Will California Be Ready?

Implementing Programs for Serious Illness

A Policy Discussion on Care and Coverage Approaches

#CASeriousIllness

May 31, 2018

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This conference builds on the 2016 conference, "Bridging the Gap: Challenges of End-of-Life Care in California," which was held in Los Angeles and hosted by the USC Schaeffer Center, the National Academies of Sciences, Engineering and Medicine, and Cedars-Sinai. The issue brief from that conference is included in the appendix. The goal of this conference is to advance policy and care delivery approaches that aim to make better, higher value care for serious illness a reality for all Californians. As a model state in the provision of care for serious illness, California is poised to lead the nation in this area. With a greying population, it is imperative that California leaders identify and plan for innovative approaches to meet the needs of patients (and their families) with serious illness. This conference aims to bring together thought leaders from both the public and private sectors to advance the policy dialogue around this important issue.

AGENDA

8:30 AM REGISTRATION AND BREAKFAST

9:00 AM WELCOME AND NATIONAL POLICY OVERVIEW

Leonard D. Schaeffer, Judge Robert Maclay Widney Chair and Professor, USC Price School of Public Policy; Chair, Roundtable for People with Serious Illness, The National Academies of Sciences, Engineering and Medicine

9:30 AM NATIONAL PANEL: HOW THE COUNTRY IS PREPARING

Moderator: **Karl Lorenz,** Section Chief, VA Palo Alto-Stanford Palliative Care Program

Amy Bassano, Acting Deputy Administrator for Innovation and Quality and Director, Center for Medicare & Medicaid Innovation

Peggy Maguire, Senior Vice President, Corporate Accountability & Performance, Cambia

Joe Rotella, Chief Medical Officer, American Association Hospice & Palliative Medicine (AAHPM)

Puneet Singh, Chief Development Officer, Aspire Health

10:30 AM BREAK

10:45 AM THE VIEW FROM SACRAMENTO

Jennifer Kent, Director, California Department of Health Care Services

11:15 AM PERSPECTIVE FROM THE PATIENT'S FAMILY

Karen Morin Green, nurse, wife and mother

11:30 AM STATE PANEL: HOW AND WHAT CALIFORNIA NEEDS TO DO TO PREPARE

Moderator: **Tom Priselac,** CEO, Cedars-Sinai

Jennifer Ballentine, Executive Director, CSU Institute for Palliative Care

Torrie Fields, Senior Program Manager for Advanced Illness and Palliative Care, Blue Cross of California

Shelly Garone, Assistant Physician in Chief, Kaiser Permanente-Sacramento

Daniella Meeker, Assistant Professor, USC Schaffer Center and Department of Preventive Medicine at the Keck School of Medicine

12:25 PM CONCLUDING REMARKS

Tom Priselac

FEATURED SPEAKERS

LEONARD D. SCHAEFFER

Leonard D. Schaeffer is the founding Chairman & CEO of WellPoint, Inc. (now Anthem), and was Chairman & CEO of WellPoint's predecessor company, Blue Cross of California. He is currently a senior advisor to TPG Capital and Starr Investment Holdings, and is the Judge Robert Maclay Widney Chair and Professor at USC. In the Federal Government, he served as Administrator of the Health Care Financing Administration (now CMS). He serves on the boards of the RAND Corporation, the Brookings Institution, USC, Walgreens Boots Alliance, Inc., and the Board of Fellows at Harvard Medical School. He chairs the advisory board for the Schaeffer Center at USC and is a member of the National Academy of Medicine where he chairs the Roundtable on Quality Care for People with Serious Illness. He has endowed academic chairs at USC, the Brookings Institution, the University of California (Berkeley), National Academy of Medicine, and Harvard Medical School. Mr. Schaeffer established the Schaeffer Fellows in Government Service program which annually supports forty undergraduates in summer government internships.

JENNIFER KENT, MPA

Jennifer Kent, appointed as director of the California Department of Health Care Services by Governor Brown in January 2015, oversees a staff of 4,000 and is responsible for the operation of Medi-Cal, the state's Medicaid Program. The department manages the spending of more than $100 billion annually in public funds that support the health of more than 13.5 million Californians. Kent had served as executive director of Local Health Plans of California since September 2013. Prior to that, she was principal with Health Management Associates Inc., from 2011 through 2013, where she advised clients on issues of health care reform. Her previous California government service included leadership roles in legislative, intergovernmental, financial and health policy areas with the Office of the Governor, the Health and Human Services Agency, and at DHCS. Kent earned a BA in government/history at Saint Mary's College of California, and received a master's of public administration from the University of Southern California.

KAREN MORIN GREEN

Karen Morin Green is an oncology and hospice registered nurse whose healthcare experience spans more than three decades. Upon completing her nursing education, Ms. Morin Green worked in an AIDS unit before moving to the Oncology and Bone Marrow Transplant Center at Cedars-Sinai in Los Angeles. She also has extensive experience as a home hospice nurse. During her seven years at the weSPARK Cancer Support Center in Sherman Oaks, Ms. Morin Green facilitated the metastatic and caregiver support groups, and also served as the oncology resource nurse for the Center. She now serves on the weSPARK Board of Directors. She is also the Southern California Team Leader of the End-of-Life Volunteers for Compassion & Choices, the nation's oldest advocacy nonprofit organization working to improve care and expand options available at the end of life.

