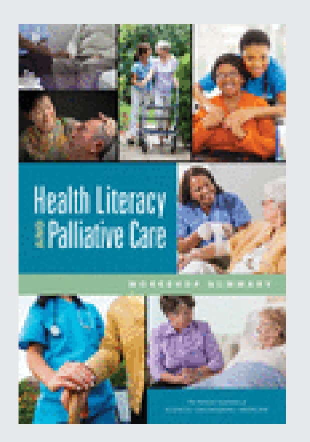

Health Literacy and Palliative Care: Workshop Summary

DETAILS

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Health Literacy AND Palliative Care

WORKSHOP SUMMARY

Joe Alper, *Rapporteur*

Roundtable on Health Literacy

Board on Population Health and Public Health Practice

Health and Medicine Division

The National Academies of
SCIENCES · ENGINEERING · MEDICINE

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This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published workshop summary as sound as possible and to ensure that the workshop summary meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this workshop summary:

CONSTANCE DAHLIN, Hospice and Palliative Nurses Association
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CATINA O'LEARY, Health Literacy Missouri
CARDINALE B. SMITH, Icahn School of Medicine at Mount Sinai Hospital

Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the workshop summary before its release. The review of this workshop summary was overseen by **Georges Benjamin,** American Public Health Association. He was responsible for making certain that an independent examination of this workshop summary was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this workshop summary rests entirely with the rapporteur and the institution.

Acknowledgments

The sponsors of the Roundtable on Health Literacy have made it possible to plan and conduct the workshop Health Literacy and Palliative Care, which this report summarizes. Non-federal sponsorship of the Roundtable was provided by the Aetna Foundation; American Dental Association; Bristol-Myers Squibb; East Bay Community Foundation (Kaiser Permanente); Eli Lilly and Company; Health Literacy Missouri; Health Literacy Partners; Humana; Institute for Healthcare Advancement; Merck & Co., Inc.; North Shore–Long Island Jewish Health System; and UnitedHealth Group. Federal sponsorship was provided by the Agency for Healthcare Research and Quality; Health Resources and Services Administration; National Institutes of Health; and Office of Disease Prevention and Health Promotion.

The Roundtable wishes to express its appreciation to the following speakers at the workshop for their interesting and stimulating presentations: Beverly Alves, Robert Arnold, John Cagle, Richard Freeman, Anne Kinderman, Carol Levine, Dana Lustbader, Virginia Marshall, Diane Meier, Stacie Pinderhughes, Tyrone Pitts, Justin Sanders, Thomas Smith, and Elaine Wittenberg.

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Acronyms and Abbreviations

ACO	accountable care organization
AHRQ	Agency for Healthcare Research and Quality
CAPC	Center to Advance Palliative Care
COPD	chronic obstructive pulmonary disease
CT	computed tomography
C-TAC	Coalition to Transform Advanced Care
DNR	do-not-resuscitate order
ELNEC	End-of-Life Nursing Education Consortium
EMR	electronic medical record
FBO	faith-based organization
GERD	gastroesophageal reflux disease
ICU	intensive care unit
MOLST	Medical Orders for Life-Sustaining Treatment
NCI	National Cancer Institute
OECD	Organisation for Economic Co-operation and Development

POLST	Physician Orders for Life-Sustaining Treatment
SNF	skilled nursing facility
TAME	time, assessment, management, and education
TPN	total parenteral nutrition
UPMC	University of Pittsburgh Medical Center Health System

1

Introduction[1]

"Palliative care provides a specialized, holistic approach to providing medical care for people with very serious illnesses, and the focus of palliative care is on providing relief from symptoms and improving the quality of life for patients," said Bernard Rosof, Chief Executive Officer of the Quality in Healthcare Advisory Group, as an introduction to the topic of this workshop on health literacy and palliative care.[2] "It is our hope that this workshop will help to further disseminate knowledge about the need for and the benefits of palliative care, and in particular, about how important it is to organize and deliver this care in a health literate manner."

In general, said Rosof, low health literacy is a barrier to receiving high-quality health care, but this is particularly salient for people living with serious or chronic illnesses requiring complex management regimens, having significant symptoms, or involving treatment with significant side effects. The ability to understand the scope of the illness, what is necessary to treat the illness, and how to live with serious illness as comfortably as

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[1] The planning committee's role was limited to planning the workshop, and the workshop summary has been prepared by the workshop rapporteur as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants, and are not necessarily endorsed or verified by the National Academies of Sciences, Engineering, and Medicine, and they should not be construed as reflecting any group consensus.

[2] This section is based on the presentation by Bernard Rosof, Chief Executive Officer of the Quality in Healthcare Advisory Group, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

possible is a critical factor in determining patient treatment outcomes and quality of life.

To explore the relationship between palliative care and health literacy, and the importance of health literate communication in providing high-quality delivery of palliative care, the National Academies of Sciences, Engineering, and Medicine's Roundtable on Health Literacy convened this 1-day public workshop featuring presentations and discussions that examined the effect of low health literacy on all aspects of palliative care. The statement of task for this workshop is below:

> An ad hoc committee will plan and conduct a public workshop to explore the impact of health literacy on palliative care. The workshop will feature invited presentations and discussions of the effect of low health literacy on all aspects of palliative care. The topic may encompass but will not be limited to end-of-life care and may also cover shared decision making, chronic disease and pain management, care models and other areas of interest within palliative care. It will also include the interaction between patients and patient families and providers, as well as the knowledge of palliative care and its principles among providers. The committee will define the specific topics to be addressed, develop the agenda, select and invite speakers and other participants, and moderate the discussions. An individually authored summary of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

Rosof noted that the workshop was designed to include the interaction between patients, their families, and providers, as well as the knowledge of palliative care and its principles among providers. The workshop featured invited presentations and discussions on topics that included the role of interpersonal communication between health care team members and patients and their families, the need to train health care team members on appropriate communication skills, and the role of integrated care teams in providing palliative care. The workshop also provided examples of successful palliative care programs from a variety of settings.

ORGANIZATION OF THE SUMMARY

The workshop (see Appendix A for the agenda) was organized by an independent planning committee in accordance with the procedures of the Academies. The planning committee's members were Cindy Brach, Marian Grant, Renee McLeod-Sordjan, Diane Meier, Yael Schenker, and Paul Schyve. This publication summarizes the discussions that occurred throughout the workshop and highlights the key lessons presented, practical strategies, and the needs and opportunities for improving health literacy in the

United States. Chapter 2 provides an overview of the link between palliative care and health and the case for integrating palliative care principles and practices across the entire spectrum of health care for individuals with a serious illness. Chapter 3 discusses interpersonal communication and the patient experience and includes the perspective of a patient's spouse who had to serve as the primary caregiver with little external support. Chapter 4 explores the need to improve the communication skills of health team members and some of the strategies that can be used to improve those skills. Chapter 5 lays out the case for delivering palliative care using integrated teams that include family members, social workers, nurses, and spiritual advisors. Chapter 6 provides examples of successful programs for delivering palliative care in four different settings. Chapter 7 covers the Roundtable's reflections on the key lessons learned at this workshop.

In accordance with the policies of the Academies, the workshop did not attempt to establish any conclusions or recommendations about needs and future directions, focusing instead on issues identified by the speakers and workshop participants. In addition, the organizing committee's role was limited to planning the workshop. The workshop summary has been prepared by workshop rapporteur Joe Alper as a factual summary of what occurred at the workshop.

2

Communication: Palliative Care's Transformational Procedure[1]

The workshop opened with an overview presentation by Diane Meier, Director of the Center to Advance Palliative Care (CAPC) and Vice-Chair for Public Policy, Professor of Geriatrics and Palliative Medicine, and the Catherine Gaisman Professor of Medical Ethics at the Icahn School of Medicine at Mount Sinai Hospital, who made the case for integrating palliative care principles and practices across the entire health care spectrum for anybody with a serious illness. Before addressing that topic, she noted that the real challenge in health literacy does not rest with patients and their families, as many discussions on the topic assume, but with the health system. "The obligation to be literate in what matters most to patients and families is ours. It is not their obligation to be literate about our culture."

Health spending, she then said, is highly concentrated among the sickest patients (see Figure 2-1), which she said is appropriate. "Spending money on very sick people is not waste," Meier emphasized. "How we spend that money is a different question, but conflating high spending with waste should stop." Health care spending data show that 1 percent of patients, the sickest and most vulnerable, account for 25 percent of all spending, and 5 percent of patients account for 50 percent (Schoenman

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[1] This section is based on the presentation by Diane Meier, Director of the Center to Advance Palliative Care (CAPC) and Vice-Chair for Public Policy, Professor of Geriatrics and Palliative Medicine, and the Catherine Gaisman Professor of Medical Ethics at the Icahn School of Medicine at Mount Sinai Hospital. The statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

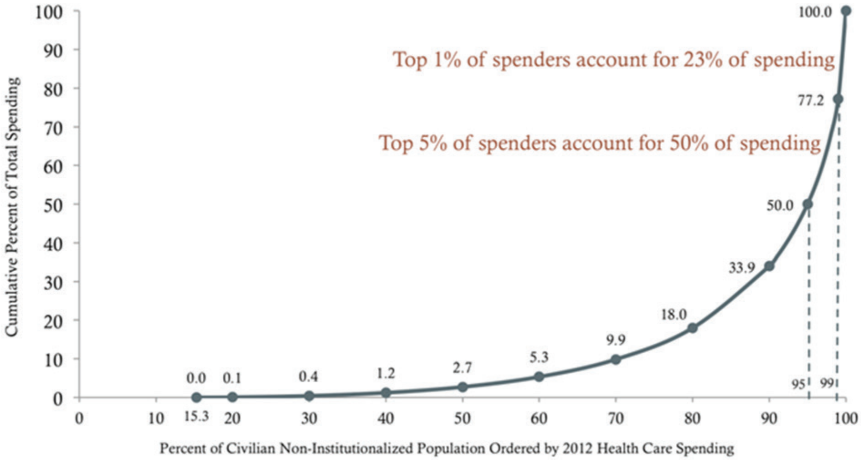

FIGURE 2-1 Concentration of health care spending among the top spenders.
SOURCE: Schoenman and Chockley, 2012.

and Chockley, 2012). Given data showing the positive effect of palliative care on both the quality of care and the cost of care for the sickest patients (Meier, 2011), applying the principles and practices of palliative care more broadly is crucial to any effort to improve value in the U.S. health system, said Meier.

As an example of an illiterate health system, Meier recounted the story of Mr. B., an 88-year-old man with dementia who was admitted to the emergency department for management of back pain resulting from spinal stenosis and arthritis. Upon admission, his pain registered 8 on a scale of 10, and his 83-year-old wife reported he was taking 5 grams of acetaminophen daily for pain, a toxic dose. Mr. B. had been seen four times in the emergency department over the previous 3 months, and though Mr. B. pleaded not to be taken to the hospital again, Mrs. B. felt she had no choice but to call an ambulance given that her husband's pain was terrible and that she could not move him herself, Meier recounted.

Meier became involved with Mr. and Mrs. B. when the attending physician in the emergency department called her and said he had a couple who were "abusing the emergency department for lower back pain" and wondered if she could see them even though the patient was not dying. Meier went down to the emergency department with her medical student and found Mr. B. in terrible pain and agitated from being brought to the emergency department—Mrs. B. had tried reaching Mr. B.'s doctor after hours and had gotten a voice recording saying "If this is a medical emergency, hang up and call 911," which is what she did. "Who is illiterate here?" said Meier. "She did exactly as she was told because it was a medical emergency. She could not move him, and there was nobody available to help her. Yet the perspective on our side is that this couple is abusing the emergency room."

