

Palliative Care Centers in the U.S.: Emergence, Lessons Learned and Advice from Pioneers



Randy Curtis, MD, MPH, was a medical student at Johns Hopkins School of Medicine in the late 1980s, a time when the AIDS epidemic was hitting Baltimore in a big way. “We were caring for a lot of young men who were being hospitalized and dying from a disease we barely understood,” recalls Dr. Curtis.

As fear of the epidemic spread across the country, the nation’s medical providers were charged with helping a staggering number of patients through painful deaths in hospitals. And those patient experiences, Dr. Curtis says, varied widely.

“I had repeated experiences where on the one hand a patient dying in the hospital felt very supported,” he remembers. “But then for a patient in the room next door, tended to by the same doctors and nurses, the end-of-life care was a disaster. I knew we could support seriously ill people and do it well, but it was more common that we didn’t.”

A decade later, Dr. Curtis went to the University of Washington to further his training, first as a resident in internal medicine and then as a fellow in pulmonary and critical care medicine. There he witnessed a similar pattern of care for patients with serious illness. “I kept feeling that there was an opportunity to do serious illness care well, to educate clinicians, and build palliative care services to provide additional support for patients and their families,” says Dr. Curtis.

Importantly, many of the fundamental resources already existed within the university to deliver patient-centered and family-oriented serious

illness care. “For decades, there had been pockets of excellence in palliative care around the University of Washington,” he says. “They just weren’t connected.”

Palliative care is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.
– Center to Advance Palliative Care

Today, Dr. Curtis is the director of the Cambia Palliative Care Center of Excellence (Cambia PCCE) at the University of Washington—a cross-disciplinary hub that integrates research, education and patient-centered care to support patients with serious illness and their families. The Cambia PCCE is one of a handful of centers that are purposefully breaking down the silos in health care to foster the collaboration needed to change the patient experience through palliative care. Because they reside within academic health care systems, the centers enable doctors, nurses, social workers, researchers, spiritual care providers and other specialists from different departments

(e.g., family medicine, surgery and pediatrics) and divisions (e.g., infectious disease, oncology and cardiology) to work together. This interdisciplinary approach complements the fundamental nature of palliative care. “What I like about the center structure,” says Dr. Curtis, “is that it doesn’t require us to fit into one of those boxes.”

The penetration of palliative care in U.S. hospitals has increased in the last four decades; 67% of U.S. hospitals with 50 or more beds have palliative care teams, according to the latest report card from the Center to Advance Palliative Care (CAPC). Still, for many patients in need, the services are either too little or too late, or don’t reach them at all. Understanding how to identify people and families in need; how to design experiences and deliver care according to what matters to them; what makes a meaningful impact on their pain, suffering and quality of life; and how best to train, allocate and pay for the resources to support them are pressing challenges. The four palliative care centers profiled here offer perspectives on these issues and demonstrate the need for additional support from institutions as well as public and private funders to ensure that people who would benefit from palliative care services have access to them.

A deeper understanding of the need for palliative care centers

The need for palliative care is well established. Data from the National Palliative Care Registry™ suggests that between one million and 1.8 million patients admitted to U.S. hospitals each year could benefit from palliative care and yet are not receiving it.ⁱ

As increases in life expectancy bring new challenges in managing a larger population of people over the age of 65 with complex, chronic conditions, the need for palliative care services will continue to grow.

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Thanks to the efforts of early leaders and supporting funders, the benefits of palliative care are clear. In 2010, Dr. Jennifer Temel and her colleagues published the results of a randomized, controlled trial in the *New England Journal of Medicine* that showed that early palliative care extended the life and improved the quality of life for patients with metastatic non-small-cell lung cancer. These findings helped shift the prevailing belief at the time that palliative care should be reserved for patients when measures to treat or control disease were no longer effective. Instead, as the study proved, palliative care, “with its focus

on management of symptoms, psychosocial support and assistance with decision-making, improves the quality of care and reduces the use of medical services” when introduced at the time of diagnosis, in conjunction with other curative or medical therapies.ⁱⁱ

Today, palliative care is recognized as adding an extra layer of support that improves quality of life; alleviates pain and suffering; reduces caregiver burden; and potentially lowers health care costs. It includes both primary palliative care (provided by all clinicians caring for patients with serious illness) and specialty palliative care (provided by clinicians with palliative care specialty training).