PANELISTS

NATIONAL PANEL

KARL LORENZ, MD (MODERATOR)

Karl Lorenz is a general internal medicine and palliative care physician, and section chief of the VA Palo Alto-Stanford Palliative Care Program. Formerly at the VA Greater Los Angeles, Dr. Lorenz directed palliative care research at the VA Center for Innovation to Implementation and served on the faculty at the UCLA School of Medicine. Since leaving the VA Greater Los Angeles, Dr. Lorenz has maintained several of his appointments including member of the VA's national Hospice and Palliative Care Program (HPC) leadership team, director of the operational palliative care Quality Improvement Resource Center (QuIRC), and adjunct facility staff member at RAND. Dr. Lorenz's work and leadership has been influential to the field of palliative care research. Under his direction, since 2009 the Quality Improvement Resource Center (QuIRC) has served as one of three national leadership Centers responsible for strategic and operational support of the VA's national hospice and palliative care programs. QuIRC develops and implements provider facing electronic tools for the VA's national electronic medical record to improve the quality of palliative care. In that role, Dr. Lorenz participates with the national leadership team in strategic planning, policy development, and providing resources to support operational efforts. He has contributed to the field of global palliative care, serving the World Health Organization in its development of Palliative Care for Older People and leading methods for Palliative Care Essential Medications.

AMY BASSANO, MA

Amy Bassano is the Deputy Director of the Center for Medicare and Medicaid Innovation (CMMI) at the Centers for Medicare and Medicaid Services. Prior to assuming this position in April 2016, Ms. Bassano was the Director of the Patient Care Models Group at CMMI leading CMS's efforts on bundled payments including the Bundled Payments for Care Improvement (BPCI) Initiative and the Comprehensive Care for Joint Replacement (CJR) model and the development of physician specialty models such as the Oncology Care Model. In addition, she was responsible for the Home Health Value Based Purchasing Model and the Medicare Care Choices Model. Ms. Bassano also held senior management positions in the Center for Medicare at CMS overseeing Medicare payment policy for a variety of areas including inpatient and outpatient hospitals, physicians, ambulatory surgical centers, clinical laboratories, and Part B drugs. Prior to her tenure at CMS, Ms. Bassano was a Program Examiner at the Office of Management and Budget where she was the lead Medicare analyst on Medicare Part B and D issues. Ms. Bassano has an M.A. in policy studies from Johns Hopkins University and a B.A. in history from Tufts University.

PEGGY MAGUIRE, JD

Peggy Maguire is the senior vice president, corporate accountability & performance at Cambia. She provides executive leadership and strategic direction to several key areas at Cambia, including palliative care, ethics, compliance, corporate planning and performance, enterprise risk management and corporate social responsibility. She also serves as president of the Cambia Health Foundation, where she works with a wide range of stakeholders to advance palliative care leadership, access and awareness through Sojourns, the Foundation's signature program. Ms. Maguire joined the company in 1997 as an associate general counsel and has held several posts, including chief of staff to the CEO and vice president of Legal Services prior to being promoted to her current position. Previously, she worked as an attorney at Garvey Schubert & Barer, and served as a judicial extern to the Ninth Circuit Court of Appeals. Ms. Maguire served as a member of the PEW Charitable Trust End-of-Life Collaborative, and on the advisory council for OpenIDEO's End-Of-Life Challenge. She is the immediate past chair of the national board of Friends of the Children, chair of Start Making a Reader Today (SMART), incoming chair of the Doernbecher Children's Hospital Foundation board, and a member of the All Hands Raised Leadership Council. Ms. Maguire received her BA in philosophy and anthropology from Lawrence University, her JD from Northwestern School of Law of Lewis and Clark College, and has completed the Stanford Business Program.

JOE ROTELLA, MD, MBA

Joe Rotella is the founder of CatalystHPM, a healthcare consulting firm focused on transforming health care with the principles of hospice and palliative medicine. Since 2015, he has served as chief medical officer of the American Academy of Hospice and Palliative Medicine (AAHPM). Before that, he was the chief medical officer of Hosparus for 15 years. He has contributed to many AAHPM initiatives, included *Choosing Wisely, Measuring What Matters, the Hospice Medical Director Manual* and the development of an alternative payment model for patients with serious illness. He is board certified in internal medicine and hospice and palliative medicine and has practiced in a variety of roles, including primary care physician, palliative care consultant, and hospice medical director.

PUNEET SINGH

Puneet Singh is chief development officer for Aspire Health where he is responsible for partnerships with health plans, health systems, and physician groups, as well as new product development. Mr. Singh was previously a vice president at Chicago Pacific Founders (CPF), a healthcare focused private equity fund. Prior to CPF, he was a vice president at Accretive Health, where he led corporate strategy, marketing, and communications for the company and was a member of both the operating and executive committees. Earlier in his career, he was an investment banker at Goldman Sachs, where he worked on a range of M&A and capital markets transactions across the healthcare industry. Mr. Singh is a graduate of the Wharton School at the University of Pennsylvania.

STATE PANEL

TOM PRISELAC, MPH (MODERATOR)

Thomas Priselac has been associated with Cedars-Sinai in Los Angeles since 1979 and has served as President and CEO since 1994. He has been recognized for the development of strategic and operational innovations to foster high quality, safe and efficient healthcare as well as being actively involved in healthcare delivery and finance policy development. Mr. Priselac is a former member of American Hospital Association Board of Trustees which he chaired in 2009 and also served as Chair of the Association of American Medical Colleges in 2006. He is an Adjunct Professor at the UCLA Fielding School of Public Health where he teaches principles of organizational leadership. Mr. Priselac holds a master's degree in public health, health services administration and planning from the University of Pittsburgh.

JENNIFER MOORE BALLENTINE, MA

Jennifer Moore Ballentine is an educator, consultant, advocate, and change designer with more than 18 years experience in palliative care and hospice. In 2017, she was appointed Executive Director of the California State University Institute for Palliative Care, focused on increasing awareness and access to high-quality palliative care through education and expanding the skilled workforce. Previously she served in leadership positions at Life Quality Institute, The Denver Hospice, and the Colorado Center for Hospice and Palliative Care. Throughout her career, she has served on statewide and national taskforces to craft and advance legislation, policy, standards, and regulations to enhance the care of seriously ill persons, educate clinicians, and empower communities. She currently serves on the Patient Quality of Life Coalition, the National Academy of Medicine Roundtable on Quality Care for People with Serious Illness, the NHPCO Ethics Advisory Council and Palliative Care Council. She earned a master's degree in end-of-life studies at Regis University (with graduate honors) and a bachelor's degree at Oberlin College (Phi Beta Kappa).

