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# PATHWAYS to Improve End-of-Life Care — A Community Approach

by Myra Christopher

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*Midwest Bioethics Center responded to the SUPPORT study with a strategic initiative called PATHWAYS to Improve End-of-life Care: A Community Approach. This article introduces that initiative and reviews its substantial contributions in the broad sense. The effects of this program, although its evaluation has yet to be completed, are far-reaching because PATHWAYS tackled the problem of dying, not as a medical problem, but as a problem for the community as a whole.*

In 1994, Joanne Lynn presented a monumental project to the American Association of Bioethics, meeting jointly with the Society for Health and Human Values and the Society for Bioethics Consultation. The project, called the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), was the largest study ever done concerning the care of seriously ill and dying patients. Joanne Lynn and William Knaus were principal investigators. The information Dr. Lynn provided had a chilling effect on all present.

Based on the eight-year study — funded by the Robert Wood Johnson Foundation, implemented at Beth Israel, Duke University, UCLA, St. Joseph's and MetroHealth hospitals, and interpreted at George Washington University—we learned that dying in the United States was even more dreadful than most of us had imagined.

SUPPORT was premised on the notion that end-of-life care is inadequate in this country because health care professionals, patients, and their families do not communicate. In its first phase, SUPPORT gathered baseline data on four specific categories:

- length of stay in intensive care units,
- advance planning,

- management of pain, and
- knowledge of patient preferences.

The data were so alarming that investigators decided not to publish the results until a second phase, the “fix-it phase,” could be completed.

Phase two centered around a cadre of specially trained nurse consultants who facilitated conversation among key stakeholders. A nurse was

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assigned to each patient involved in the study. Those involved in the project reported that they were very optimistic about the progress being made. “Everyone felt better with the nurse . . . around,” Dr. Lynn said, in a documentary about the project.

At the end of phase two, however, when the data were analyzed and specific outcome measures displayed, the investigators found no difference between phase one and phase two. SUPPORT demonstrated, not progress, but, as William Knaus put it in the SUPPORT documentary: “we create scenarios worse than death every day in our hospitals.”

## How People Die

According to SUPPORT, many people in this country die alone; often unconscious and on ventilators, and isolated in intensive care units (the latter for an average of ten days). Of those in the study who were conscious at the time of death, more than half (53 percent) reported being in pain. Do-not-resuscitate orders were usually not written until the patient was within forty-eight hours of death; and even when patients had made an advance directive, two-thirds of the time, their doctors had never read the document. Further, the majority of patients in the study reported that their physicians had never discussed the possibility of death with them.

Having heard Dr. Lynn's presentation, we — Midwest Bioethics Center staff, board, and other key constituents — began a vigorous examination

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of our obligations concerning this information. By the time SUPPORT was published in the *Journal of the American Medical Association* (November 1995), the Center had significantly explored its implications for Kansas City. The dialogue intensified in spring 1996, when two MBC staff members were invited to LAST ACTS, a leadership conference on end-of-life care, also sponsored by the Robert Wood Johnson Foundation (RWJF).

At this meeting, RWJF staff announced that the foundation intended to use its vast resources to improve care of the dying. Shortly after the LAST ACTS conference, Midwest Bioethics arranged a meeting at the Robert Wood Johnson Foundation offices in Princeton, New Jersey, where we shared

our belief that the SUPPORT approach had been misguided from its inception because it was based on the perception that end-of-life care is a medical issue. From our point of view, dying is a societal issue, and changing how society approaches death requires a multifaceted, community-based approach. We argued that Kansas City could provide a "living laboratory" for experimenting with this model, and that we were the right organization to orchestrate such an initiative. We also asked for their help.

## A Strategic Decision

In discussions following Dr. Lynn's presentation, Midwest Bioethics Center had made a dramatic, strategic decision.

Like most ethics centers, MBC had taken a broad approach to bioethical issues. The Center had always incorporated end-of-life care as one of its working domains; after all, issues such as withholding or withdrawing life support, advance care planning, physician-assisted suicide, and surrogate decision making have always been the core of the bioethics movement. But the Center had approached these issues as part of a larger spectrum of bioethical issues, including, for example, informed consent, genetics, care of persons with HIV, and organizational ethics.

