

circle of life award



2008



CIRCLE of LIFE™
Celebrating Innovation in End-of-Life Care

The Circle of Life Award: Celebrating Innovation in Palliative and End-of-Life Care is supported in part by the California Healthcare Foundation, based in Oakland, California. Major sponsors of the 2008 awards are the American Hospital Association, AARP, the American Association of Homes and Services for the Aging, the Catholic Health Association, and the National Hospice and Palliative Care Organization & National Hospice Foundation; the Center for Practical Bioethics is a Circle of Life cosponsor.

The Circle of Life Awards celebrate innovation in palliative and end-of-life care. The 2008 awards honor the achievements of hospitals, health systems, and hospices that are expanding both the art and science of palliative and end-of-life care. Through research, quality improvement, and innovations to reach underserved populations, they are raising the bar for the field. Their stories are told in this booklet.

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- AARP
- The American Association of Homes and Services for the Aging
- The American Hospital Association
- The Catholic Health Association of the United States
- National Hospice and Palliative Care Organization & National Hospice Foundation.

The Center for Practical Bioethics is a co-sponsor of the 2008 awards. The support and active involvement of these organizations testify to the increasing importance our society is placing on high quality palliative and end-of-life care.

On behalf of all of these organizations, we thank the hospitals, health systems, hospices, long-term care homes, and community programs that shared with us their palliative and end-of-life programs through Circle of Life Award applications. Their commitment and dedication touches millions of patients and families throughout the nation every year.



Steve Franey
Chair
Circle of Life Awards Committee
2007-2008



Rich Umbdenstock
President and CEO
American Hospital Association

AWARD WINNER

pain and palliative care program
children's hospitals and clinics of minnesota

Minneapolis/St. Paul, Minnesota





The palliative care program at Children's Hospitals & Clinics of Minnesota is turning the usual model of care on its head. Instead of making sick children and their families come to them, the palliative care team follows the children.

The Pain and Palliative Care Program works to control acute, chronic, and recurrent pain in all inpatients and outpatients. The team also provides holistic, multidisciplinary care for children and teens with life-limiting or terminal diseases and their families.

A lead nurse follows a child's care from the hospital to a rehabilitation facility to home to outpatient clinic. The nurse is there to ensure continuity, even if it's at a clinic not associated with the Children's Hospitals. The lead nurse coordinates care, provides supportive counseling, and helps families identify their needs. Each family also is assigned a social worker who can follow them over time. A child life specialist, chaplain, psychologist, specialist pediatricians, and volunteers round out the team and provide the range of services families are able to access.

"A lot of times it might be easy to think, 'I'm a palliative home care nurse and the child is in the hospital so he's not mine.'" explains Jody Chrastek, coordinator of the Pain and Palliative Care Program. "But since the child is the center of the care we provide, we are aiming to follow them wherever they are."

Members of the pain and palliative care service find they are welcome in these other settings because they offer additional help and don't express an intention to take over care. "You approach it with humility, and generally people are open," says Chrastek.

They apply the same nonintrusive approach to locating hospital inpatients who need pain or symptom control and psychosocial services, using informal conversations with medical staff throughout the hospital. "We're raising awareness our services are available," says Chrastek.

Minnesota's program evolved out of its home hospice. Around 1999, staff members recognized a gap in the classic hospice model of care. "We realized there were a lot of families in deep need who didn't want to give up potentially curative medical treatment, and thereby hope, but still needed everything hospice could offer," explains Chrastek.

The home care program staff members started a grassroots effort to educate hospital staff about palliative care. "We started to reach into the hospital doing education, raising awareness," she says. "It might be five minutes at a staff meeting, or while working at the bedside with a nurse."

Since then, the program has focused on child and family needs, adjusting itself with feedback from families, often those who have already lost a child.

"As pediatric palliative care has developed over the last decade or so we learned an awful lot by listening to the families," explains medical director Stefan Friedrichsdorf, MD. Among the things parents dislike most are physicians who won't communicate with the family or other doctors or who focus only on the child's disease as a single organ system to be fixed, rather than a whole child to be treated.

Parents with a chronically or terminally sick child can find much of their time taken up with organizing care and paying for care. "We are forcing them to do things which they shouldn't need to do," says Friedrichsdorf of the American medical system. "They don't have time to be mum and dad and they regret this later." To alleviate this burden, the team assigns a lead nurse who follows the family wherever they are in the health system and works with them on logistical issues.