TORRIE FIELDS, MPH

Torrie Fields, senior program manager for advanced illness & palliative care at Blue Shield of California, leads the development and implementation of programs and processes to improve the quality of life for individuals with serious illness and their families. Fields has led the development of highly successful palliative care initiatives including benefit design, case management, caregiver support, medical home development, and policy and engagement efforts. Prior to joining Blue Shield, she worked as an applied health services researcher in a variety of settings, including health plans, health delivery systems, local and federal health departments, and in university research laboratories. In addition to her work with Blue Shield, Fields acts as a consultant and curriculum developer for the Center to Advance Palliative Care and California State University Palliative Care Institute. Fields holds an MPH in health management and policy from Portland State University, a Certificate in Gerontology from Portland Community College, a BS in sociology from Portland State University, and a BA in communication theory from University of California-San Diego.

SHELLY GARONE, MD

Shelly Garone is board certified in Internal Medicine and Hospice & Palliative Medicine. She earned her BA in philosophy from Tufts University and her medical degree from Tulane Medical School. She did her internal medicine residency at UC Davis Medical Center in Sacramento, and completed a one-year pulmonary/critical care fellowship at Cedars-Sinai in Los Angeles. She joined Kaiser Permanente in 1999 as a hospitalist where she worked with a team to create and build the Kaiser Palliative Care Department. In 2014, Dr. Garone took over the Continuum and began to work in Skilled Nursing Facilities. In 2015, she assumed an APIC role over not only the Continuum, but also Oncology Care, Quality, and Patient Safety. She recognizes that people are most vulnerable during the times between hospital and home, between diagnosis and survivorship, between health and sickness. It is precisely these times, when bridges linking different venues of care and different providers of care must be built and maintained. She works endlessly on creation of those bridges, trying to find innovative ways to build systems to link care so that the patient never "falls through the cracks."

DANIELLA MEEKER, PhD

Daniella Meeker is an assistant professor at the USC Schaeffer Center and in the Department of Preventive Medicine of Keck School of Medicine, and adjunct information scientist at the RAND Corporation. She directs the Informatics Program in the Southern California Clinical Translational Sciences Institute and is a professor at the Pardee RAND Graduate School. Her engineering research focuses on distributed architectures supporting integration of research, data analysis, and practice. Her data policy research includes investigations in how to improve the safety of health information technology and clinical quality measurements. Other projects have included development of collaborative platforms for knowledge management, machine learning, and health and behavioral economics. Dr. Meeker earned her PhD in computation and neural systems from the California Institute of Technology.

USC Schaeffer
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Issue Brief

NO. 6 · APRIL 2017

CENTERING END-OF-LIFE CARE ON PATIENT PREFERENCES AND VALUES

Too often in the United States, patients near the end of life and their families get caught up in a fragmented health care system ill-designed to know their preferences and values let alone honor them. Despite significant growth in recent years of palliative care for all seriously ill patients and hospice care for dying patients, much work remains to make high-quality, patient-centered care at the end of life the rule rather than the exception. In late 2016, the USC Schaeffer Center for Health Policy & Economics, Cedars-Sinai, and the National Academies of Sciences, Engineering and Medicine brought together patient advocates, providers, payers and policymakers to examine how to bridge the gulf between the care patients say they want at the end of life and the care they actually receive. This issue brief summarizes the conference proceedings and explores key issues in end-of-life care, including challenges faced by the care team; improving advance care planning; meeting the needs of diverse patients; overcoming community and family challenges; and designing policies to meet patient values.

A Touchstone for End-of-Life Care: What's Important to You?

It's a simple, straightforward question—what's important to you? Yet, it's a question too rarely asked of patients and families facing the uncharted wilderness of serious illness and end-of-life care in the disjointed U.S. health care system.

Asking that simple question, however, can make all the difference, as patient advocate Elizabeth Bailey knows well. In a former life, Bailey was a film producer, the generalist among specialists, charged with keeping everyone on set on the same page and the production on schedule.

Bailey's life changed a decade ago when her then 81-year-old father—who still practiced law, had a wide circle of friends and "mixed a very mean gin martini"—embarked on a medical misadventure of catastrophic consequences that started with sudden onset of double vision. In hopes of helping others, Bailey shared the story of her father—Louis Davenport Bailey—and her family's health care jouney at the end of his life at a conference co-hosted by the USC Schaeffer Center for Health Policy & Economics in late 2016 to map out strategies to improve the quality of end-of-life care (see page 5 for more about the conference).

Instead of seeing his internist, her father's default was to see an eye specialist, who ordered a biopsy and prescribed 100 mg of prednisone daily. Despite a pharmacist questioning the dose, Bailey's father didn't want to second guess his doctor and started the medication. The biopsy was negative, but through a miscommunication, Bailey's father, whose only health problem was a mild case of type II diabetes, continued taking the high daily steroid dose.

"It is at this point whenever I am telling this story to a doctor friend that he or she invariably asks me: 'And how long before your father went crazy?' Not long. In short order, my father landed in the ER….as a family, we were thrust into a completely foreign universe with its own highly specialized culture and language. It was sudden and extreme, and we simply did not understand what was going on," she said.

The Wilderness of Care

With coma-inducing high blood sugar levels and steroid-induced psychosis, Bailey's father was hospitalized for a month, giving her a firsthand view of fragmented hospital care where multiple specialists focused only on their area of expertise. This led to miscommunications and information vacuums, combining to make frail elderly patients worse rather than better.

"Necessity demanded that I figure out some kind of system to manage his care… Who were his doctors? When did they round? What were his pills? ....And this is where I brought in my film experience," she said. "As a producer, I fundamentally started producing our way out of the hospital because when I was in my dad's hospital room, at a certain point, I was like, this is the worst run film set I've ever been on."

