

Editorial

Integrating Palliative Precepts across Communities of Care

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The Circle of Life Award™: Celebrating Innovation in End-of-Life Care grew from an observation by Christine Cassel, MD, that "there are no awards for excellent care given to the dying ... the feeling of professional satisfaction is not based on easing death for the hopelessly ill". The American Hospital Association and The Robert Wood Johnson Foundation believed that this must change and so, with the leadership of Dr. Cassel, created the Circle of Life Awards as part of an effort to modify the culture of dying in the United States. Our hope was that this award could encourage the shifting of professional attitudes and culture that had equated death with a failure of science to a more proactive vision of the many constructive elements of just what successful palliative care entails.

This issue of *Innovations in End-of-Life Care* features the three 2003 award-winning programs, in this, the award's fourth year. Each year the winning organizations seem to personify a different theme that captures a critical direction for palliative and end-of-life care. The first year, the honored organizations illustrated how broadening and redefining *who* can be a volunteer and *what* volunteers *do* can propel a program to progress and achievements that transform lives, deaths, and communities—even without a strong financial base.¹ The organizations in the second year demonstrated how organizations can extend the reach of palliative care and end-of-life care by reaching out to new populations and new types of institutions.² The third year, the organizations exemplified strong collaboration between hospices and hospitals—bringing together the best of their joint resources to serve their communities better.³

This year, the three winning organizations—Providence Health System in Portland, Oregon; the Hospice & Palliative CareCenter, in Winston-Salem, North Carolina; and the University of California, Davis Health System, in Sacramento, California—all aim to push beyond labels, traditional boundaries, and institutional walls to disseminate and fully integrate palliative precepts into all parts of their respective communities.

At Providence Health System, the "community" is the entire integrated health delivery system. Palliative and end-of-life care begins with thinking about health care proxies and life-sustaining treatment in the doctor's office and continues at each step of the care process. Proxies and preferences for life-sustaining treatment are included in the electronic medical record that follows patients through the system. Along the way, a wide variety of palliative services and programs are available with multiple entry points to help the chronically and critically ill and

their families. As an integrated delivery system, Providence is able to influence how its physicians address these issues with patients as well as ensure that those enrolled in its Program of All-inclusive Care of the Elderly (PACE) have considered life-sustaining treatment preferences and are getting the supportive palliative care they need to improve the quality of their lives. Progress throughout the system is regularly measured using an index created by the system, and results become part of a system-wide *dashboard* on system performance. End-of-life care is one of five clinical priorities that are used to evaluate and provide bonuses to all 1,000 managers in the system.

One noteworthy element at Providence is the active palliative care benefit. Leaders created this bridge program to meet the palliative care needs of a group of patients who did not fit neatly into current reimbursement schemes, and so their needs were more easily overlooked.⁴ This program was modeled after Franciscan Health Systems West's *Improving Care Through the End of Life* program, one of the winners of the first Circle of Life Award.⁵ This echoing demonstrates perhaps, both the value of the award in promoting and disseminating promising practices, and the robustness of this particular intervention, which attempts to create more seamless care for these patients who were previously "invisible" to the health care system.

Academic medical centers known for clinical research, medical education, specialized services and tertiary care are not usually in the forefront of palliative and end-of-life care. At the University of California Davis Health System, however, attention to palliative care is woven throughout the medical community and is integral to health care delivery, research, education, and outreach. The West Coast Center for Palliative Education and Research can be viewed as the hub of palliative care activities in the UC Davis system, and it has clearly influenced how the entire health system views its research, education, and patient care mission. They have engaged in clinical research to substantiate the value of palliative care for those undergoing aggressive therapy in clinical trials, and challenged the belief that these two types of treatment are incompatible. The original "Simultaneous Care" program, funded by The Robert Wood Johnson national program office Promoting Excellence in End-of-Life Care, brought palliative care to patients engaged in clinical trials via home visits by nurse/social worker teams. Researchers found that patients who received Simultaneous Care had a much higher rate of hospice referrals. Furthermore, having access to a nurse/social worker team visits for home visits with round-the-clock phone access for follow-up are elements that enhance coordination of care and patient choice.⁶

Other activities at UC Davis have explored the understanding of pain management, and the needs of residents in assisted living facilities. Medical students at UC Davis School of Medicine find palliative care is integrated into all four years of their curriculum, with a practicum for fourth-year medical students, which has attracted students from throughout the U.S. The residency program for Internal Medicine aims to integrate palliative care precepts for all patients across the disease continuum. Palliative care outreach to rural physicians and communities through telemedicine and the establishment of a hospice in nearby correctional institutions are additional elements supported by the Promoting Excellence grant.