“I spent a lot of my career early on trying to convince people that palliative care was important, and I don’t have to do that anymore,” says Dr. Curtis.

Just one in three (33%) physicians say they had “a great deal” or “some” exposure to palliative care education and training in medical school, while less than half (45%) received “a great deal” or “some” exposure during their residency.
– “Living Well at the End of Life: A National Conversation,”
by The Cambia Health Foundation and the *National Journal*

What’s needed now is a coordinated focus on:

- Improving access to primary and specialty palliative care
- Training clinicians about palliative care
- Generating evidence-based research to support decision-making

Karl Lorenz, MD, MSHS, professor of medicine at Stanford University and section chief of Palliative Care Programs, says, “For many people even in really good health care systems, palliative care is an afterthought, serendipitous, and it’s late.” In fact, for elderly people with cancer, research shows that 77% of palliative care consultations occur in the last four weeks of life.ⁱⁱⁱ Dr. Lorenz opines, “We have to be proactive and need to heighten our awareness and visibility of the patients and families we want to serve.”

However, to avoid creating an empty promise that palliative care will be available to meet the growing demand for such services, additional workforce development is needed. Today, there is only one palliative care physician per 1,200 people with serious illness in the U.S., compared to approximately one cardiologist for every 71 individuals experiencing a heart attack and one oncologist for every 141 patients newly diagnosed with cancer.^{iv} The reality is that there will never be enough palliative care clinicians to meet the needs of seriously ill

patients. This fact puts more emphasis on the demand to train primary care clinicians and other generalist health care providers in the discipline.

In 2011, the Cambia Health Foundation partnered with the *National Journal* to conduct a three-part series of nationwide opinion polls about palliative care called “Living Well at the End of Life: A National Conversation.” Among other findings, the polls exposed gaps in workforce development and capacity—revelations that culminated in the Foundation’s decision to invest in and help develop emerging, national palliative care leaders to shape the future workforce through its Sojourns Scholar Leadership Program.

“When I was going to med school there was no discussion like this, not even during fellowship. I think it’d be helpful to be educated somewhat by the professionals—the people who are really good at communication and sensitivity issues.”
– Conversation Starters: Research Insight from Clinicians and Patients on Conversations About End-of-Life Care and Wishes

Finally, the research to support palliative care interventions is scarce. In a piece for the *New England Journal of Medicine*, Scott Halpern, MD, PhD, MBE, and founding director of the Palliative and Advanced Illness Research Center (PAIR) at the University of Pennsylvania, writes that, “One of the most sobering facts is that no current policy or practice designed to improve care for millions of dying Americans is backed by a fraction of the evidence that the Food and Drug Administration would require for approving even a relatively innocuous drug.”^v

Palliative care centers: Pulling the field together

Palliative care centers that are rooted in academic health care systems have the unique advantage of drawing expertise from different departments and divisions—creating the collaborative, interdisciplinary and intra-professional approach to care, which seriously ill patients need. Following are four examples of centers in varying phases of development that represent the next generation of progress in palliative care.

The Cambia Palliative Care Center of Excellence (Cambia PCCE)

Established in 2012 at the University of Washington (UW), the Cambia PCCE is the only center of its kind in the Pacific Northwest. The Cambia PCCE is embedded within UW Medicine, which incorporates four hospitals, including two academic medical centers and two community hospitals; 12 neighborhood clinics and a clinic involved in homeless outreach; and a house-call program. The Cambia PCCE also serves as a resource for a number of other health care institutions

in the Pacific Northwest and around the country.