The SUPPORT data, however, compelled the Center to change its mode of operation and allocate its resources entirely to end-of-life care, for a designated period of three years. This decision was not without controversy, and its long-term effects are still unknown.

## Developing the Plan

"Where do we begin?" was the overriding question. Various tactics were suggested:

- the identification of barriers to good end-of-life care in Kansas City,
- the determination of key stakeholders, and
- the allocation of key decision-making points, including decisions made by individuals, institutions, and policymakers.

Finally, a plan emerged that included five goals, three loci of concern, thirteen strategies, and dozens of projects. We named the initiative PATHWAYS to Improve End-of-life Care: A Community Approach.

PATHWAYS was organized around three areas of concern: professional education and development, institutional change, and citizen/patient engagement. Its goals were to

- improve advance care planning, including more discussion about one's resuscitation status,
- improve pain management and symptom control,
- increase hospice referrals or hospice-like care,
- shorten ICU stays for dying patients, and
- inform the citizens of Kansas City about their rights and how to act on them.

PATHWAYS' strategies included

- establishing a palliative care consortium, to develop agreement about the definition and precepts of good palliative care, and a palliative care curriculum, to be presented at a community-wide conference;
- using the Center's hospital ethics committee consortium to develop a resource manual on palliative care for local hospitals that could also be shared with the Center's long-term care consortium and regional home health-care agencies and ethics groups;
- providing continuing palliative care education for practicing physicians;
- focusing the Center's nursing ethics intensive on palliative care for a three-year period;
- establishing palliative care teams in key Kansas City hospitals, intending for them to eventually evolve into palliative care consultation teams;
- "reengineering" the Center's advance directive program to focus more on the advance

care planning process and less on signing documents;

- encouraging and supporting all three local medical schools in collaborating to integrate palliative care into each of their curricula;
- engaging clergy and faith communities in improving better spiritual care to the dying;
- increasing media coverage of end-of-life issues locally and nationally;
- collaborating with the local law school to develop a course in end-of-life law;
- learning about the views of diverse cultural groups regarding dying and death, especially Spanish-speaking people and African-Americans;
- educating nurse aides in long-term care facilities about palliative care; and
- piloting a project in local nursing homes.

### **A Precarious Climate**

The Kansas City health care environment has been mercurial for more than a decade. Fierce competition has prevented much needed work from being accomplished in our community. When we planned PATHWAYS, we were very accustomed to working in an environment of constant change and chaos. However, we were unprepared for what has happened in this three-year period.

Since PATHWAYS began, Kansas City's health care delivery system has been in unprecedented tumult. Several CEO's and long-time leaders have been replaced under difficult circumstances. Columbia/HCA withdrew from Kansas City, leaving three hospitals "up for grabs." The dean of one of our three medical schools was discharged in an administrative feud played out in our newspapers. One hospital recently closed, and one of our largest systems laid off 250 staff members in one day, mostly upper level managers and executives.

Our managed care plans are struggling to survive. Medical directors and CEOs have come and gone at an alarming pace. Simultaneously,

our long-term care facilities, especially those that we have often thought of as the “providers of last choice” have also been rocked by the effects of prospective payment. Frail, elderly people with complex diagnoses are simply thought of as too risky financially to be admitted, especially for nursing homes operating too close to the margins. At the same time, many of our hospices have converted from not-for-profit to for-profit status, creating competitiveness and lessening cooperation; and investigations by the Office of the Inspector General have created an atmosphere of fear and alarm among hospices and home health providers.

I have described this volatile environment only to convince readers that if PATHWAYS could be done in Kansas City from 1997 to 2000, it can be done anywhere.

