
Serving the seriously ill and those who care for them

A holistic approach to palliative care

Executive Summary

While person-focused, or patient-centered health care is not a novel concept, efforts to put it into practice are. Yet the tide is turning as an aging, more culturally diverse population is demanding more personalized—and personal—attention.

The numbers speak for themselves. Approximately 90 million Americans have a serious long-term illness, and this number is expected to more than double in the next twenty-five years.ⁱ For those over sixty-five years of age, 68 percent have one or more serious long-term conditions.ⁱⁱ Who's tending to their care? Four in ten Americans care for parents or others with serious conditions.ⁱⁱⁱ As a result, there's a growing interest in and need for palliative care: specialized medical and comfort care focused on providing patients relief from the symptoms, pain and stress associated with serious or life-limiting illness.

Although palliative care seeks to provide patients, families and caregivers with relief, traditional models are fragmented by medical specialty and transitions between health care settings—from the hospital to home or long-term care facility, for example. The disjunction results in communication gaps, confusion and additional burden for everyone, making it difficult for patients to receive the care they need. In New York City, for example, the average person with a serious illness is receiving care from 12 different specialist physicians, with no single individual coordinating care.^{iv}

There's also an issue with patients being able to voice what they really want. According to The Conversation Project, 90 percent of Americans think it's important to have the conversation about their wishes for end-of-life care, yet only 30 percent of them have actually had these conversations.^v

Finally, the referral process is murky. Patients are not being referred often enough or quickly enough to palliative care resources that could have a dramatic effect on their quality of life.

Closing these gaps calls for wider adoption of a new approach to palliative care—one that’s not limited to end-of-life discussions and can co-exist with curative care. The shift requires a more holistic standard that:

- Puts a patient’s physical, social and spiritual needs at the center of a care delivery plan to improve quality of life
- Expands access to care for patients, family members and caregivers
- Engages communities and policymakers
- Encourages investment in industry solutions

Retooling palliative care—how it’s defined and delivered—will be a significant step forward in how health care is delivered across the entire continuum of care, putting the individual front and center.

How We Got Here

In one version of the Hippocratic Oath, physicians traditionally promised, “Whatever house I may enter, my visit shall be for the convenience and advantage of the patient.” Over time, the practice of modern medicine has drifted away from focusing on the patient as an individual with questions, opinions and desires to one bent on treating patients as an aggregation of organ systems.

While this impersonal model took on more weight, the cry for reform became louder. In 2001, the Institute of Medicine released its landmark “Crossing the Quality Chasm” report, which emphasized the need to shift the focus back to the patient:

“Patients should be given the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them.”^{vi}

Today, new forces are creating even more demand for person-focused palliative care, including a changing market, patient awareness and increasing caregiver needs.

Market forces

In 2014, the Institute of Medicine issued another landmark report titled, “Dying in America: Improving Quality and Honoring Individual Preferences Near End of Life.”^{vii} It lists several contextual factors that shine a spotlight on advance care planning, including:

In one version of the Hippocratic Oath, physicians traditionally promised,

“Whatever house I may enter, my visit shall be for the convenience and advantage of the patient.”

- The increasing number of elderly Americans, including those with some combination of frailty, significant physical and cognitive disabilities, multiple chronic illnesses, and functional limitations
- Growing cultural diversity of the United States population, which makes it ever more important for clinicians to approach all patients as individuals, without assumptions about the care choices they might make
- Structural barriers in access to care that disadvantage certain population groups
- A mismatch between the services patients and families need most and the services they can readily obtain
- Palliative care services not keeping pace with the growing demand
- Wasteful and costly systemic problems, including perverse financial incentives, a fragmented care delivery system, time pressures that limit communication, and a lack of service coordination across programs
- The resulting unsustainable growth in costs of the current system over the past several decades