Before what she called her accidental and fortuitous involvement with Mr. B., he had been subjected to four ambulance rides to the emergency department, been hospitalized three times, developed a urinary tract infection from having been catheterized and became septic, and was declining functionally and cognitively simply from being hospitalized and suffering from complications. In addition, the family—primarily Mrs. B.—was in enormous distress, explained Meier. She noted that the attending physician had called Meier not because it was hospital policy, and not because of any intent to improve quality for patients like Mr. B. and his family, but because he had been a medical student at Mount Sinai years earlier and had spent a 1-week mandatory rotation in the palliative care service and happened to have been assigned to her. "Obviously, this should happen by design, not by accident," said Meier.

After spending considerable time with Mr. and Mrs. B. assessing the situation, Meier decided to try ultra-low-dose morphine to see if that could address Mr. B.'s back pain and MiraLax for his constipation. Again, good fortune came into play because the pharmacy across the street from Mount Sinai carried the necessary formulation, an uncommon occurrence. While the student was fetching the prescription, Mr. B. had received a minute dose of morphine, which he tolerated well and enabled him to relax and even walk to the bathroom. Meier spent time teaching Mrs. B. how to administer the ultra-low-dose morphine and MiraLax, writing instructions in block capital letters and using teach back to ensure she understood the directions. Meier noted that it took three tries before her instructions were clear enough for her to become convinced that Mrs. B. knew what to do. She also phoned the director of Mount Sinai's house calls program and arranged for a visit to the family's home the next morning. What the visiting team found was a disaster waiting to happen, said Meier. There were loose throw rugs everywhere, electrical wires crisscrossing the floor, no grab bars in the bathroom, no elevated toilet seat, and the only thing in the refrigerator was leftover Chinese food. "Why was that?" asked Meier. "Mrs. B. could not go out to go grocery shopping because she could not leave Mr. B. alone. He would freak out and either try to follow her or fall in trying to follow her." Lacking a computer, Mrs. B. could not order food from one of the delivery services operating in New York, but she did have a phone and called the Chinese restaurant next door.

With the family's permission, Meier contacted the church where Mr. and Mrs. B. had gone before traveling became a problem. It turns out that there was a new pastor at the church who had not known the couple and so did not realize they were no longer attending services, but who immediately connected them to the church's friendly visitor program. Now, a member of the congregation or a high school student in a community service program spends a few hours with Mr. B. three times per week, enabling Mrs. B. to go shopping and spend time with her friends, which Meier said was probably the most important result of her involvement with this family. The palliative care service also organized Meals on Wheels for the family and contacted a daughter living in California, who now orders groceries online for her parents and visits them more often now that she knows what was happening back in New York. The end result is that 2 years later, Mr. B. is doing fine, and there have been no 911 calls, emergency department visits, and no hospitalizations since Meier's initial involvement.

Mr. B.'s experience is not atypical, said Meier, who noted data showing that 75 percent of older Americans visit the emergency department at least once in the last 6 months of their lives because they do not see an alternative (Smith et al., 2012). These patients, she said, are typically not end-stage cancer patients, and most do not have a serious disease. Rather, she said, they are "condition driven." Mr. B., for example, did not have heart failure, cancer, chronic obstructive pulmonary disease (COPD), or end-stage renal disease. He was simply frail, and impaired, both cognitively and functionally. "Being old plus caregiver exhaustion are driving his utilization," said Meier.

Health systems, she said, should be screening patients for palliative care using criteria that include functional limitation, frailty, dementia, exhausted and overwhelmed family caregivers, and social and behavioral health challenges, and she noted that data from the Medicare Current Beneficiary Survey support these criteria (see Figure 2-2). For example, 61 percent of the top 5 percent of spenders are functionally impaired, suggesting that functional status would be the single most important criteria for targeting high-risk patients, yet the most widely used electronic health records do not require documentation of functional status.

Dementia, she said, is another major predictor of risk for high levels of spending (see Table 2-1), largely, she added, because of caregiver exhaustion that results from a lack of social supports. She cited data (Bradley et al., 2011) showing that the United States has among the lowest ratios of social services to health services expenditures among countries in the Organisation for Economic Co-operation and Development (OECD) (see Figure 2-3). Belgium, Denmark, Germany, Italy, and Sweden, for example, spend about $2.70 on social supports for every dollar spent on medical care. In contrast, the United States spends 70 cents on social supports for every dollar spent on medical care. "Hence the dementia data," said Meier. "Hospitals are a substitute for absent social supports."

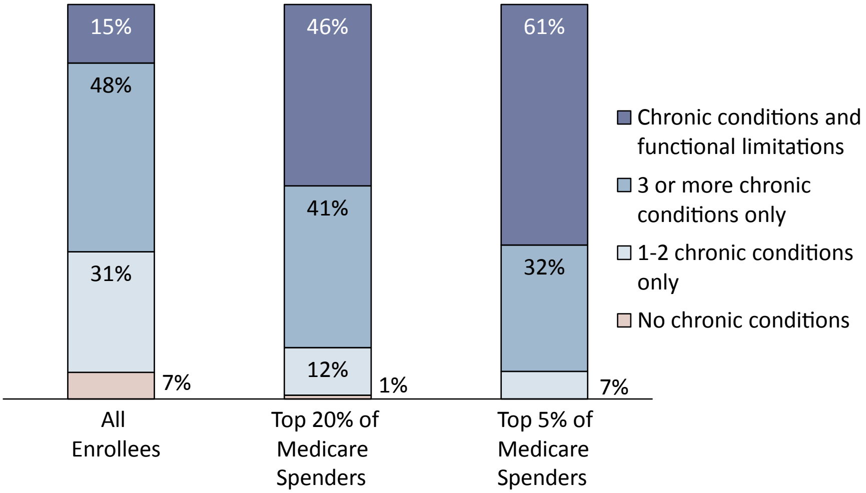

FIGURE 2-2 Distribution of enrollees by groups of enrollees.
SOURCE: Presented by Diane Meier on July 9, 2015.

TABLE 2-1 Use of Health Services by Medicare and Medicaid Patients with and Without Dementia

	Dementia	No Dementia
Medicare SNF use	44.7%	11.4%
Medicaid NH use	21%	1.4%
Hospital use	76.2%	51.2%
Home health use	55.7%	27.3%
Transitions	11.2%	3.8%

NOTE: NH = nonhospital; SNF = skilled nursing facility.
SOURCE: Presented by Diane Meier on July 9, 2015.

When this country does experiment with a more rational allocation of funding that helps patients stay at home, quality does improve and spending falls, she noted. Based on reports from the 25 states that allow Medicaid to pay for home- and community-based long-term services and supports, rather than incentivizing them to go into a nursing home, patients who take advantage of that waiver cost the system one-third as much as those who choose nursing home care (Thomas, 2014). Similarly, increasing funds for Meals on Wheels programs by 1 percent nationally would keep an estimated 1,722 older adults with low-care needs out of nursing homes

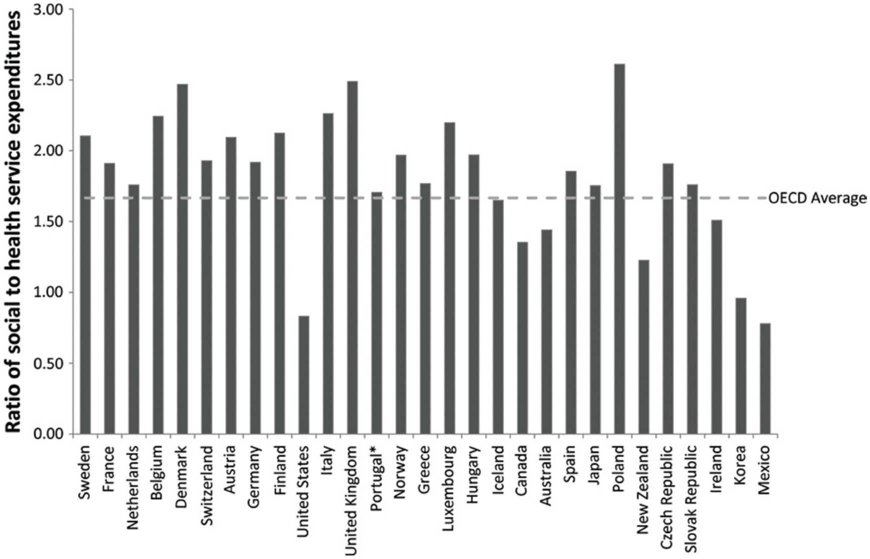

FIGURE 2-3 Ratio of social services to health services expenditures for OECD countries, 2005.
NOTE: OECD = Organisation for Economic Co-operation and Development.
* Expenditures for Portugal are from 2004, owing to missing data for 2005.
SOURCE: Bradley et al., 2011.

and save 26 states an estimated $109 million in reduced Medicaid spending, which would more than offset the cost of providing the meals (Thomas and Mor, 2013). Unfortunately, Meier added, funds for Meals on Wheels were cut in half during the federal budget sequester, and these funds have yet to be restored.

In explaining what palliative care is, Meier emphasized that the definition that Bernard Rosof gave in his introductory remarks does not mention prognosis, end-of-life care, death, or dying. Rather, it focuses on improving quality of life by addressing pain, symptoms, and the stress associated with serious illness. Mr. B., for example, was not dying and is doing well with the supports that were put in place. He would not, in fact, be eligible for hospice care, which is what many people associate with palliative care. “Is he benefiting from palliative care? Enormously,” said Meier. “If we stick to prognostic criteria, we are missing the boat.”

Palliative care is provided by an interdisciplinary team that works with patients, families, and other health care professionals to provide an added layer of support, Meier explained. It is appropriate at any age, for any diagnosis, and at any stage in a serious illness. It is important to make a conceptual shift, she added, that moves away from thinking about palliative care as something that occurs when there is nothing more that can be done for a person to thinking about it as care delivered at the same time as treatment (see Figure 2-4).

Data show clearly that palliative care improves quality and by doing so reduces spending and does so, said Meier, not by rationing health care dollars or withholding necessary care but by heading off preventable crises and meeting people's needs where they are, including nursing homes. As an example of palliative care in a nursing home setting, she recommended an article in *The New Yorker* (Mead, 2013) that described how an Arizona nursing home focuses care for dementia patients on what the residents say they need as opposed to doing so on strict schedules and regulatory requirements. To illustrate the power of palliative care in the home setting, she cited a randomized controlled trial from Kaiser Permanente in which patients with heart failure, COPD, or cancer were enrolled in either a home palliative care intervention or usual Medicare home care. Though the patients in the palliative care intervention received more home visits, they required fewer physician office visits, used the emergency department less, were hospitalized less, and spent fewer days in skilled nursing facilities (Brumley et al., 2007) (see Figure 2-5). Meier noted that Kaiser Permanente can measure and capture these cost savings because of the way its system is organized.

She then listed five key characteristics of effective palliative care:

1. It targets the highest risk people.
2. It asks them what matters most to them.
3. It supports family and other caregivers.