### **Successes, Failures and Non-Starters**

In this issue of *Bioethics Forum*, Midwest Bioethics Center staff and volunteers describe some successes of PATHWAYS projects, and there have been many. You will read about the leadership Kansas City physicians and nurses brought to the project, about a unique collaboration among our three medical schools, and about the significant work accomplished by our ethics consortia. We describe innovative projects being implemented by nurse leaders in Kansas City, and the incredible success of *Compassion Sabbath* — our initiative designed to engage clergy and faith communities. We also tell of our excitement about *Caring Conversations*, a program to promote inter-generational learning and advance care planning.

Although PATHWAYS officially concludes at the end of this year, data will not be collected and analyzed until late 2000 and 2001. Still, we have decided to tell our story in this issue of *Bioethics Forum*. We take this step because we are aware that many communities in the United States are undertaking PATHWAYS-like projects. We hope that by providing a model and describing our story, we can help other communities develop their own projects to improve the care of seriously ill and dying persons. We are aware that in doing so, we

risk the “SUPPORT syndrome”; that is, although we believe that PATHWAYS is a success, our data may not show that we accomplished all our goals. In fact, we are fairly certain we have not wholly succeeded. However, we believe that both processes and outcomes are important when engaging in social reform of this magnitude.

More than 1,500 professionals and 500 organizations have participated in various parts of the PATHWAYS project. Doctors, nurses, social workers, chaplains, administrators, lawyers, clergy,

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adult educators, journalists, and others have attended programs, worked on task forces, engaged in educational programs, or staffed PATHWAYS hospital teams. Eleven hospitals have established palliative care work groups; many more have undertaken pain improvement initiatives.

More than seventy-five institutions sent nurses to the Annual Nursing Ethics Institute; eight nursing homes have been directly involved in our long-term care pilot, and many more are using the PATHWAYS resource manual to initiate reform efforts on their own. All three medical schools have worked collaboratively with the Center on curriculum reform. Our hospices have freely provided the time and expertise of their staff members to help Center staff and other providers in the Kansas City area learn more about their model of caring for the dying.

Many organizations unrelated to health care have also participated in PATHWAYS. Several hundred churches, synagogues, and mosques are involved in *Compassion Sabbath*. Five of the area’s seven Shepherd’s Centers have worked with Center staff to refine *Caring Conversations* and to develop its leadership training model, and several

agencies that provide social services to our minority populations participated in PATHWAYS-related activities.

Local media have also participated, though not to the extent we had hoped. A local talk-show host on our National Public Radio affiliate provided ongoing opportunities to converse with his listeners about end-of-life issues, and the Center is now working with two local affiliates of National Public Television on a Bill Moyers' series, *On Our Own Terms: Dying in America*. The Moyers series is scheduled to air in September 2000.

As expected, PATHWAYS has encountered occasional challenges, disappointments, and failures. Wavering commitments and support were among such obstacles. Perhaps the greatest challenge we faced was a discontinuity of leadership in the health care community. Several project and team leaders who made solid commitments at the beginning of the project were not able to keep their promises because of changes in their employment.

Participation in the managed care ethics consortium was one of our biggest disappointments. Although a solid curriculum was developed for managed care case managers, and several case managers appealed to members of our consortium to support palliative care educational programming, we were never able to solicit sufficient support from the chief executive officers and medical directors to provide this training, and it remains undone. Eventually, and with regret, the Center decided to disband the managed care ethics consortium.

Funding for PATHWAYS has also been a challenge. Our dream of underwriting PATHWAYS with a single source of funding could not be realized. Instead, its funding resembles a patchwork quilt. Some projects, for example, *Compassion Sabbath*, were adequately supported with funding from the Robert Wood Johnson Foundation. However, to date, we have funded only half the necessary budget for the medical school curriculum project. Lack of funding also delayed the progress of other projects. For example, although we have solid data to prove that

*Caring Conversations* leads participants to think and act differently about advance care planning, we have not yet found funding for its community-wide roll out.

Local medical staffs rallied to the Center's cause, however, and provided substantial funding for PATHWAYS projects; and our hospital participants have born the entire cost of their PATHWAYS involvement for three years.