Eventually, her father was discharged, but "he was never completely whole again," she recalled. "This first horrific health crisis set in motion years of decline punctuated by one hospitalization after another." Over the next 10 years—what she calls "our years in the wilderness," Bailey and her sisters cared for their father, juggling their families, careers and his expenses, as they grappled "with a health care system set up for rescue care, not the social services my father needed to be cared for at home," and that few Americans can afford for any length of time.

The experience set Bailey on a new career path. While caring for her father, she earned a master's degree in health advocacy, worked as an advocate for hospitalized patients and wrote a book to help people navigate hospital stays: *The Patient's Checklist: 10 Simple Checklists to Keep You Safe, Sane and Organized.*

Help From an Unlikely Source

After exhausting their financial resources, Bailey and her family "reluctantly" turned to the "much-maligned VA" for help, which turned out to be a godsend. "All physicians…under one umbrella and essentially at one hospital, one set of electronic medical records so everyone could communicate with each other, easy access to my dad's medical records, and an easy email system to communicate with his care team," she said, adding that these structural supports made caring for her father no less time consuming but much less stressful The final six weeks of her father's life "began the way it does for so many frail elderly, with a calamitous fall," she recounted. At the hospital, the family early on sought a palliative care consult—a service Bailey only knew about because of her work as a patient advocate. "End-of-life care is unscripted. It's improvised," she continued. "It is moment to moment for families and patients, but because we had asked for the palliative care team to be involved, and we had regular family meetings, we could make decisions based on the question that started every conversation with my father: 'Mr. Bailey, what is important to you?'"

As her father began to eat and drink less and less during the summer of 2016, the family, which wanted to move him home but didn't have the resources for the round-the-clock care he needed, managed to get him admitted to hospice care in a VA palliative care unit.

"Even here, I had to really advocate and agitate for him to be transferred…because his prognosis was surprisingly optimistic, that he could live six months or longer," she said. "The palliative care unit would only take and consider patients with three months or less to live. There was no way my dad was going to live three months, and I am forever grateful to the social worker and the palliative care doctor at the main VA campus who pushed for my dad to be accepted."

Her father only lived for two weeks after his transfer, but it made all the difference for him and the family. "There was quiet and peace which made a place for acceptance. We were able to truly be present and to live in the moment, and these moments of grace multiplied," she said, adding, "By continually asking and being guided by what is important to you, my dad was able to die as the person he was in life, and for that, I am filled with gratitude."

Improving Care One Unique Death at a Time

Research shows that there are essentially three common trajectories toward death in the United States.[1] About 40 percent of the 2.6 million Americans[2] who die each year travel a path similar to Bailey's father, "experiencing long-term dwindling of physical function and growing frailty" before dying as a result of an acute condition like an infection or a broken bone that wouldn't have killed a less frail person.[3] The other two paths include people—

typically those with late-stage cancer or another underlying fatal condition—who experience relatively good health and then a rapid decline followed by death—this group includes about 20 percent of people who die in a year. A quarter of people with conditions like heart failure or emphysema typically face a long series of complications, often resulting in hospitalizations, before they ultimately die after rescue attempts fail.

Given the vastly different circumstances of seriously ill patients nearing the end of their lives, there's no question that they have different medical, social and spiritual needs. A patient with late-stage cancer might need and want hospice-based palliative care, while others with longer illness trajectories might want and need help with activities of daily living so they can stay safely in their own homes. The lack of affordable, patient-centered long-term care—whether in patients' homes or in assisted living or skilled nursing facilities[4]—too often means 911 and hospitalization are the default for dying patients without the resources for around-the-clock care in a less intense setting.

Asking that central question—what's important to you?—of each dying person in such differing circumstances is a Sisyphean task in today's fragmented, high-tech, low-touch specialized health care system. Slowly, however, as death emerges from the guarded whispers of American life into mainstream conversations through work such as Bailey's and others, people are beginning to grasp that the current health care system too often fails to provide end-of-life care consistent with patient preferences and values.

The barriers to such care are formidable and include a "fragmented system with perverse financial incentives that contribute to uncoordinated care, avoidable hospitalizations, and in many cases, unnecessary costs," according to Leonard D. Schaeffer, who welcomed people to the conference. On a more optimistic note, Schaeffer, who served on the Institute of Medicine's expert panel that issued the 2014 consensus report *Dying in America*,[5] said, "With over 10,000 baby boomers a day turning 65, the pressure to identify, to document and to deliver end-of-life care that reflects the patient's values and preferences will accelerate."

About two-thirds of the audience agreed that the quality of end-of-life care in California has improved in recent years, pointing to policy changes like Medi-Cal coverage of palliative care services and educational efforts to engage clinicians in improving end-of-life care. Nationally, Medicare coverage of physicians' time to discuss end-of-life care with beneficiaries was cited as another step forward. As Kate O'Malley of the California Health Care Foundation said, "The climate has really changed…it takes a change in the culture of health care to really get us to where we want to be, so I think there's certainly a long way to go, but the levers for change are in motion."

Another participant observed that it's difficult to know whether progress is being made or not, saying, "I'd like to be an optimist but I really don't know. And it gets to a more profound issue, which is really, why is it that we don't know and why don't we have really good and public statewide knowledge about the experience of patients and families near the end of life?"