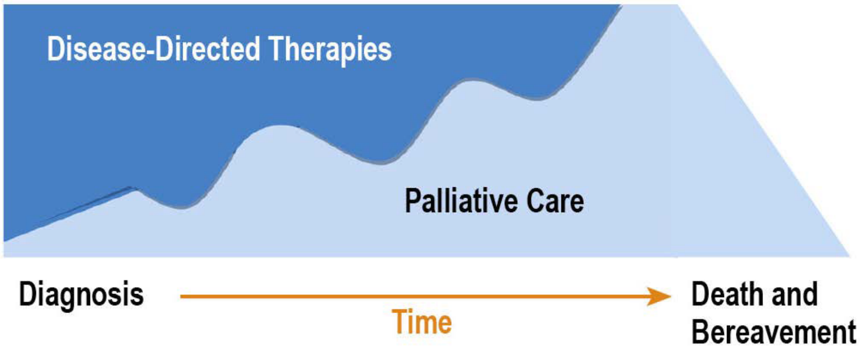

FIGURE 2-4 A conceptual shift for palliative care.
SOURCE: Presented by Diane Meier on July 9, 2015.

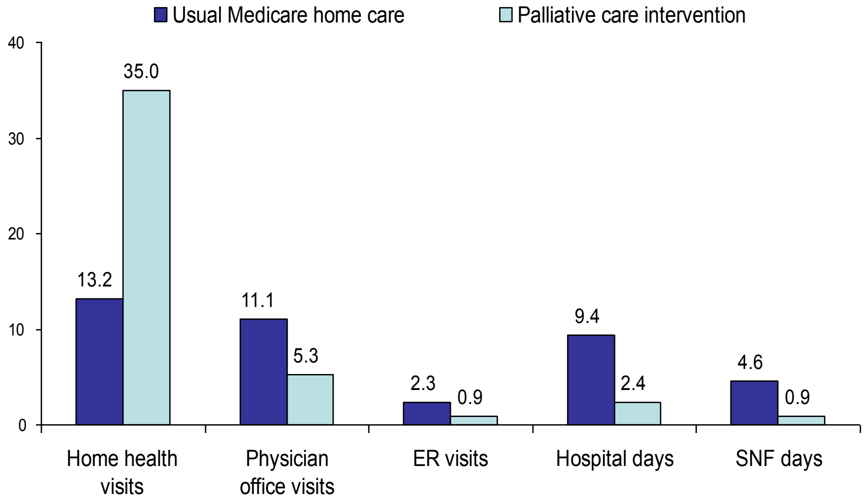

FIGURE 2-5 The value of palliative care at home for the chronically ill.
NOTE: ER = emergency room; SNF = skilled nursing facility.
SOURCE: Presented by Diane Meier on July 9, 2015.

4. It includes expert pain and symptom management.
5. It provides 24-hour access to services, 7 days per week.

The place where health literacy is most involved, explained Meier, is in goal setting, which requires asking the person and family what is most important to them, and she told the stories of four of her patients to illustrate this point. The first story was that of Mr. R., a 67-year-old Latino man that she met on the palliative care service after he had been on a ventilator in the hospital for 4 months. Meier asked Mr. R., who had no family visitors, if he wanted to be removed from the ventilator and allowed to die, and he did not. After fitting his tracheotomy tube with a speaker valve and bringing in a Spanish translator, Meier discovered Mr. R. had a son he wanted to see. After a great deal of research, the staff social worker located a son in Chicago and paid his way to New York to visit his father. The son revealed that his father had been terribly abusive to him and his siblings, and none of them had seen their father for decades. Nonetheless, the son came, the father asked for forgiveness, and the son forgave his father. The patient died on his own the next day. "Where is the illiteracy here?" asked Meier.

She then told the story of Mr. W., a 44-year-old man with acquired immunodeficiency syndrome (AIDS) encephalopathy who had been on a ventilator, dependent on total parenteral nutrition (TPN), and unresponsive for 2 months. Still, his mother and sister, one of whom was always at his bedside, refused to let him die, and staff was angry, considering this behavior abusive to the patient. Over a weekend, Meier sat down with the mother and sister and asked what they were hoping to accomplish. The response was logical: they wanted to fatten him up so that the open coffin, which was mandatory in their faith community, would not make it obvious that he had died of AIDS. After Meier explained that TPN would not reverse the muscle wasting that had occurred and that the funeral home could do much more to restore his looks, the family decided to remove support and Mr. W. passed away that Monday.

Mrs. P., a 60-year-old first-generation Greek immigrant who ran a hot dog stand in Central Park, had a witnessed cardiac arrest in Central Park, was resuscitated by a bystander, but had severe anoxic encephalopathy and never regained consciousness. Though she still had brain activity, she had spent 6 months on a ventilator receiving TPN and had developed the worst pressure ulcers anyone on staff had ever seen. Her three adult children visited regularly, frequently coming to blows in the intensive care unit (ICU) and requiring the intervention of hospital security personnel, but it was her daughter's behavior that led staff to call Meier to intervene. This daughter spent every day at her mother's bedside and brought her 6-year-old after school to sleep on a hard plastic chair next to her grandmother's bed every evening, which staff felt was abusive. Meier and a nurse she works with sat down with the daughter and asked her to tell them about her family. "Out poured this incredible story of child abuse by this mother and all of the sudden the behavior made perfect sense," said Meier. This family was used to suffering—that is what they did to each other. As soon as the daughter became conscious of this fact, she agreed to take her mother off of the ventilator. "Nobody had asked what the back story was," said Meier.

Her final tale was about Jenny, who's story Meier had told in an article for *Health Affairs* with the approval of the patient and her family (Meier, 2014). The article, Meier explained, was an oncologist's response to her question about what he hoped to accomplish with intrathecal chemotherapy for Jenny, a nonsmoker diagnosed at 59 with non-small-cell lung cancer that had metastasized to the brain. Meier had been on Jenny's care team for 2 years because Jenny, a psychologist, knew that her oncologist could not talk to her about what would happen as the disease progressed. Toward the end of her life, the oncologist offered intrathecal chemotherapy, and Jenny asked Meier what she thought about this treatment. Not knowing enough to respond then, she told Jenny that she or the oncologist would get back to her. Meier went to her colleague and asked him what he hoped to accomplish with this procedure, and after a long pause, he said it would not help her but that he did not want Jenny to think he was abandoning her. "The oncologist did not know any other way of showing his care and love for his patient other than to give her intrathecal chemotherapy because his training included nothing about accompanying patients when chemotherapy no longer helps," said Meier. She added, "I am very grateful to that oncologist because he taught me more than I ever had understood before about what motivates my colleagues when they do things that don't make sense to me. It is love. It is not venality. It is not greed. It is not indifference."

Though initially given a prognosis of 6 to 12 months to live, Jenny lived more than 6 years after her diagnosis thanks to the efforts of her oncologist, enjoying many trips to Europe with her husband and daughter. Over the last year of her life, she received both palliative care and treatment as her symptoms worsened, and when treatment was no longer effective she was referred to hospice at her home. When Meier went to visit her there, all Jenny wanted to talk about was how her oncologist never called or came to visit and how hurt she was by that. With her permission, Meier called the oncologist and told him that Jenny wanted him to visit, but he did not understand why because there was nothing he could do for her. "She wants to see you to thank you and say goodbye, that she is very grateful to you," Meier told her colleague. He did visit her and she died soon after.

Literacy and palliative care intersect at the question, "What is most important?" said Meier, and she cited the results of a survey of older people at a senior center and assisted living facility who were asked to rank the order of what was most important: living longer, achieving symptom relief, or remaining independent (Fried et al., 2011). Some 76 percent of these seniors responded that independence was the most important, followed by pain and symptom relief, with staying alive ranking last. "How is the health care system designed?" asked Meier. "Just the opposite."

Meier noted that some 40 million family caregivers like Mrs. B. provide 37 billion hours of unpaid care worth $470 billion per year while putting themselves at high risk of death, disease, and personal bankruptcy. She also quoted from a book by Atul Gawande (2014), who said, "I learned a lot of things in medical school, but mortality wasn't one of them," and from *The New Yorker* cartoon by Peter Vey (2003) in which a doctor is telling his patient, "There is no easy way I can tell you this, so I'm sending you to someone who can." While these anecdotal comments point out the challenge of addressing health literacy as a problem of the health system, not of patients and families, Meier said that there is hope thanks to the eight Institute of Medicine (IOM) reports calling for better access to palliative care. "The IOM report that I was privileged to participate in calls for palliative care as a standard of care essentially for people with serious complex illness," said Meier.

What has to happen to realize the IOM's recommendations, she said, is that the practices that are helping Mr. and Mrs. B. have to be expanded to the home and community setting for every patient with a serious illness. Every oncologist, cardiologist, primary care doctor, and nurse in a nursing home have to be trained in the core principles and practices of palliative care because there will never be enough palliative care specialists to come close to meeting the nation's needs. She applauded the American Cancer Society for running a series of ads that illustrate the importance of palliative care. These ads, she said, convey the central idea that palliative care sees the person beyond the cancer treatment and gives the patient control, and they make the point that palliative care represents a big shift in focus for health care delivery that works to improve the lives of patients. She closed her comments by noting that in the past, physicians considered themselves successful when they cured ovarian cancer or myeloma even though patients lived with terrible consequences of this treatment, such as severe neuropathic pain. In contrast, patients today are living longer and with a better quality of life thanks to the incorporation of palliative care principles.

3

Interpersonal Communication

The workshop's first panel session featured three presentations that explored the role of interpersonal communication in determining how patients experience palliative care. Beverly Alves, a patient advocate and retired teacher who was on the steering committee for Single Payer New York and the National Coalition Leadership Conference for Guaranteed Health Care, recounted her experiences with the health care system when her husband was diagnosed with pancreatic cancer. Thomas Smith, Director of Palliative Care for Johns Hopkins Medicine and the Hopkins' Sidney Kimmel Comprehensive Cancer Center, then spoke about the challenges physicians face in communicating prognosis to patients. Justin Sanders, Research Fellow with the Serious Illness Care Program at Ariadne Labs, Instructor in Medicine at Harvard Medical School, and an attending physician in the Psychosocial Oncology and Palliative Care department at the Dana-Farber Cancer Institute and the Brigham and Women's Hospital, concluded the presentations by describing how health literacy hits into a scalable intervention to improve serious illness care. An open discussion moderated by Diane Meier followed the three talks.

PERSPECTIVES OF A PATIENT'S WIFE[1]

On October 4, 2006, Beverly and Joe Alves received a phone call that changed their lives forever. To that point, Joe was physically healthy but had

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[1] This section is based on the presentation by Beverly Alves, patient advocate and retired teacher, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

developed a backache after moving a large part of a tree that had fallen in the road. When his back was still hurting 6 weeks later, Beverly finally convinced Joe to see his doctor, who agreed with Joe that he had pulled a muscle and to give his back some more time to heal. Some weeks later, a doctor friend of theirs encouraged Joe to see a gastroenterologist given that he was also experiencing some mild symptoms of gastroesophageal reflux disease (GERD). The gastroenterologist also suspected Joe had a pulled muscle, but to be sure, he ordered a computed tomography (CT) scan, which revealed a mass on Joe's pancreas and led to that fateful October phone call and what became a less-than-optimal experience with the health care system.

"From the moment we learned of the mass to the day Joe passed on, we were confronted and confounded by a medical system that was uncoordinated and unable to deal effectively with what became Joe's excruciating pain, our anxiety, stress, and impending loss," said Alves. "I don't believe any one of those things caused Joe's passing, but if there had been a comprehensive plan in place with specified criteria, which would have indicated if and when Joe needed services, it would have done a lot to help us deal more effectively with the overwhelming crisis of Joe's illness and his impending death."