- **Core focus:** The Cambia PCCE focuses on implementing into clinical practice cutting-edge education and research on palliative care. This includes a strong commitment to:
 - Promoting both primary and specialty palliative care
 - Adapting new care delivery models over a variety of providers and settings
 - Developing and implementing palliative care quality metrics to assess and improve the palliative care it delivers across the health care system
 - Incorporating cultural navigators to help foster greater understanding of patient and family needs for those from other cultures

“This investment underscores our belief that, together, the Cambia Health Foundation and the Cambia Palliative Care Center of Excellence will be a catalyst for growth and innovation in the field of palliative care, both regionally and nationally.” – Peggy Maguire, president and board chair, Cambia Health Foundation

- **Funding:** Initially, the Department of Medicine and School of Medicine at UW made a five-year financial commitment to support the Cambia PCCE’s infrastructure and the salaries of those running it. While Dr. Curtis and his team supplemented the funding through additional grants, the center’s biggest investment to date has come from the Cambia Health Foundation.

The relationship with the Foundation started with two, three-year, project-based grants—one awarded to Dr. Stuart Farber to set up a palliative care training center and the other to Dr. Curtis to develop a palliative care quality metrics program. In 2014, the Foundation provided a \$10 million gift to sustain the Cambia PCCE, one of the largest awards of its kind in the field and the Foundation’s largest single grant to date. The investment created three endowments totaling \$8 million to support research, education and training, and clinical leadership. An additional \$2 million was earmarked for programs and resources that could be used to leverage existing programs to further improve serious illness care for patients. “The Cambia naming grant provided us with the sustainability and opportunity to grow the infrastructure on which the center is built,” explains Dr. Curtis. “We stand out among a relatively small number of centers that have had that kind of support from foundations or individual donors.”

- **Progress:** When Dr. Curtis and his team launched the Cambia PCCE, they outlined a series of strategic goals that included developing and implementing standards for their palliative care services and quality metrics, developing screening programs to identify patients with unmet needs, and achieving Joint Commission Advanced Certification in Palliative Care. To date, the Cambia PCCE has achieved all its goals, which are summarized in its latest annual report. In March 2016, UW Medicine became the first health care system in the country to have all its hospitals achieve Joint Commission Advanced Certification in Palliative Care. UW also now offers an innovative, interdisciplinary Palliative Care Graduate Certificate Program.

The Cambia PCCE is now working on a second set of goals, which include:

1. Increasing education for all clinicians in UW Medicine in advance care planning and goals-of-care discussions
 2. Further developing proactive screening programs to identify unmet palliative care needs in patients with serious illness and their families, and then implementing a strategy to meet those needs
 3. Growing and developing community-based palliative care programs that integrate with hospital-based programs
- **Advice:** “The key is having buy-in and support from the highest levels of the institution,” explains Dr. Curtis. “There needs to be conceptual support for the importance of palliative care and financial support for building programs. Having additional funding for the infrastructure is very important too. You really need both, as either one alone isn’t enough to sustain and grow a successful center.”

Having a well-formulated strategic plan, mission and vision, as well as a leadership team to articulate them, are equally important. “You need a vision and mission that capture not only the people who are interested in palliative care but also the clinicians who are taking care of these patients all over the health care system, as well as patients, families and the public,” he says.

- **Looking forward:** For the Cambia PCCE, community-based palliative care is the next frontier. “We’ve done a great job building palliative care consultative services in the hospital,” says Dr. Curtis. “Now we need to figure out how to build community-based services and a financial model to support them.” This purview includes the ability to follow patients across care

settings, not just in hospitals and at home, but also in post-acute care settings, nursing homes and rehabilitation facilities.