Instead of making sick children and their families come to them, the palliative care team follows the children.



innovation highlights

THREE PART FOCUS ON PAIN MANAGEMENT/
PALLIATIVE CARE, END-OF-LIFE CARE, AND
INTEGRATIVE MEDICINE

EMPHASIS ON FOLLOW THE KID

STATE AND LOCAL INFRASTRUCTURE
FOR LEADERSHIP IN PALLIATIVE AND
END-OF-LIFE CARE

A number of programs and services have been established based on feedback from parents. For instance, a perinatal hospice program was started in 2000 when it became clear that parents expecting a child with serious health problems needed support before and after the birth.

An interdisciplinary pain clinic is open to any child with pain. “With chronic pain it’s really important that people dig in for a treatment course,” explains Stacy Remke, psychosocial lead for the team. A combination of physical therapy, psychotherapy, teaching of integrative non-pharmacological treatment modalities, carefully dosed medications, and close follow-up is very effective for these children, she says.

In addition, an inpatient pain management consultation team provides education for fellow staff members in pain management.

All children being treated by the pain and palliative care program have access to a wide array of non-pharmacological methods to ease their symptoms, including biofeedback, imagery, hypnosis, aromatherapy, massage, acupressure, and acupuncture.

The Pain and Palliative Care Program is playing a leadership role, working with the Minnesota government to establish reimbursement for palliative services.

And the Minnesota program is generous with its knowledge of what works in pain management and pediatric palliative care, sharing with other hospitals and hospices around the Midwest and the U.S. Requests commonly come from adult hospices with little or no experience working with children. “Maybe a sick baby is coming home and the hospice wants to prepare,” explains Remke. Children’s will e-mail information, go over it by phone, and provide 24-hour expert phone backup.

In 2003, Children’s Hospitals of Minnesota established with the help of federal funding a pilot program for pediatric palliative care education in the upper Midwest and has trained more than 500 providers.

The Pain and Palliative Care Program’s extensive reach is particularly notable because it is centered in a free-standing community children’s hospital, not a classic academic facility, making its educational and state leadership efforts particularly innovative.

The Pain and Palliative Care Program has grown in new ways partly because the organization is open to new ideas and doesn’t operate according to a hierarchical structure, team members say. Everyone on the team is heard equally, whether they are a volunteer, a child life specialist, or a physician.

The program began as a nurse and social worker-led model, encouraging consults through gentle persuasion. Even though a physician was brought in to continue the program’s work, Chrastek says, its culture remains collaborative. “We come in and say, ‘how can we help?’” she says. “That’s what palliative care is all about.” •

kaiser permanente

Oakland, California

When an organization as large and varied as Kaiser Permanente approaches something as complex as end-of-life care, the potential complications seem as limitless as the stars in the night sky. After all, it is an organization with 13,000 physicians, serving 8.7 million members in eight regions around the country. How do you bring something so huge down to the intimate level of a single human life reaching its end?

The answers are as paradoxical as the question: You do it quickly and over many years; with the efforts of a few committed individuals and a cast of thousands; with big overarching concepts and innovative projects focused on a single patient's experience.

The organization has tackled palliative and end-of-life care the way it tries to do everything: by studying what works and encouraging the use of effective methods throughout the organization. And if there aren't good data on an approach that would be appropriate for Kaiser, it promotes research from within. The organization's evidence-based review on end-of-life care didn't identify a single end-of-life approach that could be blanketed over the entire organization, but it did reveal some innovative work being done within the organization that could be substantiated and copied in other regions. "The [internal initiatives] turned out to be stunningly positive in quality and satisfaction and supported investment in their spread," notes Richard Della Penna, MD, medical director for Kaiser's Aging Network and national clinical elder care lead for its Care Management Institute.



The innovations include:

Inpatient palliative care teams.

Kaiser's Colorado region was one of several within Kaiser to explore inpatient palliative care teams. Its model included teams to address the physical, social, spiritual, cultural, psychological, and ethical aspects of care during palliative care consults. Palliative care consults are provided to any patient in all Kaiser hospitals and those which Kaiser contracts.

Home-based palliative care.

Kaiser physician Richard Brumley, MD, developed a home-based palliative care program and used controlled trials to measure the medical and economic impacts of expanded home-based care for patients with three serious diseases — chronic obstructive pulmonary disease, cancer, and heart failure. The research found significantly higher satisfaction rates and improved care quality along with lower costs.

