for baseline data against which we would assess change. Since the sites for that study were acute care hospitals, our initiative needed to examine the practices related to care of the dying in hospitals. Second, and perhaps more important, if we were to educate both patient/citizens and health care professionals about options that should be available to the seriously ill and dying, then we needed a presence in institutions that care for the dying. To present realistic options, we needed to focus our attention on, and collaborate with, hospitals.

A Community-based Bioethics Center

In the fifteen years of its existence, Midwest Bioethics Center had developed and nurtured remarkable relationships with the hospital community of metropolitan Kansas City. There are many reasons for this synergistic collaboration. The three founders of the Center were on the staff and faculty of academic medical centers on either side of the state line; and from its earliest days, Midwest Bioethics Center had relied on collaboration with health care professionals throughout the Kansas City metropolitan area. This collaboration is vital. It helped — and helps — the Center create and implement a bioethics agenda that responds to specific community needs.

As the Center grew, clinicians with experience and affiliations at Kansas City area hospitals were added to the staff. When staff recruitment reached beyond the city limits, new faculty came who were also familiar with hospital culture and needs.

In addition, one of Midwest Bioethics Center's earliest foci had been on the creation, development, and education of hospital ethics committees. Within a few years of its inception, the Center had not only trained ethics committees at all Kansas City hospitals; it had also formed a hospital Ethics Committee Consortium (ECC). ECC membership was comprised of representatives from hospitals who were institutional members of the Center or whose ethics committees had been educated by the Center. Since 1986, ethics committee members have met every other month to discuss commonly experienced ethical issues. The results of these discussions are published as guideline documents and white papers.

In 1995, the ECC convened a community-wide work group to target the major content areas for the Center's three-year strategic plan to improve care for the dying. The five PATHWAYS themes that emerged were advance care planning;

treatment redirection; resuscitation status; pain and symptom management; and the psychological, social, and spiritual care of the dying. Separate working groups were established to study and make recommendations in each of these areas.

The results of this collaborative effort were published as a guideline document consisting of five chapters, each of which follows a prescribed formula. A philosophical and clinical overview of each theme is followed by a glossary of technical terms that are pertinent to the chapter. Authors identify desired outcomes or goals for end-of-life care and list the barriers to achieving these goals. The document then recommends dozens of practical strategies for addressing and overcoming the barriers to each goal. Finally, each section contains bibliographical references and samples of documents, tables, and forms that have been cited within the chapter.

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This document — the result of hundreds of volunteers working thousands of hours — was extremely well received and disseminated widely throughout the Kansas City area. As a result of networking among hospital staffs, Center staff presentations, and Midwest Bioethics Center website announcements, many facilities around the country are now using this same document— and it has also been adapted for use in nonhospital settings. Versions are now available for long-term care facilities and for home health and hospice agencies.

The PATHWAYS Guideline Document stands on its own as a significant and successful strategy aimed at the hospital world. But Center staff believed that even more progress was possible. We asked ourselves, for example, how we would know if the strategies offered in the manual had been successfully implemented. We had claimed that it was a "how-to" manual for hospitals who wished to improve the care of the seriously ill and dying. The claim would, we realized, fall flat unless we could provide evidence of impact and positive change. With this impetus and intention, we fleshed out the PATHWAYS Hospital Project.

The Project

MBC staff identified nearly three dozen acute care facilities in the metropolitan Kansas City area. Throughout the first quarter of 1997, Myra Christopher, the Center's president and chief executive officer, met with area hospital chief executives. She presented the SUPPORT study and suggested that hospital staff might want to participate in a demonstration project in direct response to its dismal results. When the number of volunteer institutions reached eleven, the Center stopped accepting applications because our ability to provide liaisons between the Center and each hospital was stretched to the limit. And, with fully a third of all Kansas City's hospitals involved, we felt that we had sufficient footing to be able to demonstrate the difference PATHWAYS strategies would make if they were appropriately implemented.

The hospitals selected for the project represent a true cross-section of the metropolitan area's acute care landscape. Participating hospitals are public and private, urban and suburban, teaching and nonteaching, religious and secular, academic research centers and community institutions. The following hospitals participated:

- Bethany Medical Center, Kansas City, Kansas
- Providence Medical Center, Kansas City, Kansas
- St. John's Hospital, Leavenworth, Kansas
- St. Joseph Health Center, Kansas City, Missouri

- St. Mary's Hospital, Blue Springs, Missouri
- Trinity Lutheran Hospital, Kansas City, Missouri
- University of Kansas Hospital, Kansas City, Kansas
- St. Luke's Hospital, Kansas City, Missouri
- Shawnee Mission Medical Center, Merriam, Kansas
- Heartland Regional Medical Center, St. Joseph, Missouri
- St. Luke's Northland Hospital, North Kansas City, Missouri

We sought a balance between encouraging each hospital to craft a plan that was customized to its own milieu and the effort to identify common criteria at each site through which to show an areawide impact.