The problems she and Joe encountered began almost immediately. To start, the gastroenterologist's office failed to schedule Joe's biopsy in a timely manner, and it took repeated calls from Beverly to schedule the pancreas and liver biopsies. By then, Joe was in substantial pain, and they were both anxious to learn what was wrong with him. While waiting for the biopsies, Beverly began searching for an oncologist. The first one, recommended by an acquaintance, had such a dehumanizing manner that they left his office feeling as if Joe was already dead. "He silently read the reports of Joe's magnetic resonance imaging (MRI) and CT, making faces of horror," she recounted. After giving her husband a cursory exam, he turned to her, looking into her eyes, and he said there was no hope. "No hope, while Joe was sitting just a few feet away, and no matter what I said or asked, this doctor had something negative to say in reply," said Alves. "Without hope, there is no life."

All of this time, Joe was in pain—what was in fact a tumor pressing on a nerve in his back—and his family physician was writing emergency prescriptions for pain medications that had to be refilled every 48 hours. Alves recalled watching her husband counting pills to see if he would have enough to last 48 hours knowing he needed a higher dose to control his pain. Making matters worse, Joe and Beverly lived in the country, and getting to the pharmacy in town in winter was often difficult. "It was a true nightmare," said Alves.

Joe finally had a biopsy, except the surgeon did not biopsy Joe's liver for some reason. When Beverly tried to query the surgeon, she was intercepted by a nurse. "No one seemed to understand or care," she said. The gastroenterologist called a few days later, informed Joe that the results of the biopsy were not good, and then hung up before providing a referral to an oncologist or a prescription for his intense pain. "We were left on our own to get Joe the care he needed."

By then, Beverly had been networking and through a friend got the name of a surgeon at Albany Medical Center, but when she called to make an appointment she was told that while the surgeon was available, the scheduler was out. After 3 days of repeated calls trying to schedule an appointment, Beverly began to sob, which finally moved someone to schedule an appointment with the surgeon 2 days later. However, with no liver biopsy, the surgeon said he could not determine what course of action to take, and referred Joe for a liver biopsy, which revealed that the cancer had spread to his liver. The surgeon arranged for Joe to meet with an oncologist.

As soon as Joe learned he had inoperable metastatic pancreatic cancer, he volunteered to do clinical trials. "He wanted to do this not only to help himself, but to help make things better for mankind, and the oncologist said he would fight this with us together," said Alves. "We left the hospital that day with our heads held high with hope in our hearts. The next week was Thanksgiving, and we had one of the nicest Thanksgivings we had ever had because we had some hope."

Unfortunately, during Thanksgiving weekend, Joe's cancer produced thrombotic clots, which caused him to have a stroke. There were no neurologists in the rural county where they lived, so the Alves waited in the emergency department while the attending physician fruitlessly searched for neurologists in other areas and Joe became paralyzed. Finally, around 5 a.m., Joe was rushed to Albany Medical Center. "The people who worked at Albany Med were caring and dedicated, but there was no system to coordinate care there," recalled Alves. "The analogy I use is it should have been a ballet, but instead there were many great ballroom dancers." Albany Medical Center, she added, did not have a palliative care program then and still does not nearly 9 years later.

She remembers Joe being a wonderful patient who did his best to help those who were helping him. He was stoic despite being in monumental pain. One night, she recalled, his pain was so intense that he repeatedly asked for more pain medication. "Joe's pain became so intense he started to weep. My heart broke and I wept along with him. When the nurse came into his room and saw us both weeping, she worriedly asked what is going on. Joe said we are sharing sorrow," recounted Alves. The nurse, nearly brought to tears herself, told them she had made repeated requests to the pharmacy through both voicemail and e-mail, but there was nobody to speak to directly in the pharmacy, even in the case of emergency. While Joe did eventually get additional pain medication, Alves witnessed a similar scene the next night in which a young woman, who she characterized as little more than a girl, was standing at the nurse's station, weeping and pleading for pain medication. "This is unacceptable," said Alves. "It is inhumane."

Along with intense pain, Joe was highly anxious, yet he was never referred to a pain management specialist or given adequate medication for his anxiety. Alves noted that shortly after her husband died, a psychiatrist told her that a living will should request medications to reduce pain and anxiety because the dying process can itself produce anxiety.

One week before Joe passed, he looked very ill, and Beverly asked the oncologist liaison if her husband needed hospice. The answer was no because nobody had said he had 6 months or less to live. The same night, a hospitalist, who she said was a very caring doctor, told her he did not think Joe would make it through the night. "I was aghast," said Alves. "Nothing major had happened during the day. It was just different interpretations of Joe's conditions made by different people because there was no coordination of care." The hospitalist, she said, had Joe moved to a single room and staff asked her for directions regarding end-of-life decisions because they could not find the living will Joe had brought with him to the hospital.

"Watching your loved one die is a terrifying and agonizing experience," she said. "It is one thing to be sitting safely in your attorney's office making out a living will and another to confront the impending loss of your beloved. I knew Joe had signed a do-not-resuscitate (DNR) order, but at that point, I was nearly stuporous." She asked to speak with the hospital's ethicist and while he gave her good advice, he did it over the phone. "When a patient is dying, family members are in crisis too and also need support, but I was alone," Alves recalled.

The ethicist told her to ask her husband what he wanted done if something happened during the night, but he was in great pain and exhausted and did not want to discuss anything. When she asked him specifically if he wanted to be on a ventilator, he did say no, and she gave that information to staff. Nobody bothered to enter it into his medical record, however, resulting in further confusion and anguish later that night when a resident came in to talk to them about ventilation and resuscitation. Joe never got back to sleep that night, and early that morning he told his wife that the odds were not in his favor and that he was facing death. Alves was beside herself, but then she remembered something that Rabbi Pesach Krauss had written in his book, *Why Me?* (Krauss and Goldfischer, 1988). Krauss, who was a chaplain at Memorial Sloan Kettering Cancer Center, wrote that when he spoke with patients who were very ill and fearful, he would ask them what they wanted to do with the time they had left. Beverly asked Joe that question, and he said he wanted to enjoy himself at home. Beverly told this to Joe's oncologist, but that doctor, the same one who told them less than 1 month before that we would be a partner with them, told her to put Joe in a nursing home. "I can still remember and probably always will my knees starting to buckle under me when he told me this," said Alves. "I felt like he was just tossing Joe away."

At that point, her plan was to place Joe in a new hospice facility in her county for a few days until she could connect with a home health care planner. The day before his planned move, a hospice nurse visited him, saw how badly he was suffering, and concluded that the staff at Albany Medical Center had no idea on how to ease Joe's pain. She asked staff to start him on the pain medication he would receive at hospice, and his pain finally subsided and he was able to relax.

Alves recalled that when she and Joe first started on this journey together he had said he would do everything he could do to get better. He asked her only one question. "He asked me what I would do if he could not go on anymore. I told him I would let him go, and when the time came, with much pain and deep sorrow, I did," she said. The next morning, December 18, while she was in the bathroom in Joe's room, he passed away quietly.

In recounting some of the many incidents that caused her husband to endure needless pain and anguish, Alves said she hoped she was conveying the message of how palliative care would have gone a long way to helping ease his suffering and her grief at seeing it. "Fortunately, before Joe passed, we were able to tell each other we knew we were the right partners for each other. Joe told me I was the queen of his heart. He was the king of mine," said Alves. "I feel blessed that we were able to hold on to each other and cherish the time we had left in spite of his terrible illness and the problems we encountered, but it could have gone the other way because of things that did and did not happen during Joe's illness." She added that the last few days of a person's life are important. "As badly as I still feel about Joe's passing, I would feel much worse if things had not been good between us when he passed."

After Joe died, Beverly asked friends if they would want to be told if they had a serious or life-threatening illness. "Our friend, George, said it best. He said he would want to be told. 'You are very sick, but we are going to do everything we can to help you,'" recalled Alves. She added that while many medical professionals are bright and filled with essential medical knowledge, they need to learn to speak to a patient and the patient's family and loved ones with compassion. "Patients are human beings with hopes, dreams, fears, and sorrows," said Alves. "They are not simply an accumulation of cells, organs, and systems. To treat only a disease or an injury is to be merely a body mechanic."

She then offered some advice to the health care professionals at the workshop. "When speaking with a patient, especially one who is critically ill, pause, take a breath, think, listen, or pray," said Alves. "Treat patients and their family members the way you would want to be treated, the way you would want your family members to be treated. Be a partner with your patient in their healing. Studies show that people heal better when they have a support system, so be part of that support system because even if you cannot cure your patient, it will make all the difference in the time they have left. Then you will truly be healers."

COMMUNICATING PROGNOSIS[2]

Thomas Smith began his presentation by offering Alves an apology for what she endured on behalf of all medical oncologists everywhere, and offered hope that the next generation of oncologists would do better. He acknowledged that he and his colleagues are not doing a good job about communicating prognosis, but he also offered the possibility that there are ways to do better, including listening to and learning from stories such as the one Alves had just told.

He then provided two definitions as context for his talk. *Literacy*, he said, is the ability to read and write, and *readability* can be measured using indices such as the Simplified Measure of Gobbledygook (SMOG) or the Rapid Estimate of Adult Literacy in Medicine (REALM) (Dumenci et al., 2013). Most hospice brochures, he said, would score at a sixth grade or higher level using these types of measures. Literacy, added Smith, is different from health literacy, which is the degree to which an individual has a capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions. According to 2003 statistics, some 98 million incidents of poor outcomes, additional hospitalizations, lower compliance, higher mortality, and reduced use of hospice resulted from health illiteracy. Factors contributing to health illiteracy include race, age, education level, poor vision, and comorbidities (Matsuyama et al., 2011). Given that medical care is more complex than in 2003, Smith said that this number is likely to be higher today, though he and his colleague Robin Matsuyama have been unable to find updated statistics.

The benefits of health literate palliative care are plentiful, said Smith. Ten randomized clinical trials of palliative care added to usual care, versus usual care alone, among patients with a variety of serious illnesses, for example, found no harm in any trial. There was a compelling increase in better satisfaction and communication with providers, less depression

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[2] This section is based on the presentation by Thomas Smith, Director of Palliative Care for Johns Hopkins Medicine and the Hopkins' Sidney Kimmel Comprehensive Cancer Center, and the statements are not endorsed or verified by the Academies.

and anxiety with more prognostic awareness, and an increase in hospice referrals (Parikh et al., 2013). In most cases, quality of life and symptom control were better and costs were lower by at least $300 per day. Four of the then trials showed that even with increased prognostic awareness, patients lived longer.