- Other areas of focus for the Cambia PCCE will include helping accountable care organizations (ACOs) and others focused on population health integrate palliative care into their models, as well as continuing to build the future workforce and leadership through emerging leaders like participants in the Cambia Health Foundation’s Sojourns Scholar Leadership Program. The Cambia PCCE and UW have had three physicians and two nurses who have been selected as recipients of the Sojourns Scholar Leadership Program: Caroline Hurd, Claire Creutzfeldt, Daniel Lam, Lynn Reinke and Tatiana Sandak.

The Palliative and Advanced Illness Research (PAIR) Center

Launched in January 2017, the PAIR Center at the University of Pennsylvania comprises 12 core faculty, 35 affiliated faculty, 15 trainees, more than 20 research staff, and a growing roster of collaborations with many of the largest health system partners in the U.S.

- **Core focus:** Led by Scott Halpern, MD, PhD, the PAIR Center focuses on developing the highest-quality experimental research to advance policies and practice to improve the lives of all people affected by serious illness—ultimately, the 5% of Americans who account for 50% of health care costs. According to Dr. Halpern, this focus incorporates:
 - Palliative care interventions and advance care planning
 - Transitional care models
 - Ways to deliver intensive care
 - How to better allocate organs to patients with end-stage organ dysfunction

“One of our major goals,” explains Dr. Halpern, “is to use a variety of big data techniques to identify patients in the community and hospital, in outpatient clinics and other places who have unmet palliative care needs.” In parallel, the PAIR Center is focusing on processes to determine which patients benefit from receiving specialized services versus receiving primary palliative care. Through large, randomized trials with large health systems, such as Ascension Health, Dr. Halpern and his team are testing the comparative effectiveness of different approaches to palliative care delivery.

- **Funding:** Financial support for the PAIR Center comes from the School of Medicine, the University of Pennsylvania Health System and local philanthropies.
- **Progress:** While the strategy for the PAIR Center is still unfolding, Dr. Halpern and his team have identified three broad categories of metrics against which they'll measure success:

1. Research: Conventional metrics around the number of papers published in high-impact journals and the amount of external funding secured for research occupy three-to-five-year goals. What the team is really after is evidence that their research is changing practice—a five-to-ten-year metric.

2. People: Over the next three years, the PAIR Center aspires to recruit five national leaders in the early- to mid-phases of their careers in research, as well as build and maintain the existing and growing cadre of internal faculty and staff by providing a place to work that's having a social impact.

3. Collaborations: Expanding its partnerships with the leading health systems across the country as well as with groups within the university's health system is key to the PAIR Center's goal of changing health care delivery.

- **Advice:** Dr. Halpern built the PAIR Center from the university's comparative advantage, leveraging its brain trust of highly trained, sophisticated physician scientists. "It's critical to understand the landscape, identify a unique need and gain a high-level commitment from your institution," says Dr. Halpern. He spent a lot of time talking to others in the field to understand what niches remained open. "I concluded that the niche we needed to fill was perfectly aligned with our advantage of rigorous scholarship," he explains.

Dr. Halpern could show a portfolio of \$20 million of external funding in peer-reviewed research, largely funded by the National Institutes of Health, as well as the ability to mentor others in the field to secure funding. "With that kind of track record of success, combined with the health system's own interest in benefiting from research in this area to improve the quality of care they provide for a relatively sick population through their referral system, it was a win-win situation," he discloses.

Finally, Dr. Halpern stresses the importance of building a great team and creating a place where people want to come to work every day. "That's the key to keeping talented people around—people who are efficient in a complex environment," he says.

- **Looking forward:** Aside from the measurable goals the team has outlined, Dr. Halpern is focused on recruiting as many physician and non-physician social scientists as possible, along with training the next generation of investigators to identify population-level approaches to care delivery that are efficient and equitable for the sickest Americans.

Stanford University Palliative Care Center

The Palliative Care Center at Stanford is a work in progress, expanding on the success of the inpatient clinical program that Dr. Stephanie Harman and Judy Passaglia, CNS, RN, ACHPN, established in 2007. Under the leadership of Drs. Karl Lorenz and Stephanie Harman, the center is organized around improving outcomes for patients and families in the health care system and focusing on implementation science and translating knowledge into practice; the goal is to advance clinical excellence alongside rigorous learning. "It's an endeavor in which research and education are partners but not ends in themselves," says Dr. Lorenz.