In Winston-Salem, North Carolina, the Hospice & Palliative CareCenter (HPCC) has made the community its partner in providing palliative and end-of-life care. When the hospice saw a need for support for pediatric patients with life-threatening conditions and their families, it did more

than establish a pediatric hospice program; it brought together almost 50 community organizations to form the Pediatric Community Alliance. It established the Community Partnership for End-of-Life Care that has brought together critical sectors of the community to help people think and talk about care of the dying. The Caregiver Consortium brings together a number of not-for-profit social service groups to support family caregivers. Its programs and services are closely linked with the local medical schools and medical centers. In this issue of *Innovations*, the FOCUS program is spotlighted. This is a comprehensive, coordinated disease management program for patients with chronic obstructive pulmonary disease (COPD) and congestive heart failure (CHF). A key element is the nurse/social worker team that makes home visits at any time of day or night to respond to exacerbations and so allow the patient and caregiver to manage symptoms at home. These home visits have decreased emergency room visits and hospitalizations due to exacerbations.⁷

One of the strengths of this award is that it, too, seeks to be integrated with a broad community. It is sponsored by the American Hospital Association in conjunction with the American Association of Homes and Services for the Aging, the American Medical Association, and the National Hospice and Palliative Care Organization—a recognition that no one type of provider can effect this type of change alone.

What deems each of this year's Circle of Life Award winning programs innovative is their dedication to making palliative and end-of-life care mainstream priorities and the ways they have embedded these concerns for their communities into the warp and weft of their care. The leaders of these programs have a clear understanding that if palliative and end-of-life care are viewed as the job of specific individuals and departments—no matter how committed and tireless—ultimately they will fall short of the goal of truly changing the way people die and enhancing the lives of those with chronic disease and the critically ill. To succeed, these leaders have taken on the daunting triumvirate of financing, culture, and systems of care, to one degree or another in each of their settings.

These three organizations share a common mission of bringing clearly needed services, not just to those with days or months left to live, but to all who would benefit—and to do so without restrictions on other types of treatment. Their efforts raise the bar and help consumers of health care expect this level of service as part of quality medical care. Inevitably, this kind of mission-driven care can collide with the very real limits of money and time, which often translate into staffing. These innovators know that giving patients living with complex, life-threatening diseases round-the-clock access to clinicians knowledgeable in disease management and the psychosocial dimensions of patient experience ultimately improves patient care. The question then becomes whether health care systems can sustain these kinds of creative efforts in these difficult economic times. These three organizations, working in different health care settings, each demonstrate that this economic challenge is fierce, but can be met to some degree, although it may take creative commitment to do so.

To integrate palliative care and end-of-life care within a community—regardless of how community is defined—also takes a profound cultural shift that can only be achieved with committed and dynamic leadership, outreach and education, and tireless coalition-building. These Circle of Life recipients have stories to tell us of how they have worked toward this cultural shift. Elucidating these experiences, naming the challenges and how they were

overcome, as well as the value of overcoming them, are all part of what sustains cultural change. Membership in larger efforts such as Supportive Care of the Dying, in the case of Providence Health System, or having access to the technical assistance of the national program office of Promoting Excellence in the case of the UC Davis Health System both reinforce and sustain the hard work of the individuals involved. In North Carolina, the longstanding history of HPCC as a leader in end-of-life care in Forsyth County and its environs, with its many existing community partnerships facilitates its efforts to promote exemplary pain and symptom management and patient and family-centered supportive care earlier in the disease trajectory. The communities that define these organizations carry and sustain the cultural values that undergird their efforts.

Last, systems of care must keep incentives in place that make the new goals part of the standard of care, and falling short cause for an incident report. The continuous quality improvement model employed by the Hospice & Palliative CareCenter in Winston-Salem, North Carolina brings an explicit model into play, so that staff can monitor their own success in an ongoing way using immediate goals and evidence to steer their course. Providence Health System in Portland, Oregon has also engaged in a quality improvement effort, as well as being part of a larger effort. Original tools such as standing orders for urgent care kits in the home, at HPCC help reinforce these new systems of care.

Just as these health systems are taking on the challenge of how to mobilize their communities for better end-of-life care, ultimately, to sustain their efforts, we as a country will have to decide if we have the will to enact the means to meet the needs of our growing elderly and frail population. In the meantime, these creative leaders offer insights and inspiration to others pursuing these goals.

References:

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