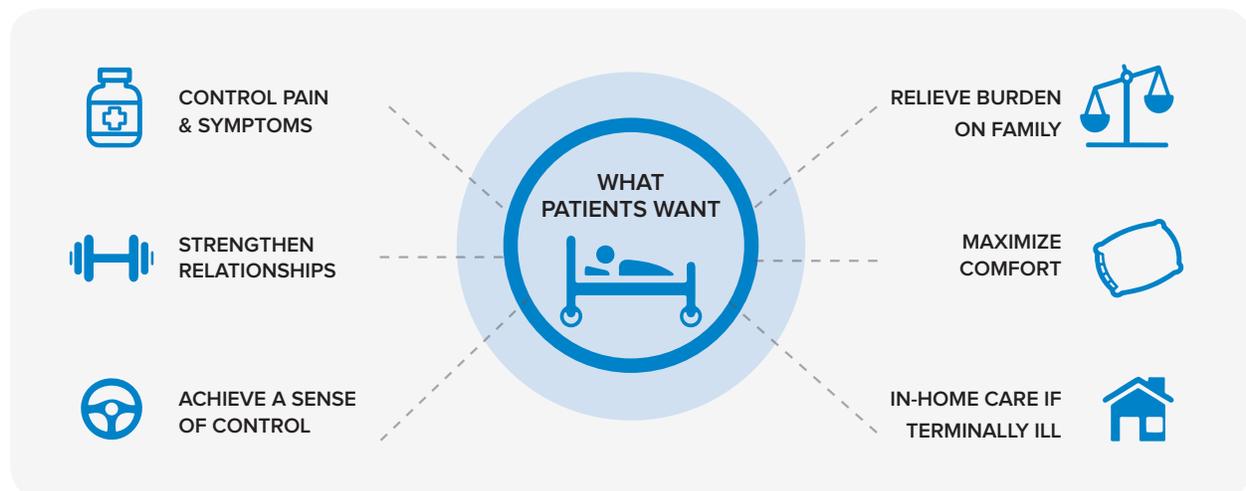
What patients want

Patients want to talk about their options and their wishes relative to care, wherever they are on that spectrum. Surveys show that they have clear opinions about what's important to them when it comes to end-of-life care:

- Control pain and symptoms
- Maximize comfort
- Achieve a sense of control
- Relieve burden on family
- Strengthen relationships with loved ones
- To be cared for in their own homes if terminally ill^{viii}

- 1) In thinking 'bad stuff won't be quite so bad' if you don't talk about it
- 2) By delaying discussion about 'bad stuff until you absolutely have to'
- 3) In thinking that 'cutting to the chase' will save time and decrease patient distress"^x

Often it comes down to time and training. Holli Martinez, program director of the University of Utah Palliative Care Service, confirms this, "When we query physicians about why they're not having conversations about advance care planning with patients who have chronic illnesses that they know will progress, they tell us they just don't have the time or the education about how to do this."



At a summit held in Seattle in May 2015, cancer patients and providers came together to talk about what they hoped palliative care could look like in the future: "shared decision-making, clear and sensitive communication about prognosis, improved emotional and symptom management support (particularly after hours), patient mentorship, engagement with caregivers and ongoing discussions about treatment goals and priorities with payer participation to ensure these needs were met."^{ix}

One of the biggest barriers is that many providers don't know how to open the conversation with their patients. Whose responsibility is it to ask the difficult questions? Dr. Anthony Back, co-director of the Cambia Palliative Care Center of Excellence at the University of Washington, says, "Physicians miss opportunities to educate patients about what may be ahead in one of three ways:

The gray area around having these conversations may soon gain clarity however, as Medicare recently announced its plans to reimburse doctors for having regular conversations with patients about medical treatment at the end of life. This proposal is a significant step forward for patients and their providers—recognition that the health care system values patient autonomy at the end of life.

What family caregivers need

Family members have specific needs, too. They're usually the ones holding everything together when a family member or loved one is chronically ill, managing care and communicating with provider teams. That responsibility takes a toll at all levels. A MetLife study reveals that employees with eldercare responsibilities suffer from fair or poor health; are more likely to report having diabetes, depression, hypertension or pulmonary disease; have more stress at home; engage in greater health risk behaviors such as smoking and alcohol use; are more likely to miss work than other employees; and have higher medical costs.^{xi}

To help caregivers cope, many employers have started offering eldercare support, such as referral services. Besides offering paid time-off programs, telecommuting arrangements and flexible schedules, employers should also consider outlets for stress reduction (e.g., on-site yoga), decision-support systems, financial incentives that encourage participation in preventive health benefits, and free legal and medical advice.^{xii}

Ultimately, family caregivers need to be involved in care coordination sooner. A *Health Affairs* article recommends, “As palliative care moves ‘upstream,’ that is, earlier in the course of illness, and into the ‘mainstream,’ as part of standard medical care, it is essential to bring family caregivers into the discussion, hear their concerns, and develop meaningful policy responses.”^{xiii}

The momentum for a new focus on palliative care is palpable.

Palliative Care: A Common Definition

Laying the groundwork for a new approach to palliative care requires support for a common definition. Despite increased awareness, many people, including physicians, may associate palliative care only with the end of life—a classification that’s too narrow. Decoupling palliative care from hospice and end of life is key to giving it a broader reach.