- **Core focus:** The philosophy and goal for the center, as Dr. Lorenz elucidates, is to be a place of dynamic exchange, supporting broad adoption of primary palliative care. "We want to create connections, bring people together and improve community support," he says. "As opposed to the traditional organization of an academic enterprise, which is specialty-based for the most part, the center here is intended to be a collaborative environment that takes advantage of the broader needs that patients have and that palliative care as an approach aspires to address. This is very important, because we have no hope of accomplishing our goals if we maintain the lens of a boutique, specialty practice."
- **Funding:** While the center has not yet started fundraising, Dr. Lorenz cites philanthropy as a valuable component—from both a financial perspective and the impact it has on other areas such as leadership development and external validation. "It's important to have philanthropy, because recognizing our value is difficult in conventional terms," he explains. "We aren't easily accountable from a cost and revenue perspective. Philanthropic investment provides the external validation for others to see the center's value and it attracts others to support us."

Dr. Harman is the recipient of a 2017 Sojourns Scholar Leadership Award. In addition to a \$180,000 grant, she will receive leadership development training and focused mentorship for her project, titled "Harnessing Machine Learning to Improve Palliative Care Access." The electronic medical record and its reams of data have become perceived as barriers to patient-clinician interactions.

She seeks to improve palliative care access through machine learning. In collaboration with Drs. Kenneth Jung and Nigam Shah at the Center for Biomedical Informatics Research, Dr. Harman has built a model that identifies patients at a high risk for mortality in the next year.

The Stanford team will use the risk estimated by the model to prompt timely palliative care screening and evaluation on the inpatient medicine services, with the goal of increasing access to basic palliative care and specialty palliative care services.

Dr. Harman explains, “We are examining the implementation lifecycle of a predictive model, from a machine learning project to the design of a workflow for clinical use and its deployment in clinical practice at our medical center to improve care for seriously ill patients.”

- **Advice:** Dr. Lorenz says the most important ingredient in establishing the center so far has been bringing it forward with broad institutional support. The center was established with a task force commissioned by Dean Lloyd Minor and chaired by Drs. Harman and Norman Rizk, CMO and senior associate dean for Clinical Affairs. Representatives of both the health system and academic leaders from medicine and surgery as well as health system leaders were critical partners in the planning process. “As we launch, our partners are the source of clinical energy for innovation, pilot funds and vision for the ongoing work of the center.”
- **Looking forward:** As the center takes shape over the coming months, Dr. Lorenz and others will be looking at ways to attract a community of scholars and investigators, establish metrics, foster public dialogue in the communities they serve, and improve the experience of patients and families at the end of life. “The spirit of our center, from the health care and community view, is to ask how we can proactively identify the right individuals for the right care and bring them support at one of the most difficult periods of their lives,” says Dr. Lorenz.

University of Colorado Palliative Care Center

Founded in 2008 by Jean Kutner, MD, MSPH, professor of medicine at the University of Colorado School of Medicine, the Palliative Care Center at the University of Colorado traces its beginnings to a palliative care consult service; the addition of relevant curriculum in the nursing and medical schools; and a population-based palliative care research network (PoPCRN) that Dr. Kutner helped establish ten years earlier. “As we grew each area—clinical, education and research—we realized we had enough critical mass to coalesce all the pieces and declare ourselves a center,” Dr. Kutner explains.

- **Core focus:** The Palliative Care Center at the University of Colorado focuses on providing people with serious illness and their families access to high-quality, evidence-based palliative care across all settings by expanding clinical programs, education and research.
- **Funding:** Throughout its evolution, the center has been largely funded through a combination of internal, private and public sources, including significant grants from the National Institutes of Health.
- **Progress:** On the clinical side, patient volume continues to grow—and along with it, the support staff. Thirteen board-certified physicians, seven advanced practice providers, two chaplains, two social workers, a nurse, a music therapist, and an art therapist now staff the Consult Service—a program that received the Gold Seal of Approval from the Joint Commission.