In June 1997, Center liaisons explained the rationale of PATHWAYS to the CEOs of these hospitals and what the Center was requesting of each hospital as a participant. The major request was for institutional support; for example, the hospitals needed to provide time for hospital-based staff to meet regularly to assess the needs of their institutions. We also requested that each hospital designate leaders (ideally a physician and nurse combination), and a multidisciplinary team. In addition, the Center expected participating hospitals to be receptive to the recommendations of their PATHWAYS teams.

Center liaisons reassured participants that they would not impose a single template on all hospitals. Rather, each institution would assess its own facility to determine what practices and policies were already being used or considered to improve care of the dying. We expected that preliminary internal research would indicate that each facility was in a different place in relation to this project and that each one's unique focus would reflect its own culture and diversity.

An early meeting between the Center and the hospitals' executive leadership was important for two reasons. First, it provided an opportunity for the CEOs to hear again what their commitment was and to understand that each of their colleagues had heard the same message and made the same agreement. While this step always has strategic significance, it seemed especially meaningful given that the then current climate of health care was marked by competition and, in some instances, distrust.

The meeting was also important for a second reason. These institutional leaders needed a sense of collegiality and solidarity to approach this important issue, which they shared and which evoked strong feelings. They would leave the meeting, we hoped, commissioned to lead an initiative that would have profound implications.

Two months later, the team leaders from each site met. In the months since their initial recruitment, a series of mergers had reshaped the health care landscape in Kansas City. Immediately, Center staff faced the first test of its pledge to allow the institutions to determine what would work best for them. The team leaders were not, in every instance, the physician-nurse combination we had suggested.

Among the eleven sites, a group of three hospitals had become part of the same system. This system then created one multidisciplinary team of staff based at each hospital under the leadership of a member of corporate management. Two Catholic institutions also merged their accompanying long-term and home care agencies to form a single system. A physician and nurse from the larger medical center served as a team leader with a nurse at the smaller center. In another variation from the proposed arrangement, a chaplain and nurse provided leadership to their hospital's multidisciplinary work group.

In the eight weeks that followed, the PATHWAYS teams observed their institutions; they researched policies, protocols, quality assurance standards and measurements, and reviewed other materials that might indicate ongoing attention to issues related to the five thematic areas that PATHWAYS was investigating. During the same period, they

assembled colleagues who would become their in-house collaborators and familiarized themselves with all five chapters in the PATHWAYS manual.

At the end of two months, the team leaders reconvened. As each hospital team began to construct the framework of a project that would best fit its institution, the Center and teams also began determining the common indicators of change that would enable us to track all eleven project sites.

All hospital teams agreed to gather baseline and postproject data in two areas. First, the eleven facilities would track the increase in the occurrence of advance care planning conversations between providers and patients. This indicator is important for two reasons. It would encourage hospitals to foster the occurrence of such conversations and ensure that their content was communicated to all those involved in the patient's care.

Second, the hospitals agreed to document their method of pain management. Hospital staff members were asked to assess a patient's pain level, treat the pain, then reassess and treat again, repeating this cycle until it was clear that the pain had been adequately treated. Pain assessment and treatment also had to be carefully and fully documented, which would help ensure the hospital's constant awareness of the need to regard pain as a fifth vital sign and apprise all care team members of the patient's pain status.

As each team custom-tailored the plan for its institution, team members collected data on these criteria. They reviewed the charts of approximately 10 percent of the patients who had died in the hospital in the year before PATHWAYS began. A similar chart review will be conducted six months after the "official" PATHWAYS initiative. Indeed, that so much activity in each institution will take place following the project indicates the substantive impact of this collaboration.

Early Findings

The teams met quarterly to report on their activities. These sessions were helpful for all involved as they provided an opportunity to share ideas, discuss common concerns, and brainstorm solutions when they were needed. They were also used to clarify uncertainties about next steps and to encourage each other to persevere. Marge Barnett, RN, a team leader at the Kansas University Medical Center, notes that the group meetings were "one of the great joys of participating in this project. . . . We learned what others were doing, problem-solved together, and shared ideas that were helpful."

"It's great," she said, "to be able to unite in a common desire to improve end-of-life care."