Advanced Illness Coordinated Care Program. This program helps patients with serious illnesses such as COPD and cancer better understand their condition and plan for future needs. A social worker sees patients and their

surrogate decision makers during six structured visits focused on worries and practical concerns of their illnesses.

As part of its palliative care effort, Kaiser embarked on a large series of rapid cycle improvement collaboratives involving about 70 teams from northern and southern California. "The biggest impact was that we had several hundred people learning about a new area, about the challenges associated with caring for people with advanced illnesses," said Della Penna. "It's the cultural transformation we're all working with."

While this evidence-based process takes time, once the organization decides it has a valuable and effective model, it can quickly implement it throughout the system. The inpatient palliative care team model is already being spread among 37 hospitals, and Kaiser is building a national dashboard that includes use, place of death, and patient/family satisfaction to measure its effectiveness.

While Kaiser is unique in design, Della Penna believes its work to promote palliative care within its system contributes to large-scale understanding of what works in this field. "It shows we can do it," he says. "Even if you don't have the same model policy makers can incent providers to collaborate and cooperate to the benefit of beneficiaries."



innovation highlights

NATIONAL PROGRAM WITH LOCAL INNOVATION

ADVANCED ILLNESS COORDINATED CARE PROGRAM

FOCUS ON FULL CONTINUUM OF CARE

lifepath hospice and palliative care

Temple Terrace, Florida

Firmly rooted in a tradition of research and evidence-based care, LifePath Hospice and Palliative Care in Florida has been providing high-quality, systematic hospice and palliative care for over two decades. The hospice is bolstered by multiple partnerships, including academic medicine which has enabled it to pursue a research agenda while being a leading provider of care in its communities.

LifePath is one of the largest independent not-for-profit hospices in the nation and cares for more than 2,600 patients each day. Its approach to everything from patient care to employee standards is evidence-based. The organization cares for nearly 60 percent of all deaths in its four-county service area in west central Florida.

LifePath has offered an open access model of care for more than a decade, allowing hospice patients to receive chemotherapy, radiation therapy, cardiac infusions, etc. “We chose to do that because we did not want patients and families to have to choose between hospice care and aggressive treatment,” explains Ronald Schonwetter, MD, executive vice president and chief medical officer of LifePath.

LifePath runs four freestanding acute inpatient hospice houses and a residential house for those who cannot be cared for in their homes, as well as its own pharmacy and durable medical equipment companies. The organization maintains a 24-hour admissions service to keep the doors open to those needing hospice services.

“We really pride ourselves in maximizing access to care, being evidence-based and looking at things



from that point of view,” says Kathy Fernandez, president and CEO. “As a leader in the hospice industry we want to be sure we are leading with facts and by example.”

LifePath has added to the scientific literature on hospice and palliative care and uses that research to change policy and practice. For instance, a recent study identified risk factors among hospice cardiac patients who required emergency room visits or hospitalizations. As a result, the organization will be able to identify high-risk patients and provide interventions to avoid these occurrences. Its research center joined forces with a University of South Florida research group and created the Center for Hospice, Palliative Care and End-of-Life Studies.

LifePath has also partnered with four local hospitals to establish palliative care programs, each tailored to the hospital’s culture. They established a subsidiary, Axis Palliative Healthcare, to provide palliative care services to those in need of such care who may not be appropriate for or desire hospice care. In one hospital, the palliative care service generated over 500 consultations

in its first year. The organization is also working with one of the hospitals on a pediatric palliative care program.

Providing doctors-in-training with the latest ideas in end-of-life and palliative care is achieved through a partnership with the University of South Florida, which has had a required medical student rotation through the hospice since 1996. LifePath and the university also developed a hospice and palliative medicine fellowship program to train post-graduate residents choosing to become specialists in that area.

The organization maintains a research-based competency program for employees and teaches and evaluates employees to those standards. The standards for orientation encompass not only the skills required to practice hospice and palliative care but also values and human behavior. LifePath also offers professional development classes both to employees and members of the community ranging from lifestyle improvement to conflict resolution and teamwork. “We define what compassion looks like in our organization,” explains Mary Lou Proch, LifePath’s director of education. “And we assess competency accordingly. What does being present look like? Do you use appropriate body language? We make sure our values are there.”



innovation highlights

RESEARCH COLLABORATION
WITH UNIVERSITY

TRAINING AND EDUCATION PROGRAMS

JOINT STAFFING OF HOSPITAL PALLIATIVE
CARE TEAMS

providence hospital palliative care service

Washington, D.C.