A 2010 study (Temel et al., 2010) in particular got everybody's attention, Smith noted. This trial randomized usual care versus usual care plus one palliative care visit per month for 151 newly diagnosed non-small-cell lung cancer patients. This study found that the patients assigned to early palliative care not only had a better quality of life than did patients who only received standard care, but they survived almost 3 months longer (Greer et al., 2012) with less aggressive care at the end of life (Roeland et al., 2013). Though prognostic awareness increased in patients receiving palliative care (see Figure 3-1), those patients experienced less depression and anxiety and had better mood (see Figure 3-2). Early palliative care also increased documented resuscitation preference, increased the number of patients who received hospice care 7 days or longer before death, and nearly tripled the number of days spent in hospice (Greer et al., 2012). "Show me another branch of medicine that improves quality of care,

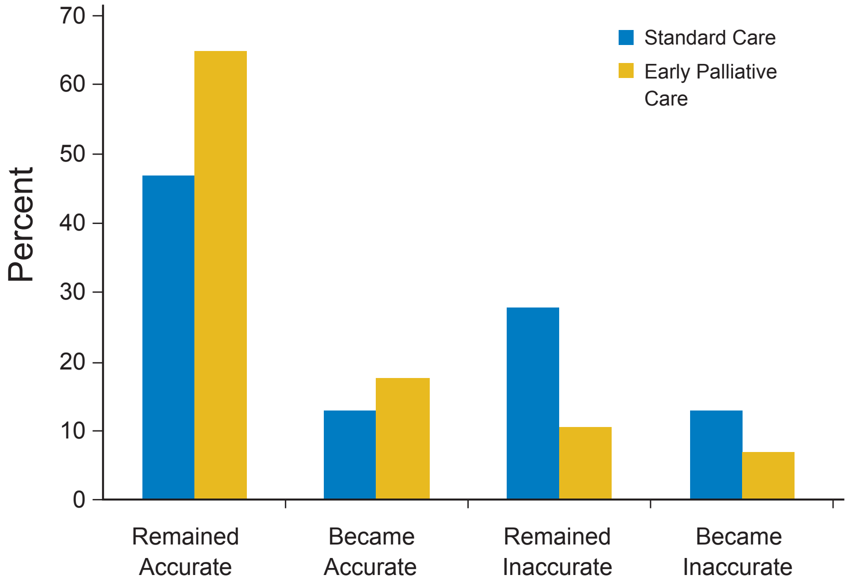


FIGURE 3-1 Improvement in prognostic awareness among patients receiving palliative care.
SOURCE: Temel et al., 2011.

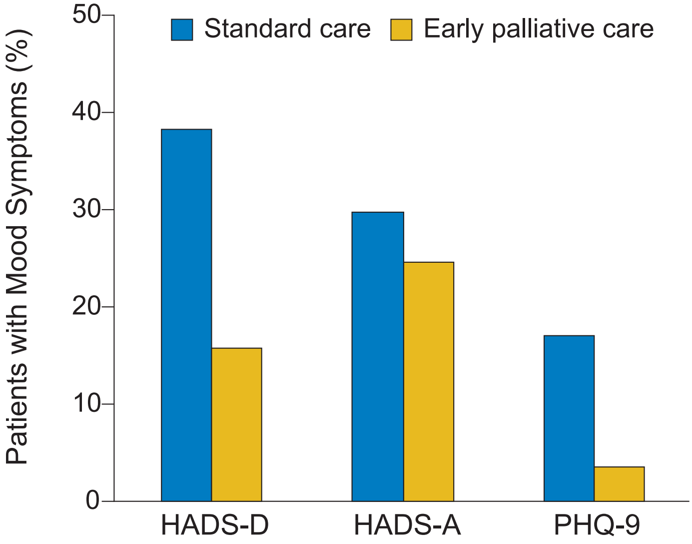


FIGURE 3-2 Palliative care allows cancer patients to experience less depression and anxiety.
NOTE: HADS-A = Hospital Anxiety and Depression Scale-Anxiety; HADS-D = Hospital Anxiety and Depression Scale-Depression; PHQ-9 = Patient Health Questionnaire.
SOURCE: Temel et al., 2010.

improves the quality of lived experience for people, and lowers cost," said Smith.

To explain the success of palliative care, he and colleague Betty Ferrell from the City of Hope developed the acronym TAME—time, assessment, management, and education. The time required, he explained, is about 1 hour per month. There have to be formal assessments for symptoms, spirituality, and psychosocial factors. There needs to be management protocols in place and educational tools to help patients and families learn about prognosis, coping skills, advanced directives, hospice, and legacy. Though not complicated, said Smith, these have to be scripted to get the best results.

Smith said he was not surprised that palliative care increased time of survival given a study he conducted showing that better pain management increased survival time in cancer patients by more than 3 months (Smith et al., 2002, 2005). More recent studies have found similar results with regard to increased survival times associated with palliative care for cancer patients (Bakitas et al., 2015), and a study involving patients with dyspnea who received integrated palliative care and respiratory care compared to the usual respiratory care found that palliative care reduced the chances of dying at 6 months by 30 percent (Higginson et al., 2014). “If this was a drug, we would be at the FDA [U.S. Food and Drug Administration] demanding its approval,” said Smith.

Despite results such as these, communication today between doctor and patient is not satisfactory, said Smith. One study found, for example, that only 17 percent of lung cancer patients could guess that their prognosis with stage IV disease was less than 2 years (Liu et al., 2014), while another study found that 69 percent of patients with stage IV lung cancer and 81 percent of stage IV colon cancer did not understand that chemotherapy was unlikely to cure their cancer (Weeks et al., 2012). Whether a patient responded accurately to questions about the likelihood of chemotherapy curing their cancer was not associated with race or ethnic group, education, functional state, or a patient’s role, but it was associated with being in an integrated care network and with lower scores for physician communication. “If your physician was blunter with you, you understood better,” said Smith. These observations, he added, contrast sharply with data showing that 80 percent of patients want to know the full truth about their diagnosis even though it may be uncomfortable or unpleasant (IOM, 2013). He noted, too, that oncologists such as himself almost always tell their patients that their disease is incurable, but then in collusion with their patients, they quickly transition the discussion to one of treatment options and schedules, leading to false optimism. The subject of prognosis never comes up again for most patients, he said.

The same data set showed that the chances of having inaccurate prognostic awareness increased in Latinos, African Americans, and Asian Americans. Smith said he did not know if this disparity resulted from who the patients were, who was or was not presenting the information, what the patients are hearing, how they are being told, or some combination of these factors. Another study, with similar results, found that patients overestimated the likelihood of cure after surgical resection of lung and colorectal cancer (Kim et al., 2015). Women and unmarried individuals were slightly less likely to have inaccurate prognostic awareness, but African Americans and Asian Americans were more likely to believe surgery would be curative.

Smith briefly discussed a study showing that video presentations about end-of-life decisions are more effective than just talking to patients at influencing the patient’s perceptions and decisions (Volandes et al., 2008). This finding was consistent regardless of race and literacy level, and regardless of educational level. He noted that African American physicians were far more likely than their Caucasian colleagues to want to be resuscitated, be on a ventilator, or have artificial feeding, while Caucasian physicians were more likely to want physician-assisted suicide (Mebane et al., 1999). However, when asked if tube feeing in terminally ill patients is heroic, 28 percent of African American physicians replied yes compared to 58 percent of Caucasian physicians.

Smith noted that the Internet is not a good source of information on prognosis either (Chik and Smith, 2015). He and a colleague checked the American Cancer Society's website, the National Cancer Institute's (NCI's) Cancer.gov, uptodate.com, and at least one disease-specific website looking for information about prognosis for stage IV cancer. Only 26 out of 50 websites had some notation of 5-year survival, and only four websites gave any information about what the average person could expect in terms of median survival. Only 13 websites noted that stage IV cancer was a serious and usually life-ending illness. On a positive note, nearly all had some information about hospice and palliative care, though none gave specific recommendations.

Most hospice and palliative care information, even from nationally prominent palliative care organizations, is written above the recommended sixth grade level and is not readable (Ache and Wallace, 2009; Brown et al., 1993), said Smith. About one-third of these materials require university-level literacy skills for full patient comprehension. "End-of-life patient education materials should be revised for average adult comprehension to help informed decision making and to aid in closing the gap in health literacy," said Smith. Studies have shown, in fact, that better communication about prognosis changes the process of care. For example, a question prompt list has been shown to increase the number of questions people have about end-of-life and prognostic issues (Clayton et al., 2007), and Smith noted that he and his colleagues are creating a question prompt app. Video decision aids also help patients make better choices about end-of-life care (El-Jawahri et al., 2010; Volandes et al., 2013), and electronic prompts given to physicians have been shown to increase the number of people who express their preferences for life-prolonging interventions and resuscitations (Temel et al., 2013). Teaching patients about standards of care will even change the median time to a DNR order from 12 days to 27 and reduce the hospital death rate from 50 percent to 19 percent (Stein et al., 2013), Smith noted.

He and his colleagues have created decision aids to help patients make better end-of-life decisions. One such aid was developed for the American Society of Clinical Oncology for use with patients with stage IV lung cancer (Smith et al., 2011). It presents answers in response to common questions such as, "What is my chance of being alive at 1 year?" and "What is the chance of my cancer shrinking by half?" (see Figure 3-3). The decision aid also answers questions such as, "Are there other issues that I should address at this time?" that provides information on resuscitation, family and spiritual issues, financial matters, and hospice. "The interesting thing about this aid is that it does not take away hope," said Smith, who noted that measurements taken before and after patients used the aid showed that if

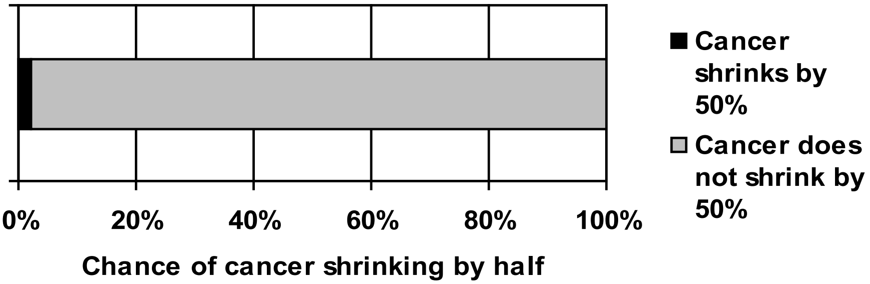


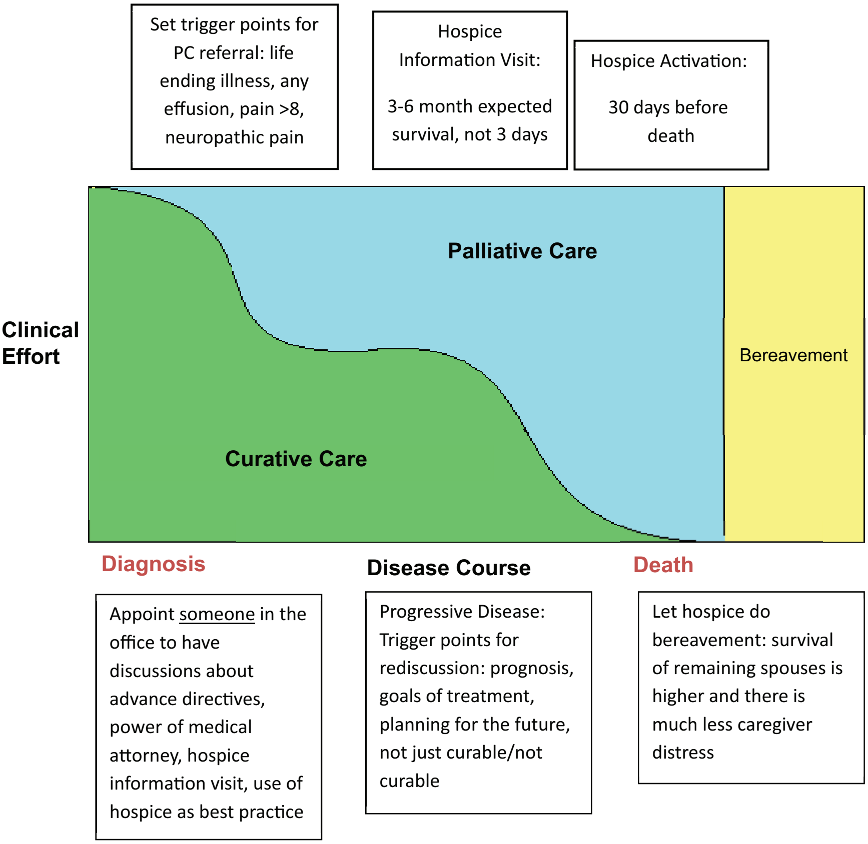
FIGURE 3-3 Decision aid to answer the question, "What is my chance of this cancer shrinking by half?" for patients receiving third-line therapy for stage IV lung cancer.
SOURCE: Presented by Thomas J. Smith on July 9, 2015.

anything, the level of hope increased slightly (Smith et al., 2010). He added that the California Healthcare Foundation plans to release truthful decision aids for the 10 leading causes of cancer deaths in late 2015.