“End of life is a big piece, but palliative care is appropriate for any seriously ill patient whose future is uncertain,” explains Dr. Randy Curtis, co-director of the Cambia Palliative Care Center of Excellence at the University of Washington. “They may recover from that illness or injury and their palliative care needs dissolve.”^{xiv}

The Center to Advance Palliative Care (CAPC) stresses the importance of seeing the person beyond the disease and offers a comprehensive definition:

Palliative care, also known as palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of palliative care doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.^{vi}

Palliative care has well-documented benefits for both patients and family members. According to CAPC, people receiving it “report better quality of life, ability to function, understanding of their options and feeling back in control of their lives.”

Looking deeper, CAPC cites more detailed benefits of palliative care and dedicated palliative care teams, including:

- Reducing high levels of pain, suffering and distress among patients with serious illness, at any age and at any stage of disease
- Improving communication among patients, families and health care providers
- Addressing the needs of family caregivers as they cope with and care for a loved one with serious illness
- Reducing unwanted, unnecessary and painful interventions
- Improving quality of care and survival
- Improving patient and family satisfaction^{xvi}

A 360-Degree Approach to Palliative Care

Public opinion research shows that 92 percent of people think it is important that palliative care services be made available at all hospitals for patients with serious illness and their families.^{xvii} Such strong support for palliative care is not surprising. “Anything you want to go well in your life, you plan—whether it’s pregnancy, weddings or retirement,” says Holli Martinez. “But when it comes to end of life, it takes even more planning in a world that currently focuses on elongation of life.”

The good news is that the number of palliative care programs within hospital settings has increased by 138 percent since 2000.^{xviii} Still, there aren’t enough programs, and the ones that do exist are falling short.

What’s the ideal scenario? Dr. Steve Pantilat, director of the University of California, San Francisco Palliative Care Leadership Center, has a vision:

“Hopefully, one day people will select their health insurance and their providers with this kind of service in mind. This is what pregnant women do today by asking providers: ‘What does the birthing suite look like? Who is on call? What’s your C-section rate?’ Those are legitimate questions when you anticipate having a baby.

So I can imagine a world in which the same thing is true with palliative care services. People will ask: ‘How many patients die in the ICU? I don’t want that. How many people end up using hospice? How many hospices do you work with? Do you have a palliative care team? Who’s on the team? Can I get palliative care in the clinic as well?’ I don’t think anybody chooses that way right now, but I can imagine it.”^{xix}

Dr. Pantilat’s ideal foretells a system that engages people before they’re ill. What happens when a patient is already facing a chronic or life-limiting illness? Dr. Back says, “We need a system that guides patients and families through these discussions and decisions so that they get the kind of treatment they want.”

What’s it going to take to get there? A 360-degree approach that focuses on the patient and family, expands access and engages stakeholders at all levels.

Why is palliative care important?

90 MILLION

AMERICANS ARE LIVING WITH SERIOUS ILLNESS.¹



FOUR IN TEN

AMERICANS HAVE CARED FOR A LOVED ONE.²



92 PERCENT

OF PEOPLE THINK PALLIATIVE CARE SHOULD BE MADE AVAILABLE AT HOSPITALS.²



¹ “America’s Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation’s Hospitals,” Center to Advance Palliative Care, May 2011.

² Cambia Health Foundation, National Journal Survey

Putting the patient’s physical, social and spiritual needs at the center of a care delivery plan

Organizations like Regence—a family of regional health plans serving members in Oregon, Washington, Idaho and Utah—are moving forward with solutions that provide planning, communication and stability for patients and caregivers, facilitating health care needs from advance care planning all the way through completion of life. Through an extensive review of other plans in the country, the organization developed a holistic approach with benefits customized to meet the needs of members and their families, including:



Expanded benefits

- Curative treatment in conjunction with palliative treatment, including physical therapy, occupational therapy, speech therapy, and complementary and alternative medicine without pre-authorization restrictions
- Care coordination through a dedicated case manager who supports patients and families through care plan oversight across multiple providers, identifies resources and generally acts as a health care liaison
- Removal of the homebound requirement to offer home health services that include home visits to assist with daily living activities, personal care and caregiver support*
- Behavioral health services visits for individual, family and marriage counseling, and clinical social worker visits

**not until 2017 in WA, due to change in statute*



Dedicated member services team

- Staff available to explain benefits, address billing and administrative concerns, and provide additional comfort and outreach to members and their families



Caregiver support

- Caregivers supporting a loved one benefit from case manager support through education and resource identification as well as home health services and individual, family and marriage counseling



Provider partnerships

- Training and technical assistance for providers in establishing sustainable service models

Expanding access to higher quality palliative care across the community

Significant progress is already being made to give patients access to palliative care across the country, with organizations in the Pacific Northwest and Intermountain Region leading the way. For example:

The University of Utah Palliative Care Service

hosts an annual hospice and palliative care symposium, providing evidence-based education to professionals in medicine, nursing, social work and chaplaincy from Utah, Wyoming, Nevada, Idaho and Montana.