A Catholic health ministry with a mission to serve all persons, with special attention to the poor and vulnerable in Washington, D.C., Providence Hospital's palliative care program is raising the bar in caring for a difficult-to-reach population.

Program Director Karole Thomas tells of a recent conversation with a man whose needs go well beyond the pain of his life-threatening illness — even while sick he has to wind his way through the system to get financial and health insurance support. “He’s kind of lost in the system,” says Thomas. “We do a lot of assistance with people trying to navigate entitlements and insurance.”

Other programs that grew from patient needs over the program’s 20 years: bereavement care for the entire community, not just Providence patients; and the caregiver support program that educates family members not just on the basics of care, but also all the practical aspects of advanced directives and estate planning. “I go into two of our senior centers in the northeast and southeast corridors of our city that don’t get a lot of service,” says Thomas. “This developed out of the many conversations with families preparing to go home and saying they’re not prepared to care for someone at home.”

The Providence team recognizes the caregiver’s needs as significant, along with the patient’s, and works to put together a workable plan if care at home is desired. “The number one request people have is to be in their own home,” says social worker Eunice Miller. “We try to set that up with the



home hospice program. And we try to mobilize the support system in their family or community.”

At the core of the program is care given to hospitalized patients by an interdisciplinary team which consists of a nurse, social worker, and spiritual counselor. This care also follows them across the continuum. For instance, the team cares for patients who live in the hospital’s nearby nursing and rehabilitation center and partners with non-geriatricians in managing the care of elderly patients in other nursing home settings. Close relationships with local hospice programs help with efficient transfer to home care; the hospice team usually comes to the hospital before discharge to ensure a good handoff. Providence’s palliative program reaches out to the African-American community through churches as well as senior centers to provide education on end-of-life and palliative care. It has also served as a resource for other Washington, D.C. area hospitals as they’ve developed palliative care programs.

Mostly, the palliative care team never forgets whom they are serving and their particular needs. “We’re serving

a very underserved, underrepresented population,” says Miller. “Our goal is to have them die where they want to, with supportive services.” Sometimes that involves arranging transportation to a distant place. Many people in the transient Washington, D.C., area are from other parts of the country and the world, she notes, and lack local social support.

The palliative care team also hosts internal medicine residents for an end-of-life care rotation, prompting several to express interest in becoming fellows in palliative care. There is also an active education program for nurses, internal medicine residents, and attending physicians at Providence, covering such topics as psychosocial support at end of life, cultural awareness, and breaking bad news.

Providence’s program was started twenty years ago by a dedicated core group of four people; two of them — Thomas and Miller — are still there. “The dedication of our staff is very unusual,” notes Miller, noting that team members “give it all they’ve got. We all feel that way.”



innovation highlights

FOCUS ON INPATIENT, LONG-TERM CARE, AND HOME SETTING

HOSPICE APPROACH TO BEREAVEMENT SERVICES

SUCCESSFUL OUTREACH TO AFRICAN-AMERICAN COMMUNITY

AWARD WINNER

haven hospice

Gainesville, Florida





Caring for patients and families at the end of life requires a special type of care whether that is from a small palliative care program or a large and complex hospice organization. In the case of Haven Hospice, the organization has created and implemented a systematic, evidenced-based approach that focuses on access, quality care, outcome measurement, and the “human touch” so important at this time in life.

In operation since 1979, the organization carries out the balancing act in part by engaging actively in the rural communities that make up much of its Florida service area, recruiting local people as volunteers and hiring staff that live in the communities it serves.

Haven Hospice serves a large swath of north Florida, covering 16 counties, most of them rural, and spanning more than 10,000 square miles. Care is provided to more than 3,800 patients and families each year, averaging nearly 700 patients each day. Haven maintains four freestanding inpatient care centers and two designated inpatient units. It currently cares for more than 55 percent of all deaths in its service area.

Each of Haven's five offices operates more like an individual hospice organization, with its own administrator and a fair amount of autonomy within the geography that office serves. “We have attempted to create teams that are locally engaged and responsive,” says Nancy Dohn, senior director of public relations and community development for the organization.

Increasing access to care is a long standing goal of Haven's and the organization has sought innovative ways to expand access to end-of-life and palliative care, especially for underserved ethnic populations.

“We have consistently developed programs and services that help people access hospice and palliative care,” says Executive Director Tim Bowen. “It's a constant challenge because of the size of our service area and the diverse cultures found within it.”