The ultimate goal, said Smith, is to change office practice so patients who could benefit from palliative care are identified at the time of diagnosis rather than at the end of life (see Figure 3-4). "We want physicians to bring up palliative care when the cancer starts to grow, when heart failure starts to get a little worse, when diabetes starts to cause more vascular complications."

Smith is now working with all of the providers at Johns Hopkins Medicine to provide a research-based palliative care communication tattoo that would go on the forearm of every patient with a serious illness (Morris et al., 2012). The tattoo will list the following questions that patients should be asking themselves and their physicians (see Figure 3-5).

Smith concluded his talk by reiterating that 80 percent of patients want to know and understand their prognosis and that acting on that information makes a big difference in the care they receive and the quality of life they lead. He noted that some patients, for example, turn down second-line lung cancer chemotherapy because they do not think it works when in fact it does improve survival and it does improve quality of life. "Those are good things to know, and if you can understand it, maybe you can choose better," said Smith, who said he is not about denying people care. What he does want is for more patients to get helpful chemotherapy and fewer patients to get unhelpful chemotherapy, for there to be greater use of hospice, less patient and family distress, longer survival, and for patients to die at the place of their choosing. Smith added there needs to be rewards for doing this tough work, better decision aids for patients, and prompts



Set trigger points for PC referral: life ending illness, any effusion, pain >8, neuropathic pain

Hospice Information Visit:

3-6 month expected survival, not 3 days

Hospice Activation:

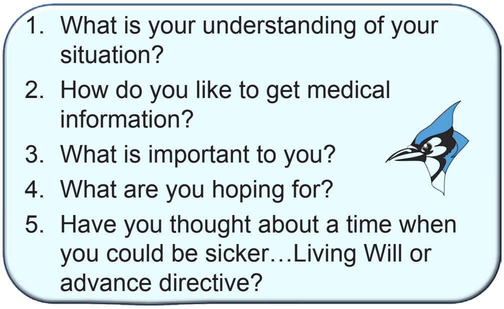
30 days before death

Appoint someone in the office to have discussions about advance directives, power of medical attorney, hospice information visit, use of hospice as best practice

Progressive Disease: Trigger points for rediscussion: prognosis, goals of treatment, planning for the future, not just curable/not curable

Let hospice do bereavement: survival of remaining spouses is higher and there is much less caregiver distress

FIGURE 3-4 Modifying practice patterns to improve patient outcomes.
NOTE: PC = palliative care.
SOURCE: Wittenberg-Lyles et al., 2015.



1. What is your understanding of your situation?
2. How do you like to get medical information?
3. What is important to you?
4. What are you hoping for?
5. Have you thought about a time when you could be sicker…Living Will or advance directive?

FIGURE 3-5 Temporary tattoo listing important questions for patients and providers.
SOURCE: Presented by Thomas J. Smith on July 9, 2015.

that remind physicians to have these discussions, such as the smartphone app that he and colleagues are developing with funds from the National Coalition for Cancer Survivorship. Physicians, he said, need better communication skills, though in the end, it may be important to have a member of the palliative care service handle this important task. "I don't think many oncologists are wired this way," said Smith.

SERIOUS ILLNESS COMMUNICATION PROGRAM[3]

The topic of palliative care and health literacy is compelling to Justin Sanders not only because of the work he does in this area but because the field continues to grapple with trying to improve comprehension of what palliative care means and who it benefits. He also said that he agrees with the sentiment that this is a health literacy issue that is as acute for physicians and other members of the health care team as it is for patients.

Just as Smith did at the beginning of his presentation, Sanders started with some definitions to set the boundaries for the concepts he would be addressing. He characterized his definition as expansive and is based on the Institute of Medicine (IOM) report *Health Literacy: A Prescription to End Confusion* (IOM, 2004), which defined health literacy as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. That report went on to describe health literacy as an emergent phenomena that occurs when expectations, preferences, and skills of individuals seeking health information meet the expectations, preferences, and skills of those providing information and services. In other words, said Sanders, health literacy is not something individuals possess, but it is something that emerges from the interaction between clinician and patient. Health literacy is also sensitive to the demand it places on a person to decode, interpret, and assimilate health messages, and as a result it is dynamic and situation dependent.

In terms of palliative care, Sanders said he would be referring to a set of services concerned with patients in all phases of serious illness, which is to say an illness that places a person at high risk of incapacity or dying within a certain time frame. He agreed with the previous speakers who said it is a health literacy problem that has physicians continuing to believe that palliative care only has a role at the end of life.

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[3] This section is based on the presentation by Justin Sanders, Research Fellow with the Serious Illness Care Program at Ariadne Labs, Instructor in Medicine at Harvard Medical School, and an attending physician in the Psychosocial Oncology and Palliative Care Department at the Dana-Farber Cancer Institute and the Brigham and Women's Hospital. The statements are not endorsed or verified by the Academies.

The Serious Illness Care Program at Ariadne Labs, he then explained, developed a systematic and systems-level approach to address two fundamental gaps in the care of seriously ill patients and their families. The first is the gap between what patients want for care and what they receive in the setting of serious illness. “Most Americans, including those of all colors and creeds, wish to spend their final days at home and want less aggressive and more symptom-focused care, especially when they are aware of a terminal diagnosis,” said Sanders. “They do not want their dying prolonged, they do want a sense of control, and they do not want to burden their family and friends.” What most patients get looks somewhat different, he said. Most Americans die in institutions, and aggressive care with little or no benefit is common. Hospice use is increasing, but the length of stay in hospice has been falling (NHPCO, 2014), and transitions in the last 3 days of life are on the rise (Teno et al., 2013). Among the consequences of this gap, said Sanders, are inadequate symptom control and poor quality of life for patients and their caregivers.

The program also addresses the gap between what is known about how to provide high-quality end-of-life care and what the health care enterprise delivers. More specifically, said Sanders, it is well documented that discussions to clarify goals, values, and priorities for care—advance care planning discussions—improve clinical outcomes as measured by more goal-concordant care, less aggressive care, more and earlier hospice care, and higher patient satisfaction and family well-being (Brinkman-Stoppelenburg et al., 2014) without making patients more anxious, depressed, or lose hope. “Early conversations about goals and priorities enhance a patient’s sense of control, providing space for planning and closure and focusing patients and families on what matters most,” said Sanders.

At the same time, he added, there is a connection between physician burnout, poor self-efficacy, and caring for patients with serious illness (Meier et al., 2001), yet clinicians feel closer to patients and better about the care they provide when they speak earlier and often with the seriously ill patients about their goals and priorities. What happens in most health care settings, however, is that these conversations occur too infrequently or too late in the course of disease progression, particularly in communities that suffer disproportionately from low health literacy. In addition, added Sanders, clinicians are not that good at having these conversations.

The Serious Illness Program addresses these gaps with a process involving the following steps:

- Identify seriously ill patients.
- Train clinicians in the use of a structured conversation guide.
- Prepare patients to participate in these conversations.
- Prompt the clinician to have the discussion.

- Have the discussion.
- Document the discussion in a single, easily locatable place in the electronic medical record (EMR).
- Provide materials to the patient to carry on the conversation with their family members.

The heart of the process, Sanders explained, is the Serious Illness Conversation Guide, which prompts the clinician to ask the patient two questions: (1) What is your understanding of where you are now with your illness? and (2) How much information about what is likely ahead for you would you like from me? At that point, the guide encourages the clinician to share the prognosis and then pose five additional questions:

- If your health situation worsens, what are your most important goals?
- What are your biggest fears and worries about the future with your health?
- What abilities are so critical to your life that you cannot imagine living without them?
- If you become sicker, how much would you be willing to go through for the possibility of gaining more time?
- How much does your family know about your priorities and wishes?

Sanders then discussed the Physician Orders for Life Sustaining Treatment (POLST) paradigm that he believes is less likely to open this space in a sustainable manner. POLST and similar paradigms are physician orders for life-sustaining treatment, and all but five states have some version of the POLST form in place. Sanders considers it problematic for several reasons, the first of which is that the POLST paradigm was created without clear thinking about how to train clinicians to have these discussions. “It seems as if the goal is to force the discussion using a tool to clarify procedural options for care, which puts the cart before the horse,” said Sanders. The horse, in this case, would be the goals and priorities that inform people’s ideas about what kind of care they want.

Continuing with this analogy, Sanders said the cart had its own problems, namely that advance directives are a contested strategy for delivering goal-concordant care in that they do not always guarantee that patient wishes are followed (Hickman et al., 2015; Mirarchi et al., 2015). In some cases, a family member may reverse a patient’s wishes, while patients themselves can change their minds in response to serious illness in ways that a POLST form may not reflect, explained Sanders. In addition, the interventions listed on the POLST form are often poorly understood by patients or family members who may not know the effect of the listed treatments, their risks, and their benefits. "Even if they did know of these treatments, how do we know that the way we are explaining them facilitates the kind of comprehension that leaves people feeling confident in their decisions," said Sanders. "That is a health literacy issue."

Thinking about health literacy as an emergent phenomena, one that emerges in a way that affects behaviors of both patient and physician, requires being acutely sensitive to the power dynamics that exist between two parties with different cultural, social, and educational backgrounds and how that dynamic affects the space in which discussions about palliative take place (see Figure 3-6). The biggest power dynamic, said Sanders, is the one between a patient with serious illness and the clinician, insurer, or health system with the capacity to cure or hold at bay the patient's disease. "We have to think about what it means when this treating clinician either allows the possibility for treatment goals to change or refers to a clinician with that

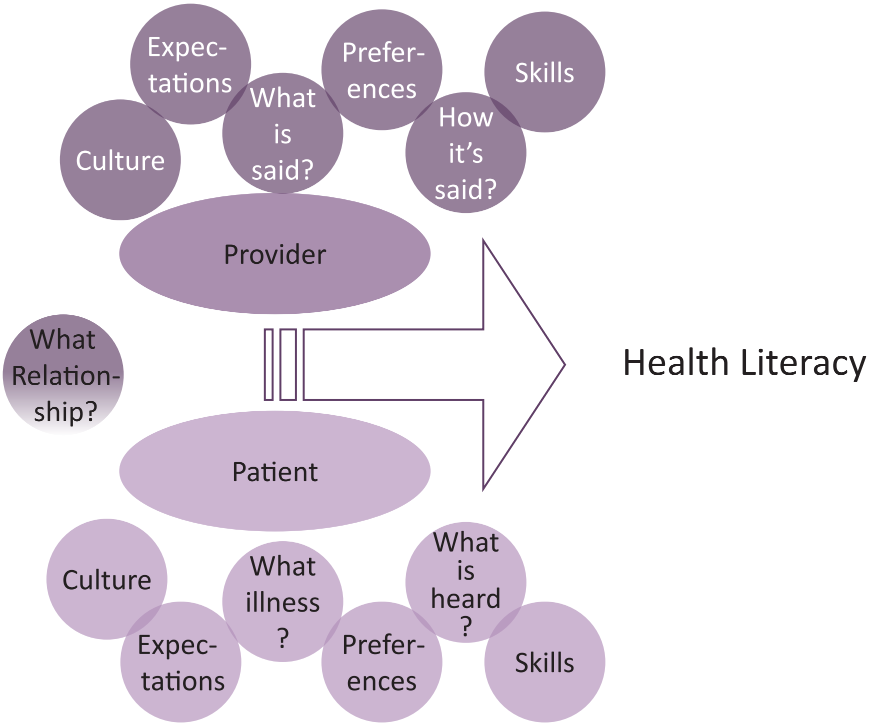

FIGURE 3-6 Many factors play a role in the power differentials that affect health literacy.
SOURCE: Presented by Justin Sanders on July 9, 2015.

power," said Sanders. Factors that widen that gap and that are relevant to health literacy include education, socioeconomic position, and race.