The Center includes 12 palliative care investigators, including one who has started a neuropalliative care clinic and is changing the field for people with progressive neurologic diseases. “When we had our annual palliative care research day recently, I wasn’t on any of the abstracts being presented,” says Dr. Kutner. “This was one of those milestones of achievement, proving that not only had we reached a critical mass but we had also developed beyond a single person doing the work, which is necessary for any center to succeed.”

Dr. Kutner, along with Drs. Christine Ritchie at the University of California San Francisco School of Medicine and Kathryn Pollak at Duke University School of Medicine, is also the co-chair of the Palliative Care Research Cooperative Group (PCRC), which is the first research cooperative in the U.S. focused specifically on advancing the science of palliative care and end-of-life research through rigorous, multi-site, evidence-based research. The organization, funded by the National Institute for Nursing Research (NINR), now has more than 400 members, representing 130 participating sites, and has conducted more than 30 research studies.

- **Advice:** Dr. Kutner confesses she was naïve when she set out to build the center. “At the time we were getting going, there weren’t role models,” she explains. “We were all trying to figure out what a palliative care center would look like. So, I reached out to the directors of successful centers here on our campus that combined research, education and clinical care. I got copies of their business plans to understand how they were funded, how they sustained themselves, what to anticipate, etc.”

Understanding your institutional structure is a priority that Dr. Kutner thinks anyone else looking to establish a center should keep in mind as well. “We basically sit within the division of internal medicine within the department of medicine, because that’s where I was the division head and could make things happen,” she says. “Going where your advocates are is important.”

- **Looking forward:** What’s needed moving forward, Dr. Kutner says, is more focus on workforce issues. To grow the field, the industry needs to expand the pipeline of trained clinicians, educators and investigators. Dr. Kutner, along with Dr. Curtis and other palliative care leaders, guides the Sojourns Scholar Leadership Program as an advisor to the Cambia Health Foundation.

A standard of practice

Palliative care is person-focused and family-oriented care that dramatically improves the experience of people living with serious illness. As such, it should be a standard of practice for every patient facing serious illness. Achieving this norm requires ongoing and collaborative commitments to advance training, evidence-based research and clinical application. The interdisciplinary and intra-professional work being done at palliative care centers across the country is helping transform the health care system and is vital to improving the quality of life for each patient and caregiver.

Experts at palliative care centers are trained to help support the unique values and goals that guide patients and families through difficult illness. That’s why the Cambia Health Foundation has invested in the Cambia PCCE, will continue to invest in the development of future palliative care leaders through its Sojourns Scholar Leadership Program, and will collaborate with other funders to advance the field of palliative care.

The four academic medical centers profiled in this paper are just a small sample of the growth of the palliative care field. However, a commitment is needed from industry leaders to fund the development of additional palliative care centers throughout the nation. It is only through this type of investment and dedication to enlarging the field of palliative care experts that we will be able to support the needs of a nation facing a rapidly increasing number of seriously and chronically ill patients.

¹ Meier D, et al. America’s Care of Serious Illness: 2015 State-by-State Report Card on Access to Palliative Care in our Nation’s Hospitals. Center to Advance Palliative Care, 2015.

² Roeland, E.J. Patterns of palliative care consultation among elderly patients with cancer. *Journal of National Comprehensive Cancer Network* April 2016.

³ Roeland, E.J. Patterns of palliative care consultation among elderly patients with cancer. *Journal of National Comprehensive Cancer Network* April 2016.

⁴ Meier D, et al. Report Card: America’s Care of Serious Illness, Center to Advance Palliative Care, 2011.

⁵ Halpern, S. Toward Evidence-Based End-of-Life Care. *New England Journal of Medicine*. 2015.