To increase access, Haven has worked to build community relationships and partnerships, for example, within Jacksonville's African-American community, starting with the First Coast African-American Chamber of Commerce (FCAAC). “We partnered with them to create a more effective way to educate African Americans about end-of-life and palliative care,” says Dohn.

One example was to promote Haven's Workplace Counseling Support Program to FCAAC members. This is a special program that offers employers support through information and education sessions taught by Haven social workers, often held at lunchtime, to assist employees who are struggling to maintain a job while at the same time being a caregiver or for those employees who are coping with the loss of a loved one.

To help further expand outreach to Jacksonville's ethnic communities, Haven established nursing scholarships for Hispanic and African American nursing students at the Florida Community College Jacksonville (FCCJ). As a part of these scholarships, the recipients spend a day learning about hospice and palliative care recognizing that at some point in their health care careers, they will need to know about it. Haven also has reached out to the growing Latino community by partnering with the Hispanic Chamber of Commerce and the local Hispanic media focusing on communicating the end-of-life care resources available.

...there's more of a focus on patient and family outcomes as well as measurement and benchmarks.



innovation highlights

PHARMACY AND THERAPEUTICS
COMMITTEE

OUTREACH TO MINORITY POPULATIONS

WORK ON OUTCOME INDICATORS

“We’ve attempted to take small steps rather than giant leaps,” Dohn explains. “We’re trying to gain trust and acceptance as a good resource and partner, while at the same time being very sensitive to the different cultures. We want to learn how we can best meet their diverse needs for end-of-life and palliative care.”

Quality care and process improvement are a high priority for Haven. The organization carries out monthly audits and studies on various aspects of the organization. These audits cover all parts of the organization, including clinical care, patient safety, and human resources to name a few. The quality improvement committee meets monthly and includes a statistician to help tease out trends.

Quality Improvement (QI) staff work with the patient care staff to give them immediate feedback on audit and study results, explains Cassie Donovan, senior director of operations and clinical services. “They take the results back immediately to the clinical teams and ask for instance, ‘What will you do to improve documentation to show this patient’s needs were addressed?’” Donovan says. “The team comes back with a solution. It’s ever-evolving.”

The QI department takes pains to make these reviews non-punitive, focusing on the processes involved not the people, remaining positive and giving awards to teams for complete reporting. “We never say, ‘It’s your fault,’ about an error or problem,” Donovan says. “We do a root cause analysis and focus on improving the process.”

As only one of two organizations nationwide working with the Centers for Medicare and Medicaid Services (CMS) as a part of the Rural Hospice Demonstration Project, Haven has collaborated with CMS to provide patient and family outcome measures as part of the government’s work to develop reporting standards for all hospices. “We’ve become a little incubator for CMS,” notes Bowen.

The emphasis on quality and patient outcomes extends to the hospice’s Pharmacy and Therapeutics (P&T) committee, which researches the medications in its formularies by disease category and symptom, reviewing the literature and creating protocols for Haven. “They’ve done it for pain, nausea, vomiting, for dozens of medications and therapies,” Bowen says. “This gives the clinical staff a much more consistent approach, and gives us our best opportunity, based on the evidence in the medical literature, to determine what therapy will be most effective.”

This kind of systematic approach to hospice and palliative care will become more prevalent as the federal government establishes new standards for hospice organizations. “As a field there’s more of a focus on patient and family outcomes as well as measurement and benchmarks,” says Bowen. “We may be ahead of that curve now, but all organizations providing hospice or palliative care are going to have to do the same thing. That will require all hospice and palliative care organizations to be more mindful of the patient outcomes of the care they provided.” •

rice hospice

Willmar, Minnesota

It's a common scenario: An elderly member of a farm family in rural western Minnesota has a serious illness and has chosen to stay home for the final months of life. At one time he would have only family and maybe a local doctor for support. But because of a unique hub and outreach model, an experienced hospice nurse is there to provide care.

The hub of all this activity is the 25-year old hospice, which is part of 140-bed Rice Memorial Hospital, a regional referral center in Willmar, a town about 100 miles west of Minneapolis. The hospice responds to calls for end-of-life care in the 14-county rural region through a network of seven satellite offices that provide full hospice services to places too sparsely populated to support their own programs.

Rice received requests from small rural hospitals in the region asking for help with hospice services, explains hospice director Leslie Erickson. "If they could link with us and have that partnership, their patients could remain in their home communities and use their local hospital and have the care come to them," she says. "That makes a huge difference."

It is also difficult to recruit staff experienced in end-of-life care to those rural areas. Rice Hospice provides that expertise.