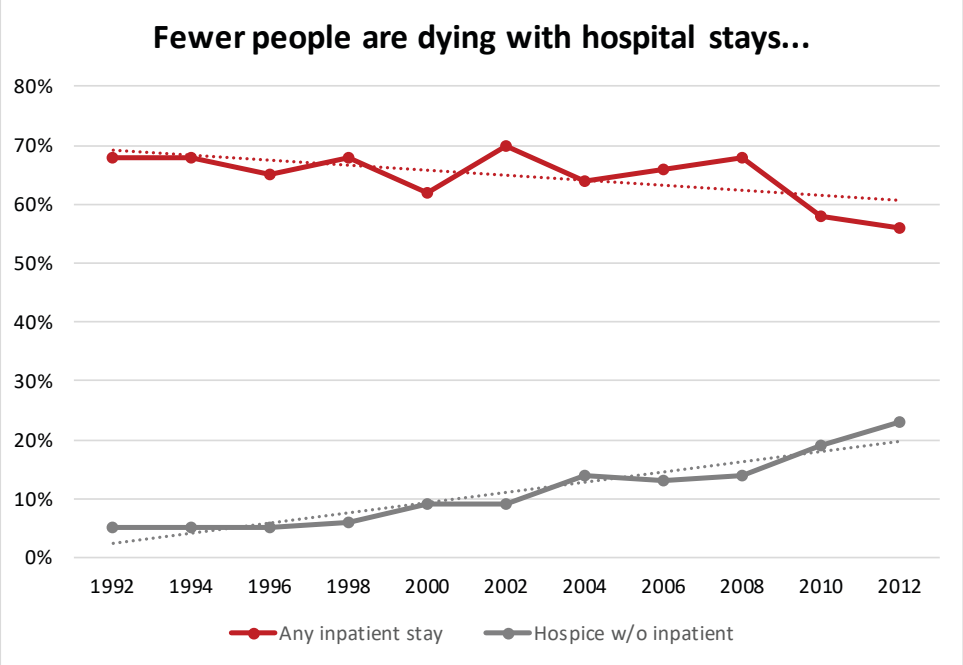
Disconnect Between Patient Wishes and Actual End-of-Life Care

The disconnect between the care patients say they want and the care they actually receive at the end of life is well documented, with about 70 percent of people reporting they would like to die at home, but only 25 percent doing so.[6] There are some signs, however, that the gap is narrowing.

Dana Goldman, Schaeffer Center director, offered several insights into how use of health care resources at the end of life has changed over the last two decades. Fewer Medicare patients are dying with hospital stays—between 1992 and 2012 the share of beneficiaries who died in a year with any inpatient stay declined from 68 percent in 1992 to 56 percent in 2012, the most recent year with available data. Similarly, the proportion of beneficiaries in the last year of life receiving hospice care without an inpatient stay climbed from 5 percent in 1992 to 23 percent in 2012 (see Figure 1). And the overall share of beneficiaries who die in a year and receive hospice care has grown from slightly more than one in five to almost half.

Figure 1

The proportion of beneficiaries in the last year of life receiving hopsice care without an inpatient stay climbed from 5 percent to 1992 to 23 percent in 2012.



Additionally, a Schaeffer Center analysis of the Health and Retirement Survey, which relies on proxy interviews for those who died, found that between 2002 and 2014, the share of people who die in a year with written instructions about their end-of-life care has increased from about 39 percent to 50 percent. The analysis also found that the share of people with written instructions to limit care in certain situations has increased from 35 percent to 45 percent, along with those saying to withhold any treatment—up from 30 percent in 2002 to 38 percent in 2014.

At the same time, however, Goldman noted that the proportion of people who want all care possible to prolong life had the greatest relative increase, from about 0.5 percent to 3.8 percent. The findings indicate that people's preferences for care at the end of life vary a great deal, underscoring the need to understand what's important to individual patients, and not approach end-of-life care with a "monolithic" viewpoint, he said.

Overcoming Barriers to Higher-Quality Care

With a goal of building a road map to better end-of-life care, conference participants worked in small groups to identify challenges and solutions to honoring patient values and preferences using the five following themes:

On the Frontlines: Challenges Faced by the Care Team

Led by Stuart Finder, director of the Cedars-Sinai Center for Healthcare Ethics, this group focused on identifying what clinicians actually experience when confronted with dying patients and how to engage patients and families in care decisions. According to Finder, an overarching issue is lack of clarity about who is responsible for what, and that the very lack of clarity makes it too easy for no one to be responsible.

When a seriously ill patient is hospitalized, a cadre of people provide very technical specialized care, he noted, adding, "There's no one who is actually taking on the responsibility to find out what the patient actually values, what it is that the patient understands about their condition, what it is that matters to that patient… and the barriers to that of course are time."

Another major problem is that people are encouraged to fill out an advance directive that spells out what they want. "That's actually the wrong question and has led to a lot of the problems in terms of the distrust that many patients have toward our systems, and then the frustration that many who work in the systems have toward patients, because they keep asking us for things that we can't give," Finder said.

"What we really need to be talking about is what is it that people value or what is it that matters to them?.... such that the kinds of interventions that we have at our disposal can be applied, used, delivered, because they fit with who the person is. So it is a different way of understanding," he said.

Possible Solutions: The group concluded that physicians ultimately must take responsibility for ensuring that the care team asks and knows what matters to patients instead of just asking what interventions they want. To accomplish this goal will require training and support not just to physicians but also to nurses, social workers, chaplains and other

members of the care team. Additionally, interoperable electronic health records (EHRs) across providers and care settings could help fragmented care make sure patients' priorities are communicated across settings.

Advance Care Planning and Delivery: Communication, Reimbursement, Aid in Dying

Overcoming the stigma and discomfort of discussing end-of-life care among both providers and patients and involving the larger community in engaging people to learn and think about what's important to them and document their wishes were key themes in the group led by Judy Thomas, CEO of the Coalition for Compassionate Care of California.

"This is a societal issue, and we need to take it out toCommunities. It's much more than just the interface with the health care system," she said. "So going to where people gather—faith communities, senior centers, book groups—any place where people gather."

At the same time, Thomas noted, "There needs to be leadership within our health care organizations from a very high level to create systems for advance care planning. So it needs to start with the C-suite."

Possible Solutions: Payers and providers need to work together to create an environment where the need for advance care planning discussion is recognized and truly valued. All healthcare stakeholders also need to work together to develop a common and understandable language and devise ways to share data and information across care settings.