Assuming that power differentials are evident in the process of advance care planning, one strategy for creating safe space is to give control to the patient. The approach that Sanders and his colleagues use is to prepare patients to have this discussion by asking their permission to have it and then assessing and honoring their information preferences. They do this by asking questions in ways that allow the patient's humanity, not the illness, to come through in a manner that actively shapes the care. "A conversation focused on the POLST form does none of that intentionally and risks exacerbating the inherent tension in the relationship by focusing on life-sustaining procedures and not to the issues of survival, suffering, quality of life, and meaning that are most important to patients and families," said Sanders. "In the POLST paradigm, we are forcing the patient and family onto our turf, into the medical model, and failing to honor the patient's experience and perspective."

The problem of obtaining goal-concordant care is particularly acute for African Americans, said Sanders, in part because of structural and interpersonal factors but also from the fact that African Americans compared to Caucasians engage in advance care planning less often (Daaleman et al., 2008). The latter stems from multiple factors that include mistrust in both clinicians and the health care system, decision making informed by religious principles, family decision-making styles, and health literacy (Nath et al., 2008). Sanders said that it is hard to know the full impact of health literacy on advance care planning (Melhado and Bushy, 2011), in part because health literacy as measured in studies that have examined its role in advance care planning is somewhat unidimensional, typically by using measures such as grade reading level. "But if we think of health literacy as emerging from both the patients' experiences and their interaction with clinicians, then health literacy might be the central issue relating to achieving goal-concordant care," said Sanders.

The key challenge he and his colleagues face is to think about how an intervention developed in a place that serves a predominantly white, middle- and upper-middle-class-population can affect other important U.S. populations, especially African Americans. "How do we move it out of a temple of science and into a temple of worship," said Sanders. Their approach, he explained, has been to conduct a series of focus groups aimed at identifying high-risk barriers to participation in conversations such as these, gaining feedback about the language and content of the Ariadne Labs Serious Illness Conversation Guide, and then modifying the guide so it can be implemented in a culturally sensitive manner. He emphasized that they are not creating a guide specifically for African Americans, but rather they are thinking about how to give guidance to clinicians about language and issues that will enable them to better create the safe place for discussing end-of-life issues. "If these modifications are useful to African Americans, they may be useful to others as well," said Sanders, who added that the process of identifying these modifications is one they can repeat with other populations.

He and colleagues have learned a number of important lessons through this process. For the most part, he said, the space in which goals of care are discussed with African Americans with serious illness is in the hospital during a crisis. These interactions are emotionally traumatic for families and add to a collective historical trauma felt acutely by members of the African American community, heightening senses of stigma and mistrust. In addition, the relationship between the patient and family and members of the clinical team, and in particular the physician, is paramount to the sense of safety for patients and families in approaching the end of life. As far as the guide itself, the questions have been easily understood and acceptable to the African American participants in the focus group. Moreover, the questions enhanced the participants' sense of feeling cared for, while the addition of the question "What gives you strength and comfort as you think about the future with your illness?" effectively elicits and allows for religious faith to enter the conversation in a way that enhances this sense of caring.

In conclusion, Sanders said that it is more useful to think of health literacy as an emergent phenomenon rather than as something that is or is not possessed by an individual. He added that for health literacy to emerge in a way that supports advance care planning and palliative care, the focus needs to move away from advance directives to scalable, translatable communication practices that help patients and clinicians enter a space together without fear of ineptitude on the part of clinicians or abandonment on the part of patients.

DISCUSSION

Diane Meier started the discussion by asking Alves for her reaction to the two presentations. In Alves's opinion, there needs to be a campaign to educate both the public and medical community about the availability and importance of palliative care, noting that she had essentially been providing palliative care for her husband even though she was a special education teacher. Shortly after Joe passed, she wrote a letter to Albany Medical Center describing what she had been doing for her husband. A friend of hers, who was the head of rehabilitation services at a local facility, read the letter and told Alves that she had been providing palliative care. Alves replied to her friend, "What is that?" She added that she thinks the medical community is moving in the right direction.

Meier then noted how both Smith and Sanders had emphasized the importance of communication about what to expect and the need to give power to patients and family members to guide the actions of the health care team. She repeated Sanders comments about the failure of the turnkey approach to advance care planning and asked Smith and Sanders to speak about the lack of fit between patient and family needs and standard approaches to end-of-life care. Smith said he takes a practical, hands-on approach that starts with knowing what he needs to do if a person's body starts dying well before that happens. He said that while he appreciates the cart-before-the-horse analogy, he also knows how difficult these questions are for a health care provider such as himself to ask a patient. For example, when he asks patients if they want dialysis, he first has to spend time talking about what dialysis is and what it entails. The same is true for ventilation.

What is important to consider, too, is that the culture of the institution factors into how these questions are asked. He noted that one of his postdoctoral fellows studied how DNR decisions were made at three institutions in the United States and one in the United Kingdom (Dzeng et al., 2015). At the UK hospital, the physician makes the decision and informs the patient, which Smith called the paternalistic model of care. At the University of Washington in Seattle, that decision is a shared one made in partnership with the patient. There, the physicians ask patients about their desires, the quality-of-life issues they find important, and their understanding of their situation. The physicians explain what it means to be on a ventilator and the odds that resuscitation will enable patients to survive. In his experience, the chances of resuscitation being successful is close to zero, and he believes patients have a right to know that to help them make better decisions.

Smith also noted a recent paper showing that the number of people making durable power of attorney assignments increased from 52 percent in 2000 to 74 percent in 2012, but that there was no change in the use of living wills (Narang et al., 2015) despite the fact that the only thing that makes a difference in end-of-life care is having a written living will or written advance directive. "Just having an appointed person makes absolutely no difference," said Smith, who added that he is tired of hearing his colleagues say that all they need to know is who the decision maker is. That is just a start, said Smith, but it means nothing unless the patient and decision maker have actually discussed what the patient wants. On a practical note, he agreed that the POLST form is often little more than an exercise in checking boxes, but that it does force there to be some discussion about end-of-life decisions. "I don't think that is a bad idea," said Smith.

Sanders agreed with Smith about the importance of the patient and appointed decision maker having a real discussion about the patient's wishes given the work that he and his colleagues have done showing that end-of-life care is determined more by family members than written advance directives. He then noted that he and his colleagues have seen in their studies that a good discussion between clinicians and patients can be psychologically beneficial and enable patients to go home and have fruitful discussions with their families. "We often hear . . . in talking with the patients about how they walk away from the conversation with their physician and have a better sense about how to talk to their families about end-of-life issues," said Sanders. He has also found through his experience in training hundreds of clinicians that when they do not ask about procedures, the procedures stop being the focus of conversation, leaving room for the clinicians to better understand their patient's most important values. That, in turn, allows the clinicians to use their training and make recommendations to patients that fit the patients' needs and that leave patients feeling cared for in that setting. He added that when health literacy issues are acute and patients are forced to make concrete care decisions to check boxes on a form, they feel lost.

Linda Harris from the Office of Disease Prevention and Health Promotion at the U.S. Department of Health and Human Services commented that Sanders's framing of health literacy as an emergent phenomenon has the potential to be powerful, but it also has the potential of challenging health care providers to take some responsibility for improving the health literacy of their patients. Given that possibility, she asked Sanders if he had any evidence that health literacy is an emergent rather than a personal characteristic. Sanders responded that this notion came from the IOM report and that his experience supports that idea. "People with poor health literacy know everything they need to know about their goals and values," he said, adding that what they do not know is how to translate that self-knowledge into understanding the details of clinical care given that clinicians can have a difficult time talking about these issues in ways that make sense to their patients. He recounted how a patient he had spoken to the day before the workshop said that the questions in the guide were good because they forced the doctor to speak like a human rather than a doctor and to truly understand what the doctor was saying. "That is why I think that health literacy is an emergent phenomenon, one that emerges from our interactions with patients as humans," said Sanders. Harris agreed that was a reasonable view and asked Sanders how the conversation guide takes that idea into account. Sanders said that a major component of the conversation guide is a set of nonthreatening questions designed to create the safe space need to have a thoughtful and thorough discussion. Clinicians, for example, are encouraged to tell their patients that no decision has to be made on the basis of a single conversation.

Wilma Alvarado-Little, founder of Alvarado-Little Consulting, noted how Smith had mentioned that some ethnic groups had less prognostic awareness than others and that Sanders had touched on some issues regarding African American communities. She then asked the panelists if there were any considerations being made for groups of patients and family members whose primary language is not English and for the deaf and hard-of-hearing communities. Before answering the question, Smith recounted a recent call his team received from a patient with liver failure who knew she was very sick and wanted to know how much time she had. The nurse practitioner did a wonderful job talking to the patient about her prognosis and that there was no way to say with certainty how much time she had to live, but after Smith returned to his office he received a frantic call from a staff member who said the family claims the patient does not want to know her prognosis and not to tell her. "What we have learned to do with every culture is to ask patients about their understanding of their situation, and how do they like to get medical information," said Smith.

He then said that his team has projects in Belize, Saudi Arabia, and Tajikistan, three places with three very different cultures. In Tajikistan, for example, he has seen a surgeon who has just operated on someone with inoperable gastric cancer tell the patient he has an ulcer, to take certain drugs, that he would be okay and then go tell the family that he has weeks to live. Again, he had learned to ask patients about their understanding of their situation and how they want to get their medical information. "Giving people those couple of simple tools is important. Having a script to start these conversations is really key," said Smith. He also noted that in Baltimore, where he has now worked for 3.5 years, he has been accused of experimenting on people's loved ones more in that time than in 28 years of practicing in Richmond. "You just have to ask, 'How do you like to get medical information? What is your understanding of your situation?'" he said. "Never make assumptions about what people want to know."

Margaret Loveland, a pulmonologist from Merck & Co., Inc., who has treated patients with end-stage chronic obstructive pulmonary disease and diagnosed many lung cancers, commented on the lack of continuity of care that was apparent in the way Joe Alves was treated. She noted that when she diagnosed a patient with lung cancer and referred him or her for radiotherapy of chemotherapy, she always took the time to follow up with and ask the questions Smith gave. She felt that patients will only answer those questions and talk to someone about these issues if they know the person. "With all of these other people coming and going, can you really have a deep conversation with somebody you don't know?" asked Loveland. Alves said that in her husband's case, the system did not work at all. "Each doctor that we went to just dropped the ball. There was no coordination of care at Albany Med," she said. She did commend a physician from the University of Indiana who did try to find an oncologist in upstate New York and who took the time to review her husband's test results.