Providing hospice care in a large geographic area can be expensive, given the rising cost of gasoline and ever-changing technology. But outreach is part of the hospital's mission, Erickson says, and the organization has learned to economize where it can.



The organization has extended hospice care to a huge swath of rural Minnesota territory in an efficient yet caring model that uses volunteers from local communities to make hospice a welcome service in small towns throughout the area. Hospice staff visits with volunteers in each satellite office about once a month to keep them motivated. "In a high-tech world we try to be very high touch," explains Evy Hatjistilianos, program volunteer coordinator.

There are two nurse teams on call at all times, each taking part of the service area. They are helped by more than 200 volunteers, who provide an array of services, including home visits, bereavement support, office work, and fundraising. Those who work with patients are trained in hand massage to comfort the patient.

Volunteers are also trained in life review, a formal reminiscing by patients. One volunteer recently put together a 16-page life review with an elderly woman patient, typed it up, and made copies for the family members.

Each local area has a community advisory committee for hospice. Members of those panels serve as the eyes and ears of the community for hospice, and vice versa, to ensure the organization is responding to local needs. They also help with fundraising and educational presentations about hospice.

More recently, Rice created a grief center that provides bereavement services to the entire community. Social worker Brenda Wiese has headed Rice Hospice's grief center for the past year. In that time she's put 14,000 miles on her car bringing counseling to areas that would otherwise not have local access to professional services.

The grief center is open to anyone in the community who needs help with loss, not just those who have a connection to the hospice. The center offers one-on-one follow-up bereavement services to family members as well as a series of mailings that go out at prescribed times during the year after death. "Having grief and loss counseling services in their own communities enables more of those in need to take advantage of these services, that are offered free of charge," says Wiese.



innovation highlights

HOSPICE AS HOSPITAL DEPARTMENT

CREATIVE OUTREACH MODEL

EXTENSIVE VOLUNTEER PROGRAM

sentara healthcare/ palliative care collaborative

Norfolk, Virginia

Palliative care is by definition a hands-on, intimate practice that's all about sensitivity to human needs. Even so, its effectiveness can be measured and analyzed. Sentara Healthcare in Eastern Virginia, a large regional health system, is using sophisticated analysis to prove that palliative care is effective and efficient. The information the system is developing could help build the vital business case for palliative care in organizations around the country.

It's important for palliative care to establish itself as an evidence-based, efficient way of providing care, along with the good it does on a human level, argues Krista Dobbie, MD, who heads the system's Division of Palliative Medicine. "Too often people look at palliative care as a 'kumbaya' thing. But it's important to know quantitatively what you're accomplishing."

The organization's Clinical and Business Intelligence Division created a computer program for Sentara's Palliative Care Collaborative that it calls "the cube." It tracks how patients referred to palliative care are moving through the system. "The cube data have been instrumental in letting us know who's getting palliative care consults, how many are dying in the hospital versus how many are being transferred home with appropriate services," explains Dobbie.

The cube also allows sophisticated analysis that compares palliative care patients with similar patients not receiving palliative care and shows how consultations reduce length of stay and costs. The patients are matched for age, gender, diagnosis, and severity of disease. "We found that, wow, we knew that care



planning and symptom management increased satisfaction, but it also really does save the hospital money," Dobbie notes.

The organization has also been systematic in expanding palliative care consults, using the rapid-cycle improvement process to accelerate change. The process helped accelerate palliative care consults in intensive care at Sentara Virginia Beach Hospital using a new screening tool. "I screened all the admissions (of one doctor on the unit) and he'd say yes or no" to a consult, explains Odette Joseph, the palliative care team's social worker. "It has definitely increased the number of consults I was able to garner."

While Sentara's size — seven hospitals and a wide array of other medical services — gives it the resources to carry out high-level analysis, it also presents a challenge when trying to maintain a seamless continuum of care for patients. So the organization created a palliative care collaborative to bring together players from its different divisions such as inpatient palliative care, home health, nursing home, and hospice, as well as a children's hospital and a

medical school. They meet every month by phone and every quarter in person. "When you're seeing another face, that entity becomes real to you, and you don't want to let that person down," says Dobbie.

Dobbie has been particularly focused on improving pain control. For example, she's worked with anesthesia at one hospital to adjust the management of young patients with diseases such as sickle cell anemia, cancer, and Crohn's disease to increase use of pain pumps, overcoming concerns about oversedation in combination with anti-anxiety medication and high-dose narcotics.