The organization has also implemented a screening system for palliative care in the medical ICU. In less than a year, they have seen impressive data with respect to decreasing lengths of stay; opening up ICU space/increasing the number of beds; and increasing throughput in the emergency department, other ICUs and the operating room. The palliative care team’s presence and partnership has changed the culture in the medical ICU too; staff members are now having conversations about palliative care with patients.

Finally, the team is launching an initiative with the amyotrophic lateral sclerosis (ALS) clinic, becoming part of the patients’ interdisciplinary teams to help with advance care planning and care needs at different stages of the disease.

Doernbecher Children’s Hospital in Oregon saw a need to educate hospice nurses who were accustomed to taking care of adults to learn take care of children. The result is Bridges, a pediatric palliative care program that helps children and families with decision-making, pain and symptom management, community support, hospice referrals and bereavement.

Among its unique programs is an initiative that ensures the team sees all babies born at less than 28 weeks or weighing less than 1,000 grams. Knowing that premature babies often have chronic health care needs and uncertain outcomes, the team meets all families and offers support on a regular schedule.

Bridges truly represents coordinated care where everyone involved is informed, communicating and on the same page—a model that could impact how health care is delivered at all levels.

Kathleen Perko, M.S., P.N.P., Bridges’ program director, says, “It alleviates anxiety for families when

they know everyone is talking to each other and that everyone actually knows each other.”

Familias en Acción (Families in Action) is making culturally appropriate palliative care, education and programs available to Latino populations in Oregon and Idaho, honoring family values, cultural differences and language barriers.

Executive director, Gail Brownmiller, explains, “In some ways, the Hispanic approach has always been more like palliative care, because it’s all about communication and relationships. Their culture is already focused on this. They are not used to asking their doctors questions though. So, we help with empowerment—coaching them on how to ask those questions and even on how to think about what they need to know before they go to the doctor.”

The Cambia Palliative Care Center of Excellence at the University of Washington (UW) has become a role model for palliative care education, metrics and implementation. The center focuses on three interrelated areas:

- Providing palliative care at UW hospitals
- Conducting research on palliative care
- Educating physicians, students and other staff and trainees in how to provide thoughtful, expert palliative care

The three-pronged approach spans several schools at the university, including medicine, public health, nursing and social work.

Dr. Randy Curtis, the center’s co-director, explains, “We saw a real opportunity for the center to provide coordination for our clinical, educational and research programs to ensure patients with serious illness and their families feel supported in decision-making and in dealing with the symptoms and the stress of serious illness.

Research and training will allow UW Medicine to learn more about delivering high-quality palliative care and to share best practices with institutions around the region, the country and the world.”^{xx}

Significant investments are being made in palliative care in Oregon, Washington, Idaho and Utah to expand access in rural and small communities, promote innovative strategies to deliver palliative care and facilitate open dialogue about serious illness and end-of-life issues through programs like The Conversation Project.

Engaging communities, policymakers and employees

CAPC pinpoints three key policy initiatives needed to overcome the current barriers facing palliative care programs across the United States:



Investment in a trained workforce to ensure sufficient numbers of specialists both to teach all clinicians the fundamentals and to directly provide high-quality palliative care for the highest-risk and most complex patients



Investment in the research necessary to establish a strong science base for palliative care and to expand palliative care’s ability to improve both quality and length of life



Investment in health care system capacity by requiring delivery of high-quality palliative care in hospitals, nursing homes and community settings through changes in measurement, payment and accreditation standards

In response, organizations like the Cambia Health Foundation are working with communities, policymakers and employees to grow conversation and awareness about palliative care:

- **Community:** Promote advance care planning and help change culture by bringing the palliative care conversation into the community
- **Policymakers:** Identify palliative care educational opportunities and work to build bipartisan understanding regionally and nationally, providing experience-based analysis of policy initiatives and engaging with key public officials as requested
- **Employees:** Encourage advance care planning among employees through integrated wellness programs

“It is not enough for a great nation merely to have added new years to life; our objective must also be to add new life to those years.”