Some hospital leaders had reservations about PATHWAYS in the beginning, and we were unable to obtain the support of our local hospital association. However, with leadership from several CEOs, physician leaders, and hospital board members, eleven hospitals had PATHWAYS hospital teams—six more than we had originally planned.

Although the health reporter for Kansas City's largest newspaper has been very supportive of PATHWAYS, we were unsuccessful at gaining support from the paper's editorial board. Several local television journalists, like the newspapers, provided services to our effort, but they did not adequately communicate the mission of PATHWAYS. We also had minimal success in engaging health care lawyers or law schools. Although a course was developed for law students, it was never published in the course catalogue. Individual health policy lawyers have participated with our hospital ethics committee consortium, but the legal community as such did not participate. The Center does, however, have a long-time positive relationship with the local bar association and we continue to pursue opportunities to collaborate with them to provide CLE programs for their members.

## Evaluation

Designing the evaluation tools for PATHWAYS has been challenging. Limited funding, a lack of experience in evaluating such a complicated initiative, and the tension between valuing the process and collecting measurable outcomes have at times impeded the evaluation process. An ad hoc group of local researchers and others experienced in project evaluation have helped the

Center design the evaluation. In addition, the Midwest Research Institute provided significant input into our thinking. Since beginning PATHWAYS, the Center has added a medical anthropologist to our staff to archive PATHWAYS and oversee its evaluation.

Our partners have also been a great help. Each PATHWAYS hospital team has undertaken its own internal evaluation and the team leaders agreed to do a pre- and postproject measurement of advance care planning and pain assessment and treatment. As we continue to work these unpaved roads, we intend to create a clear course for any future PATHWAYS-like projects.

### **Community-State Partnerships to Improve End-of-Life Care**

Nearly a year into PATHWAYS, the Robert Wood Johnson Foundation offered Midwest Bioethics Center a tremendous opportunity. Since February 1998, MBC has housed a national program office for the foundation, and I have had the privilege of directing it. Community-State Partnerships to Improve End-of-Life will provide funding and technical assistance to statewide partnerships and coalitions working to improve end-of-life care through broad-based policy changes and citizen/patient engagement. At the end of this year, Community-State Partnerships will have made twenty-three grants. Thus, the Center's experience with PATHWAYS will be shared nationally.

### **Conclusion**

Recently, Midwest Bioethics Center completed its strategic plan for 2000-2005. The Center will continue to work in end-of-life issues. Several projects that began with PATHWAYS, *Compassion Sabbath*, *Caring Conversations*, and the medical school curriculum project are not yet completed. The climax of *Compassion Sabbath* occurred the first weekend in February 2000 when nearly 500 churches, synagogues, and mosques celebrated — each within its own assembly or membership — their duties and

obligations to seriously ill and dying people. This project clearly has the potential to become a national event, and we are already in conversation with several national funders exploring how that can happen.

*Caring Conversations* also has great potential. With Shepherd's Centers International, Midwest Bioethics Center is seeking funding to take this project to several more regions. Furthermore, Community-State Partnerships to Improve End-of-Life Care will continue through much of this period. Simultaneously, however, Midwest Bioethics Center will expand its focus.

In the next five years, in addition to end-of-life issues, the Center will reactivate work it started several years ago on organizational ethics and vulnerable populations. We will also begin a research ethics initiative to support our community's research institutes and all institutional review boards. Our purpose in this initiative will be to ensure the protection of human subjects in research and measurable and just outcomes in medical research and clinical trials.

We believe that the PATHWAYS initiative proved our hypothesis: Reforming end-of-life care requires a multifaceted, multidisciplinary, integrated, community-wide approach. We will continue to report on this project as more data are gathered, collated, and analyzed. The Center will, in 2000, hold two end-of-life care conferences: a ten-year retrospective of happenings in the decade since the Cruzan decision, and a PATHWAYS summit. The summit will invite all PATHWAYS participants to share their "best practices" and most promising interventions. We will, on this occasion, celebrate all that PATHWAYS has accomplished and recommit to the work necessary to accomplish all its remaining goals. We also believe that this social corrective may take a generation; however, Kansas City is "out of the gate" and on the right path.