Barnett also acknowledged that given the atmosphere of tumult and competition among hospitals, knowing that there were colleagues throughout the city with whom she could collaborate above the competitive fray was a tremendous morale booster. "It's great, she said, " to be able to unite in a common desire to improve end-of-life care."

Midwest Bioethics Center's role was to convene the team leaders regularly and provide resources and information about what was going on throughout the city and in other parts of the country. The Center also coordinated communication among the hospital teams, and collected data on the two project-wide indicators: advance care planning conversations and pain management. Intermittently, throughout the two and a half years of the hospital project, the Center invited national speakers, including Betty Ferrell, Declan Walsh, Joanne Lynn , and others, to speak on topics related to the two common indicators.

Additionally, PATHWAYS hospital teams were encouraged to participate in other strategies, such as the Nursing Leadership Institute, the Physician Leadership group, and the Palliative Care Curriculum work group. From the beginning of the project it was clear that the team leaders were the best resources for each other in the practical matters about which they had concerns, such as how to

gain the attention and eventual support of their staff colleagues.

Carol Mulvenon RN, a team co-leader at St. Joseph Health Center and Carondelet Health System says, "I really appreciated that we were all working on PATHWAYS as a community. It made a tremendous difference to know that we could, at any time, call on colleagues around the city for advice and support."

Preliminary Findings

Certain significant findings began to emerge even before we could complete the data collection and analysis. It is striking, for example, that of eleven participating hospitals, nine have initiated Palliative Care consultation services. Every single hospital has integrated a palliative care curriculum into their education and training programs for physicians and nurses. Four hospitals have instituted monthly palliative care newsletters directed to clinical staff. Many of the participating hospitals have formally adopted steps leading to the improved assessment and documentation of pain; several institutions have created new vital sign and assessment flowsheets for palliative care procedures; two others have adopted pain as a fifth vital sign.

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One hospital saw the departure of its physician and nurse co-leaders during the evolution of the project. New leadership not only moved in and carried on seamlessly where the original leaders had been; the hospital continued to be aggressive in its efforts and now has a palliative care consultation service. This same hospital participates in a large system in which eleven other hospitals have expressed the desire to model themselves after its example and begin comprehensive palliative care efforts.

Another facility — one that is perhaps the primary medical center for an entire region of northeast Kansas and northwest Missouri, and which has a tradition of remarkable community outreach — conducted a series of focus groups and an extensive community survey to determine attitudes and practices regarding end-of-life care planning. The results were collated and integrated into the palliative care education plan for its professional staff and will be published.

Rich Morgan, MD, one of the leaders at St. Joseph and Carondelet Health System, recognized the need to educate along the entire spectrum of involved persons. "We have had to initiate efforts on all the usual fronts in order to make palliative care an integrated part of clinical attitudes and practices. We have had brown bag lunches, educational programs, newsletters and seminars, and we corner clinicians where they hang out!" Hospital participants have raised awareness so successfully that policies are now being reexamined and recast with a palliative care bent.

Conclusion

The hospital project, like so many of the strategies that comprise the PATHWAYS initiative, has helped begin the cultural shift that SUPPORT urged. Still, as we approach the end of this three-year strategic plan, it is clear that we and our hospital-based colleagues have just begun our work.

Juel Pierce, a chaplain and PATHWAYS facilitator at Heartland Regional Medical Center, likens the hospital project to a seed. "It can be frustrating for those of us working in our separate institutions when we do not know what the end product will look like. But what we do know, as we begin to record data from our participation, is that the seed has been growing and we haven't even noticed. As I begin to collect the information from our various efforts, I am struck by how much we have produced. At the same time, I see that we are at the beginning of tremendous growth."

Ann Allegre, MD, now medical director of Kansas City Hospice, was the physician leader of the PATHWAYS team at Bethany Medical Center. "The importance of the project to our institution is that it gave us encouragement and support by knowing what other hospitals were doing. In addition, [the hospital initiative] kept our feet to the fire in that it kept the project a priority, knowing that we were meeting with the other teams and were expected to report on our results."

Allegre says that the significance of PATHWAYS in the community can be seen by the way it "raised awareness about pain management, communication techniques, and other important technical areas in end-of-life care. This raised the knowledge level of medical professionals to some degree. Obviously, there is still much to do but . . . the consideration of palliative care is at least on the medical page now!"

References

The SUPPORT Principal Investigators. 1995. "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)." *JAMA* 274(20): 1591.

Quotations from Ann Allegre, Marge Barnett, Rich Morgan, Carol Mulvenon, and Juel Pierce were taken from personal telephone communications to the author, who gratefully acknowledges their assistance (December 1999).