- John F. Kennedy

Investing in senior services and the palliative care space

There has, perhaps, never been a greater opportunity for innovation in senior services related to health care. By 2029, there will be more than 71 million Americans age 65 or older, according to the U.S. Census Bureau.^{xxi} Many of these seniors will be managing chronic or age-related conditions. As the 2015 White House Conference on Aging highlighted, technology innovation has an important role to play in dealing with the “Silver Tsunami” by:

- Identifying and investing in industry solutions
- Increasing access, awareness and efficiency in providing health care and other services to seniors and those with serious health conditions
- Enabling independent living
- Providing easy access to a personalized care network
- Helping providers and payers manage healthcare logistics for their patients

Looking Forward

From patients and families to providers and policymakers, people are eager to infuse more humanity into health care at all stages. Palliative care—a microcosm in the industry—represents an opportunity to have an impact on more personalized, and personal, health care in general.

“Palliative care is attempting to bring patient and family values to the forefront, provide expert symptom control and communication, and create systems that bridge transitions of care from institution to institution,” says Dr. Back. “Thus a patient’s care plan remains intact as they transition. In this way, palliative care is central to transforming the health care system in a way that would be consistent with what the Affordable Care Act is trying to do—to guide patients and families through a whole trajectory of care.”

Progress will come from consulting physicians, institutions, payers and policymakers. And, most importantly, patients will have a strong voice in shaping its future. “This is an ongoing conversation and we need the patient voice at every point—from measuring, from designing studies, from interpreting those studies,” says Dr. Scott Ramsey, director of the Hutchinson Institute for Cancer Outcomes Research (HICOR).^{xxii}

In one corner of the country, the vision of palliative care for everyone is already taking shape. The prevalence of advance care directives in La Crosse, Wisconsin, has reached 96 percent.^{xxiii} Gundersen Health System took it upon itself to train staff and community members to help people understand and make decisions about end-of-life care. “These are conversations that we have with our patients,” says Bud Hammes, the medical ethicist who started the program. “These are open conversations involving family members, pastors, attorneys. It’s part of our community fabric now; it’s part of how we deliver care.”^{xxiv}

By normalizing the conversation around chronic illness and end of life, raising awareness for palliative care and expanding its definition, and considering all the factors that affect quality of life, there is hope for real transformation across the continuum of patient care.

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- ⁱ "America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals," Center to Advance Palliative Care, May 2011.
- ⁱⁱ Chronic Disease Management, National Council on Aging website: www.ncoa.org/healthy-aging/chronic-disease.
- ⁱⁱⁱ Susannah Fox and others, "Family Caregivers are Wired for Health," PewResearchCenter, June 20, 2013.
- ^{iv} The Dartmouth Atlas of Health Care.
- ^v Ellen Goodman, "How to talk about dying," The New York Times, July 1, 2015.
- ^{vi} "Crossing the Quality Chasm: A New Health System for the 21st Century" Institute of Medicine, 2001.
- ^{vii} "Dying in America: Improving Quality and Honoring Individual Preferences Near End of Life," Institute of Medicine, September 17, 2014.
- ^{viii} PA Singer and others, "Quality end-of-life care: patients' perspectives," JAMA, January 13, 1999.
- ^{ix} Diane Mapes, "Patients take a starring role to define, shape palliative care," Fred Hutch News Service, May 19, 2015.
- ^x "Media Landscape Opens Opportunity For Earlier, Better End Of Life Care: ASCO's Inaugural Palliative Care Symposium," Life Matters Media, October 25, 2014.
- ^{xi} "The MetLife Study of Working Caregivers and Employer Health Care Costs," MetLife Mature Market Institute and others, February 2010.
- ^{xii} Ibid.
- ^{xiii} Carol Levine and Carol O'Shaughnessy, "Family Caregiving And Palliative Care: Closing The Policy Gap," HealthAffairsBlog, July 2, 2014.
- ^{xiv} "In grave moments come insights about life choices," Consult, UW Medicine, Summer 2013.
- ^{xv} capc.org
- ^{xvi} "America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals," Center to Advance Palliative Care, May 2011.
- ^{xvii} Ibid.
- ^{xviii} Ibid.
- ^{xix} "All Palliative Care is Local: An Interview with Dr. Steve Pantilat," California HealthCare Foundation, 2013.
- ^{xx} "Cambia Health Foundation announces \$10 million endowment," Cambia Health Foundation, December 3, 2014.
- ^{xxi} "The Baby Boom Cohort in the United States: 2012 to 2060," US Census Bureau. May 2014.
- ^{xxii} Diane Mapes, "Patients take a starring role to define, shape palliative care," Fred Hutch News Service, May 19, 2015.
- ^{xxiii} Joseph Shapiro, "Why This Wisconsin City is the Best Place to Die," NPR, November 16, 2009.
- ^{xxiv} Ibid.

About Regence

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