Along with focusing inward, Sentara's Palliative Care Collaborative connects outward. Team members consult with competing hospitals creating palliative care programs and helped incubate a program at a nearby children's hospital. The organization also reaches out to bereaved children from all over the community, hosting an annual weekend event called Camp Lighthouse. "Some of these kids are just smiling for the first time," says Dorothy Weeks, patient care services manager for Sentara's hospice division. "Camp Lighthouse is one of the things that keeps us plugging along. We really do make a difference."



innovation highlights

PALLIATIVE CARE CUBE

ABILITY TO SPREAD IMPROVEMENTS

RESEARCH AND QUALITY
IMPROVEMENT FOCUS

joint palliative care programs of the uab center for palliative care and the birmingham va medical center

Birmingham, Alabama

A ten-block area of downtown Birmingham, Alabama, is becoming a hotbed of palliative care work, thought, and education that includes the University of Alabama Hospital and the Birmingham VA Medical Center. The two organizations are reaching out to involve the children's hospital, where a new palliative care team has already started.

At the heart of it all is a unique collaboration between the university hospital and the veterans facility, under the umbrella of the UAB Center for Palliative Care. The programs share doctors, with each maintaining inpatient and outpatient palliative care services. Both started individually, but in 2004 joined forces to provide state-of-the-art care, supporting important research and offering a comprehensive learning experience to medical students, graduate students, nurses, residents, and fellows. "Collaboration offers many advantages," notes Rodney Tucker, MD, medical director of the UAB palliative program. "It diversifies potential funding, exposes learners to different health care systems, broadens your patient base, and adds to the diversity and richness of the learning experience."

A vibrant atmosphere of innovation fuels palliative care in Birmingham, as the organizations open themselves to creating new services. At the VA, the Safe Harbor Program, which began in 2001, provides interdisciplinary care to hospitalized veterans, care coordination to hospice patients and home-based palliative care to patients with advanced illness not yet ready for hospice.

Meanwhile, at UAB Hospital, the center has connected with the trauma center to provide palliative care to patients and families who have



experienced an accident or sudden medical problem that puts a life in danger. The need for palliative care in trauma has been surprising and the results rewarding, as families deal with challenging issues presented by a sudden serious illness or death, Tucker says.

Another important initiative for the center is an outpatient supportive care clinic that focuses on people in active treatment, often for cancer. The clinic provides care to patients earlier in the trajectory of their illness and reduces the barriers to them accepting hospice care in the future.

The center is strongly research-based, using an evidence-based electronic comfort care order set developed by Amos Bailey, MD, director of the Safe Harbor program. The center also engages in health services, nutrition, and survivorship research.

Along with its palliative care research, the center is building a database tracking outcomes for interventions in the outpatient clinic. The resulting data are expected to support designs of outpatient palliative care, says Elizabeth Kvale, MD, director of the outpatient center.

The Birmingham center also works extensively to support the social and emotional needs of patients and their families. An art therapist works with patients and families with children facing grief and loss. Supportive and bereavement services recognize the special needs of veterans who might have limited family and social networks and need individualized help in reconnecting with the important people in their lives.

Some of these services, such as art therapy and supportive counseling, are not reimbursed through traditional health care models, Christine Ritchie, MD, director of the Center for Palliative Care, says, so we have been fortunate to have a strong connection with the community to support fundraising efforts.

The center has also expanded on traditional designs of educating doctors, with training programs for subspecialties such as medical oncology, pain management, and geriatrics. All trainees learn not just the science of palliative care, but also the art, reading one of three books and reviewing films that deal with end-of-life issues. "We want them to have a holistic, patient-centered perspective," explains Ritchie.



innovation highlights

COLLABORATIVE FRAMEWORK
AND APPROACH

EXTENSIVE TEACHING PROGRAMS
FOR PHYSICIANS

OUTPATIENT SUPPORTIVE CARE

AWARD WINNER

pediatric advanced care team
children's hospital of philadelphia

Philadelphia, Pennsylvania





The typical palliative care team has several members — a physician, nurse, social worker, and maybe, chaplain. At Children's Hospital of Philadelphia, the Pediatric Advanced Care Team (PACT) numbers 17.