Meeting the Needs of a Diverse Patient Population: Cultural Differences, Values, Disparities

Lack of cultural diversity in the health care workforce was cited as the "No. 1, No. 2 and No. 3" barrier to understanding and bridging cultural differences around end-of-life care, according to Susan Enguidanos, an associate professor at the USC School of Gerontology.

"This was seen as a huge problem, and it's not just in the hospitals and the medical groups, but it was also in community-based services. So beyond hospice, beyond home health, in all the community-based services people were accessing," she said.

Engaging diverse patients in advance care planning means having enough time for quality conversations, and "oftentimes the timing of these conversations is coming too late," she said. "It's in the moment, as we call it—in the moment, in the crisis situation, so that these conversations need to occur earlier along the lifespan."

Clinicians and other providers also need to keep the concept of patient-centered care firmly in mind and put aside preconceived ideas of the right outcome for a particular patient. "I think a lot of us get sucked into this vortex that this didn't go right because this person suffered at the end of life, but really turn it around to what's important to the patient, and for some patients, it's going to be fighting to the last end and doing everything they can, and for other patients, it is going to be that comfort," she said.

Possible Solutions: Along with attracting a more culturally diverse workforce and supporting and training existing caregivers to

About the Conference: Bridging the Gulf: Challenges of End-of-Life Care in California

As the state's diverse and growing population ages, California is at the forefront of confronting how to advance the triple aim of better care, better health and smarter spending—or higher-value care. There are few parts of the health care system where high-quality, patient-centered affordable care matters more than at the end of life.

Using the Institute of Medicine (IOM) 2014 consensus report *Dying in America* as a springboard, the conference brought together 125 multidisciplinary health policy experts, clinicians, social workers chaplains, payers and patient advocates to identify barriers and opportunities to improving the quality of end-of-life care. Held Nov. 7, 2016, in Los Angeles, the conference was hosted by Cedars-Sinai of Los Angeles, the USC Leonard D. Schaeffer Center for Health Policy & Economics, and The National Academies of Sciences, Engineering and Medicine with additional support from the Gordon and Betty Moore Foundation and Anthem Blue Cross. During the daylong session, participants shared and discussed their professional and personal experiences with end-of-life care and then broke into smaller groups to explore the following five end-of-life care issues: challenges faced by the care team, advanced care planning and communication, meeting the needs of a diverse population, new models of care, and policies to meet patient values.

understand cultural differences, the group recommended broad grass-roots efforts to engage the public in thinking about end-of-life decisions, perhaps, by looking at other successful public awareness campaigns, such as HIV/AIDS and breast cancer awareness. Other approaches include developing partnerships across local providers to pool culturally diverse providers who can frame palliative and end-of-life care in an accessible culturally competent way and hospitals and medical groups providing translation assistance if needed. The importance of EHR continuity across care settings also surfaced.

Community and Family Challenges: Contradictory Goals, New Models of Care

Broken connections—between patients and families and providers and between hospitals and communities dominated discussion in the group led by Karl Lorenz, a palliative care physician and professor at Stanford's School of Medicine. And repairing those connections requires "clear and common language" to help people understand that palliative care is not about death and dying but a much broader construct that can help any seriously ill patient.

There's also little understanding of what community supports exist to help patients who want to be cared for at home—"we shouldn't be the victims of a good choice, but we need to know what the community supports are," Lorenz said. "We just don't know. Are they (the community supports) food security? Are they dealing with loneliness? Are they addressing the taxed, overtaxed nature of caregiving for a child or a wife who's really struggling to hang on?"

And even when there are community supports, they often "miss the big middle," he said. "So the affluent have plenty to take care of their needs, and there are resources for the poor to support paid caregiving at home, for example, but the middle is vulnerable."

Possible Solutions: Bridging the gap between the health care system and the larger community is a critical element of engaging people to think and talk about advance care planning and end-of-life care. To do so will require reaching people across community settings, including schools and colleges, houses of worship, and community centers. A much larger issue, which involves payers, policymakers and others, is aligning payment mechanisms to support care provisions that are consistent with patient preferences and values.

Designing Policies to Meet Patient Values: Incentives, Payment Models, Quality Measures

Lack of clear definitions about different types of care; lack of reimbursement for caregiver support, telehealth and other components of community-based palliative care; and misaligned provider payment incentives are major obstacles to fulfilling patients' care preferences, according to Janet Corrigan, chief program officer for patient care at the Gordon and Betty Moore Foundation.

"Right now providers have strong incentives to provide procedures and curative services, and not a very strong incentive financially to spend time with patients and to help them manage their chronic conditions" she said.

Another priority area is developing quality measures to assess whether a patient's goals were expressed and whether care followed those patient goals, along with outcome measures related to pain and symptom relief, emergency department use, advance care planning, and patient and family satisfaction, she said.

The group also called for greater clarity on the role of proxies in advance care directives, she said, noting, "The clinical leadership needs to step up to the plate and own this issue, work with patients and family members around the designation of a proxy and getting an advance care directive in place." Providers need to help patients understand that the individual who serves as their proxy must be comfortable with the advance directive or the patient needs someone else to step in and carry out their wishes, she said.

Another area that needs policy attention is professional education related to palliative care in medical and nursing schools and residency programs, and possibly licensure requirements for health care professionals to have training in palliative care.

Possible Solutions: Changes in payment methods can play a significant role in making sure care more closely aligns with patient preferences and values. Often, basic elements of community-based palliative care like caregiver supports and telehealth simply aren't reimbursed. As policymakers continue to work toward

high-quality, affordable, patient-centered care, it's important that they address advance care planning and end-of-life care as key elements of payment reform. There is also a pressing need for organizations involved in quality measurement and oversight like the National Committee for Quality Assurance and the National Quality Forum to develop and endorse standardized performance measures to capture whether patient preferences and values are being met.