The team brings a mix of medical and psychosocial expertise. Along with nursing, it includes a comprehensive psychosocial program with social work, child life, art therapy, chaplaincy, bereavement, and psychology. Team physicians include three general pediatricians, an oncologist, a neonatologist, a pulmonologist, an intensivist, and a neurologist who also have responsibilities in their specialty departments as well. "These are not just people volunteering but full members of the team...who have an expertise in a particular category of diseases," says team medical director Tammy Kang, MD. "That 'from within' approach has helped us expand our ability to reach multiple areas within the hospital." These specialists are also able to help educate those in their respective specialties about palliative care and can often help foresee the palliative care needs of patients earlier in their illnesses.

Children's Hospital of Philadelphia (CHOP) includes its 430-bed children's hospital in Philadelphia and a large network of pediatric health services throughout Pennsylvania, New Jersey, and Delaware. PACT sees over 140 inpatient children each year and follows many others while at home.

The team has grown quickly over the past few years, says Kang. "Not all hospitals can just generate this team of 17 people," she says. "One of the benefits of being here at CHOP is that we have gotten the support of the administration all the way to the board of trustees."

As a center of care for sick children in the northeast, the hospital sees enough patients to keep the team busy, she notes. "I do feel we have an obligation not just to the area and our patients, but to the field of pediatric palliative care in general," Kang says, given CHOP's size and leadership role in children's care.

The hospital's approach to palliative care extends well beyond the child and recognizes the larger community that cares about a child's welfare: parents, siblings, grandparents, extended family, friends, school, and religious communities. The team offers emotional support, bereavement, and educational opportunities, as appropriate, to this wide range of people.

This expansive approach to palliative care also extends to hospice and home health agencies in the region, most of which have had little experience caring for children with life-threatening illnesses.

One case in particular illustrated the problem: A baby was born with multiple congenital anomalies to a single mother who wanted to bring the baby home, which was on the other side of the state. "We looked into what services were available in her area and we found a number of hospices, but they all did adult care," recalls Nurse Coordinator Jean Carroll. PACT offered a local hospice agency 24 hours a day, seven days a week access to a PACT nurse or physician for advice regarding symptom management and other questions, and the mother and baby went home. "It's very scary to people when the patient is a child," Carroll explained.

Partners in Pediatric Palliative Care started a few months later in early 2004. The program is open to all agencies serving children in Pennsylvania, Delaware, and New Jersey and has included agencies in New York and Maryland. Services are provided at no charge. The program has grown to 35 agencies and more than

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innovation highlights

STAFFING MODELS WITH PHYSICIANS
FROM DIFFERENT SPECIALTIES

RESEARCH TO DEVELOP METRICS

FOCUS ON CONTINUUM OF CARE

50 community-based providers attending CHOP-sponsored education meetings, held three times a year. The meetings provide education, networking, and the opportunity to discuss specific cases. PACT also provides an order set with pediatric dosages of common medications and a pediatric comfort kit including drugs that need to be in the home when a child is dying.

The program has helped allow more children to be cared for at home, explains Kang. "People have always assumed that you get your surgery here so you have to stay here," she says. "But when you ask parents, most of them would prefer to be at home. They didn't think it was a choice they could make."

Some PACT members also find themselves going to patients' homes. Child life specialists and art therapists often visit homes to help with sibling bereavement, explains Mary McSherry, the team's director of psychosocial services. "People are more comfortable when they are at home," McSherry says. "Kids who might not have been articulate or talk about what it's like to have a sibling who's very sick, suddenly they are talking."

Reaching those previously unmet needs is at the core of palliative care. And yet, the evidence basis for much of what palliative care does is not as solid as it could be, argues Chris Feudtner, a physician and PhD researcher who is using CHOP's significant research resources to pursue important questions about the relatively new field. "It's really important to cast a light on everything we think we know, and what we clearly don't know," says Feudtner.

Some of his most intriguing current work explores how parents make medical care decisions for their children. The study, funded by the National Institutes of Health, involves in-depth interviews with parents and physicians in an ambitious effort to quantify the concept of support, teasing out the cognitive and emotional parts of decisionmaking. "What does it mean to support somebody?" asks Feudtner.

"Information is crucial but it is not sufficient to make good decisions. We don't in medicine have a schema for how you help people process emotion. We've not wanted to look at this in any kind of rigorous way, but this is a wonderful opportunity to run toward the problem."

Other research focuses on a quality-measurement tool assessing care received by children (results pending); an examination of where children with complex chronic conditions have died over the past 15 years in the United States (published in the *Journal of the American Medical Association* in June 2007); and a multi-site study of pediatric palliative care teams (in process). "There are still things we can learn about how we can do better," Feudtner concludes. •

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