Next Steps

In recent years, the American conversation about end-of-life care has advanced from talk of "death panels" during the national health reform debate in 2009[7] to how best to learn about and honor patient preferences and values. A driving force behind the change in the tenor of the conversation was the 2014 release of the Institute of Medicine report: *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.*

At the Schaeffer Center conference, Philip Pizzo, a professor and former dean of the Stanford School of Medicine, who co-chaired the IOM committee that issued the report, recounted how having "some things off the table"—assisted suicide and the cost of end-of-life care—allowed the diverse IOM committee to reach consensus. And for maximum impact, the committee issued only five recommendations in the areas of:

- Delivery of person-centered, family-oriented end-of-life care.
- Clinician-patient communication and advance care planning.
- Professional education and development.
- Policies and payment systems to support high-quality end-of-life care.
- Public education and engagement.

"We had, as a framing context, the view that we were going to focus on quality and individual preferences regardless of whether that meant more or less therapy.… If someone said we want to get all that we can get in terms of care, we should respect that as much as we can, and if others said we really don't want to get much more medical care, [we want] more social care, we should respect that as well," Pizzo said.

"So the first recommendation was to really foster a seamless, efficient patient-centric health care system that's accessible and available 24/7 so that an individual facing a chronic disease or an end-of-life set of situations would know where to go when they're getting their care," he said.

Noting that the course of illnesses is often uncertain and the timing of death is rarely easy to predict, Pizzo said the IOM committee recognized that advance care planning can't be put off until people get sick because "oftentimes what takes place is these dialogues occur when there is desperation and therefore not really clear-thinking decision making taking place."

The committee's third recommendation centered on "wide-sweeping changes" in the education and life-long training of health professionals to prepare them for conversations with patients about their care preferences and values. "We've lost the connection with people. We've lost the ability to really reach out and form a human bond," Pizzo said. "We have become too digitized, too removed, too aloof to the process, and that is a really sad state of events."

Additionally, existing payment systems and approaches to care often prevent patients from getting the care they want and need. For example, under the current fee-for-service system, the typical recourse for a Medicare patient in crisis is to call 911 and go by ambulance to the emergency department, he said. Instead, payment approaches need to encourage integration of medical and social services and coordination of care across settings, according to the IOM recommendations.

"Then our fifth recommendation, which is really part of what we're doing today, is to change the public dialogue, to really engage the community in discussions about death and dying," Pizzo said. "I think there have been amazing things that have happened over the course of our time together." ■

Notes

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2. Centers for Disease Control and Prevention, National Center for Health Statistics, FastStats, Death and Mortality 2014 (March 17, 2017). Accessed at https://www.cdc.gov/nchs/fastats/deaths.htm.
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4. Reschovsky, James D., Amanda E. Lechner and Alwyn Cassil, "Bridging the Disconnect Between Patient Wishes and Care at the End of Life," National Institute for Health Care Reform, Policy Analysis No. 12 Washington, D.C. (March 2015).
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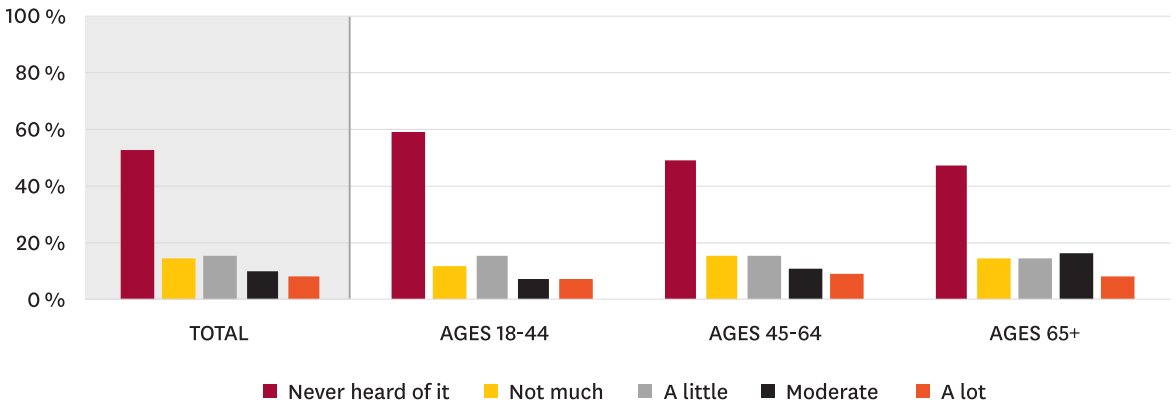
JUST IN

The USC Dornsife Center for Economic and Social Research included questions on palliative and hospice care in their most recent *Understanding America Study* survey conducted in March 2018. The *Understanding America Study* is a panel of approximately 6,000 households representing the entire United States. More information on the study is available at uasdata.usc.edu. Given the timeliness of the survey results, we include a summary of both national and California responses.

NATIONAL SURVEY RESULTS

Palliative care is still an area that is not well understood, according to the survey results, with over half of respondents in the national sample reporting that they had never heard of it. Furthermore, fewer than one in ten reported that they knew a lot. Figure one shows the responses broken down by age.

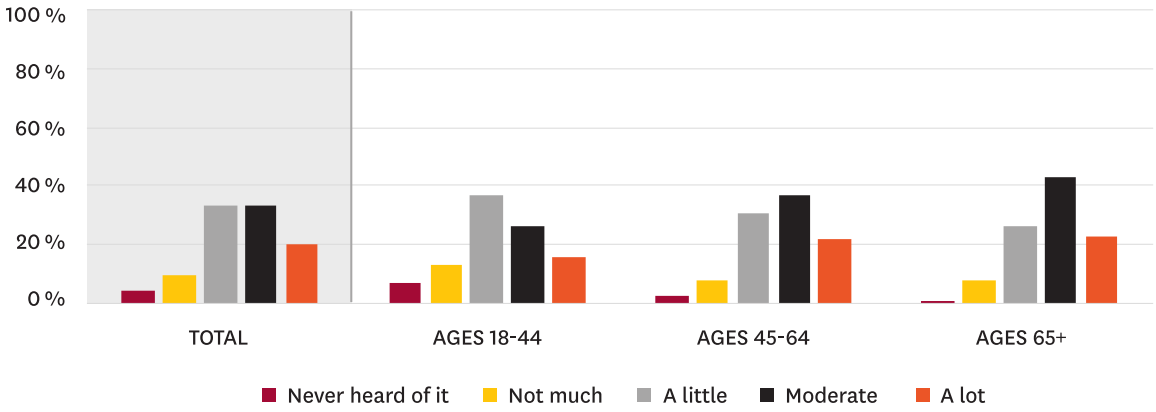
Figure 1. How much do you know about palliative care? National Sample



Source: Understanding America Study: Survey field dates: March 15- April 16, 2018. Sample size: 4572. Margin of sampling error is +/- 1.5%.

In contrast, significantly more people reported have some knowledge about hospice care, with more than half of all respondents reporting at least a moderate level of knowledge (Figure 2).

Figure 2. How much do you know about hospice care? National Sample



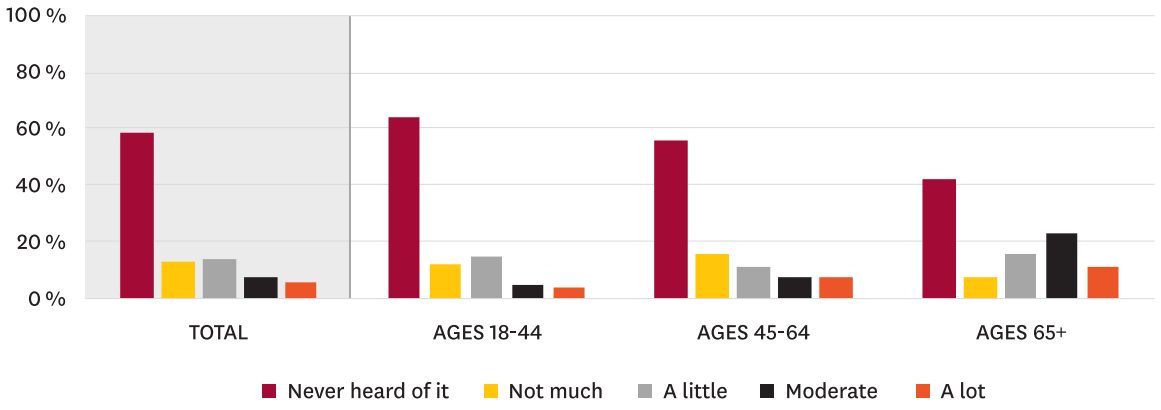
Source: Understanding America Study: Survey field dates: March 15- April 16, 2018. Sample size: 4570. Margin of sampling error is +/- 1.5%.

Across age groups, reported knowledge of palliative care and hospice care does seem to increase with age, with the group age 65 and older reporting the highest level of knowledge and those ages 18 to 44 with the least.

CALIFORNIA SURVEY RESULTS

Despite efforts to increase awareness, California survey results found slightly more individuals report having never heard of palliative care compared to the national sample. In Figure 3 we provide the results specific to California for the question "how much do you know about palliative care?" Notably, one in three respondents over the age of 65 reported having at least a moderate level of knowledge about palliative care compared to about one in four in the nation.

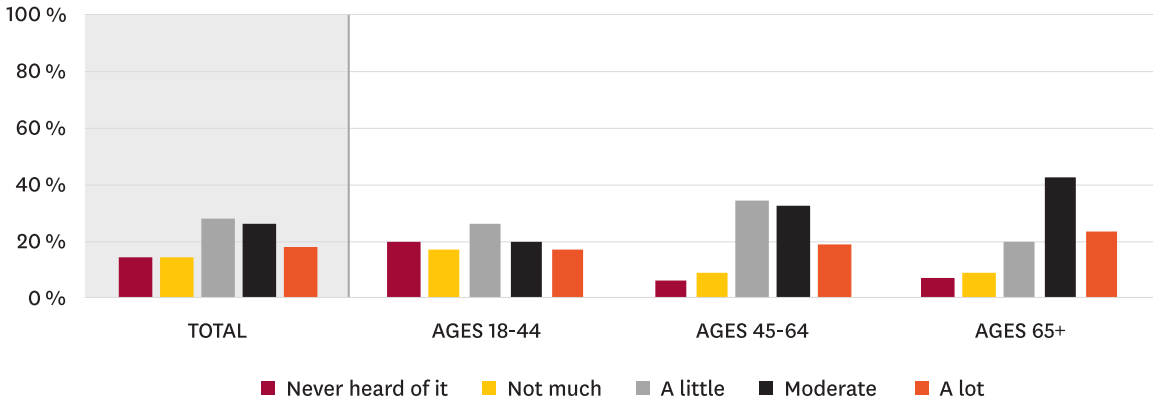
Figure 3. How much do you know about palliative care? California Sample



Source: Understanding America Study: Survey field dates: March 15- April 16, 2018. Sample size: 845 Margin of sampling error is +/-4%.

Though a similar percentage of California respondents reported knowing "a lot" about hospice care compared to the national results, more Californians report having never heard of it or knowing little (Figure 4). Twenty-eight percent of Californians surveyed reported "not much" or "never heard of it" when asked "How much do you know about hospice care?" This compares to 14 percent in the national survey.

Figure 4. How much do you know about hospice care? California Sample



Source: Understanding America Study: Survey field dates: March 15- April 16, 2018. Sample size: 845 Margin of sampling error is +/-4%.

Taken together, these results suggest what other polls and reports have found: there continues to be gaps in the public understanding about palliative and hospice care.

NOTES

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