Smith then commented that it does not have to be the oncologist or the cardiologist who has these conversations, but it needs to be somebody the patient trusts. "If your primary care physician stays involved, you are twice as likely to get the care you want," said Smith, citing a study done in Canada (Sisler et al., 2004). He would like to see primary care physicians kept in the loop and receive functional status updates as a mandatory part of care, noting that he can teach anybody in 5 minutes how to write a one-page summary to all care team members in the EMR.

He then told of a study (Dow et al., 2010) in which 75 consecutive patients coming into an inpatient oncology service with an average survival of 3 months were interviewed, and found that only 40 percent of these individuals had advance directives; the percentage was slightly lower in African Americans and slightly higher in Caucasian. However, the oncologists were only aware that 5 of the 75 patients had advance directives and only twice did the oncologists even mention advance directives. The study team asked the question, "When you are being admitted to the hospital, do you think it is important to have a discussion about advanced directives?" and 90 percent of these patients said yes. They then asked, "Are you comfortable discussing this with the team that is admitting you to the hospital that you have never met before?" and again 90 percent said yes. But when they asked the question of "Would you like to discuss this with your oncologist?" only 23 percent said yes. It turns out, he said, that for some patients and families it is easier to discuss what is going to happen to them with the referring physician than it is with the oncologist.

The lesson here, said Smith, is that somebody has to ask the two questions. It does not have to be the oncologist, but somebody needs to do it. As an example, he cited Texas Oncology, where more 80 percent of the patients have advance care planning discussions and close to 90 percent of lung cancer patients go into hospice for up to 2 months. To achieve those laudable results, Texas Oncology has made it a best practice for someone on the health care team to discuss advance care practice on a patient's first three visits, with financial penalties for not meeting that standard. Today, US Oncology, of which Texas Oncology is an affiliate, is doing this on a regular basis in all of its practices, and Smith said US Oncology could provide the tools immediately to make this practice universal. Sanders added that these tools are available universally. He also noted that he expects that a large randomized controlled trial at Dana-Farber Cancer Institute involving all of its oncologists is going to show that these oncologists feel better about their job as doctors when they are able to have these conversations with their patients.

Sanders then said his team has interviewed African Americans in the southern United States about who they think would be the best person with which to have these conversations, and the results were mixed. The clinicians they interviewed felt strongly that the patient's primary care doctor would be best, while the patients thought it would be the specialist. He added that at Dana-Farber the care team is in many ways the primary medical home for their patients. "I think whoever has the ability to have this conversation well and feels most comfortable doing it should be the one to do it," said Sanders. Meier disagreed with this idea and cited the case of Jenny C.'s doctor who was offering her futile treatment because he cared so much about her. "It would not have helped to have someone else have this discussion," said Meier. "They will keep doing what they were trained to do because it is emotional, and it is about the relationship. It is not an easy out to just assign that job to someone else."

Ruth Parker from Emory University School of Medicine commented that she was placing her hopes for improvement on Sanders and his generation of physicians who can now use all of the health literacy tools that her generation of researchers has developed. She then asked specifically about the role that cost transparency and people's ability to understand the cost of care factor into decision making with regard to end-of-life care, noting that the leading cause of personal bankruptcy is medical debt. Smith replied that there are no studies looking at how people of varying levels of literacy and health literacy understand their actual cost of treatment, and there has only been one study, which he and his team published recently (Kelly et al., 2015), in which patients were given information about how much their treatment would cost. This study found that 93 percent of patients want to know up front what the cost of care would be—the other 7 percent were too ill to answer the question—and that having this 2-minute conversation with their oncologist did not destroy the physician–patient relationship.

Smith's personal experience with patients of varying literacy, health literacy, and cultural backgrounds shows it is possible to make this information understandable. The challenge, he said, has been getting this information from his institution. "You are going to have to search at your own institution and find out what the costs are, and then you are going to have to put it in an easy-to-understand, graphical form," said Smith. He noted that the 2013 IOM report *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis* called for every health care system to be transparent about costs, but that his institution refuses to do so. When a workshop participant stated that institutions do not know what the cost of care is, Smith disagreed, and said that since November 2013 US Oncology has told every patient what the plan of treatment will cost and makes financial counselors available to help patients determine if they can afford that treatment. "That is proof positive to me that we can do this no matter who you are," said Smith.

In Sanders's opinion, talking about the cost of care is complex and raises health numeracy issues. He also wondered if physicians, who as a group of people have huge student loan debt, are best equipped to talk about the cost of care in relation to benefit, and if it is even that important to talk about the cost of care with patients. “I think the changes of care that reduce cost when we elicit goals and values are patient driven, not system driven,” said Sanders. “I think that is the most important kind of cost savings.” Smith disagreed, saying that with some third-line cancer therapies costing $150,000 per month, and the average response time being 3–4 months, patients are going to want to know what their copays will be and what the benefit of that therapy will be. “That is very different than talking about a curative therapy for Hodgkin’s disease,” said Smith. “We are going to have to have these cost discussions right up front with people, no ifs, ands, or buts about it.”

In wrapping up this session, Bernard Rosof said that what he heard from speakers so far was that every member of the health care team should be trained to ask patients about what is most important to them, not only in palliative care situations but in every setting. He also heard that physicians do not want patients to think they are abandoning them and that trust and competency are core issues. Care needs to be coordinated and both patient- and family-centered. “I think these are transcending, crosscutting issues that are important not just in palliative care but in the delivery of care to patients in general,” said Rosof. While it is possible to couch these issues in terms of systems and cultures, the bottom line is that they have to do with organizational professionalism and the way health care systems treat every patient as well as with every aspect of the physician–patient relationship.

4

Professional Training

The workshop's second panel featured two presentations on the need to train health care professionals to have health literate discussions about palliative care. Robert Arnold, Chief of the Section of Palliative Care and Medical Ethics, Director of the Institute for Doctor–Patient Communication, and Medical Director of the Palliative and Supportive Institute at the University of Pittsburgh Medical Center (UPMC), spoke about methods for improving doctor–patient communication about palliative care. Elaine Wittenberg, Associate Professor in the Division of Nursing Research and Education at City of Hope Comprehensive Cancer Center, discussed training programs for nurses. An open discussion was moderated by Renee McLeod-Sordjan, a nurse practitioner and Medical Ethics Attending for the Department of Medicine at North Shore–Long Island Jewish Health System and Clinical Assistant Professor in the Graduate Department at Lienhard School of Nursing.

TEACHING COMMUNICATION SKILLS TO CLINICIANS[1]

After remarking how angry he was about the state of the American health care system after listening to the last panel presentations, Robert

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[1] This section is based on the presentation by Robert Arnold, Chief of the Section of Palliative Care and Medical Ethics, Director of the Institute for Doctor–Patient Communication, and Medical Director of the Palliative and Supportive Institute at the University of Pittsburgh Medical Center, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

Arnold wondered why there was a need for the term *palliative care* when the concepts embodied by *palliative* should be the norm in all health care. "I think we diminish what the health care system should do by calling it *palliative care*," said Arnold. "We ought to just call it good health care." He also remarked that getting American health care to embrace palliative care seems to him to be a culture change problem and not really about any one system, and that this culture change is just not happening. He recalled reading a book (Mishler, 1985) when he was studying medical ethics that talked about a world of medicine and a world of patients and that the two never talked to one another, and realized after hearing Thomas Smith's presentation that nothing has changed. "The story that we tell in medicine is that it is all the family's fault," said Arnold.

He then commented on the book *Knocking on Heaven's Door: The Path to a Better Way of Death* (Butler, 2013), whose author, like Arnold, no longer sees doctors as healers but as skilled technicians with their own agendas. Patients such as the book's author have gotten smarter, he said, in that they believe in science but do not have the same view about their doctors because their doctors do not seem to care about what their patients' lives are like. He told of conversations he has with the house staff at his hospital who have no idea of what is going to happen after they send a terminally ill patient home or to a nursing home and have done nothing to prepare the family for what might happen and how to respond. The cause of this seeming indifference, said Arnold, is that the culture of medicine has split into little tribes, none of which know the patient.

One of the things that angers Arnold is that experts still debate which medical professional should talk to patients and families about advance directives when 70 percent of the time nobody does it. The key question to him is whether there is way to change culture so clinicians can have real conversations with their patients about prognosis and end-of-life care. He and his colleagues at Vital Talk have been trying to do just that by teaching doctors to pay attention, at the times that matter most, to what their patients are saying to them and to talk back to them like human beings, not as if they are talking to the house medical staff. Today, he added, the patients who doctors like best are the ones who can report on their symptoms and treatments as if they were medical students during rounds.

The comprehensive program that he and his colleagues developed, OncoTalk, was started 15 years ago as a 4-day intensive skills retreat, funded by the National Cancer Institute (NCI), for 115 oncology fellows from 62 institutions using actors trained to be patients. The patients were of various ages and socioeconomic backgrounds who knew no medicine, and the fellows' interactions with the mock patients were recorded before and after communication skills training sessions (Back et al., 2007). When the recordings were later played to a group of listeners, they could readily tell whether the recordings were from before or after training and were amazed at the change in communication style. Of the eight communication skills that OncoTalk emphasizes, the most important is how to deal with emotion. Doctors, said Arnold, do not like emotions, and he blamed this on the way they are trained—to learn facts and to fall back on book knowledge when confronted with an uncomfortable situation. He noted that Lesley Fallowfield at Brighton and Sussex Medical School has taken the same approach and found that not only does training improve communication between doctor and patient, but that skills continued to improve 6 months after training because the physicians liked that they could have better conversations with their patients.

What these approaches share, said Arnold, is they provide trainees with the opportunity to address barriers and to both practice the skills they were learning and watch their colleagues engage in simulated conversations. Individualized feedback is also important, as is providing a supportive and safe environment in which to learn and practice these skills that do not come naturally to most physicians. They emphasize "ask before tell" and letting the patient lead the conversation, and they teach physicians how to attend to emotions and give information in simple language based on patient need.

The problem with these approaches, said Arnold, is they are time intensive in that they need to take place over 3 to 4 days. In an attempt to remedy that problem, he and his colleague James Tulsky at Duke Medicine have been testing a theory-based, self-administered, 1-hour intervention provided on a CD-ROM designed to improve an oncologist's response to a patient's expressions of negative emotion in outpatient encounters. In a randomized, controlled trial, participating oncologists were recorded speaking to their patients during clinic visits. The oncologists then received a lecture on how to improve their communication skills, and 1 year later half of them received the CD-ROM, included didactic information, video demonstrations, and audio clips from the oncologist's own recorded conversations (see Figure 4-1). At the end of each module, the oncologist was asked to commit to try targeted communication behaviors and prior to the next clinic visit, the oncologist receives an email reminder of their commitment. The two key findings from this study, said Arnold, were that oncologists receiving the CD-ROM doubled the percentage of times they responded to negative emotions, and their patients said the doctors' communication had greater impact (Tulsky et al., 2011).

One challenge that needs addressing is that of scale, or teaching all doctors to communicate effectively with their patients, said Arnold. He and his colleagues are now engaged in a study funded by the Patient-Centered Outcomes Research Institute and the American Board of Internal Medicine to see if this intervention can be delivered as a Maintenance of Certification course for continuing education credits and still have the same positive

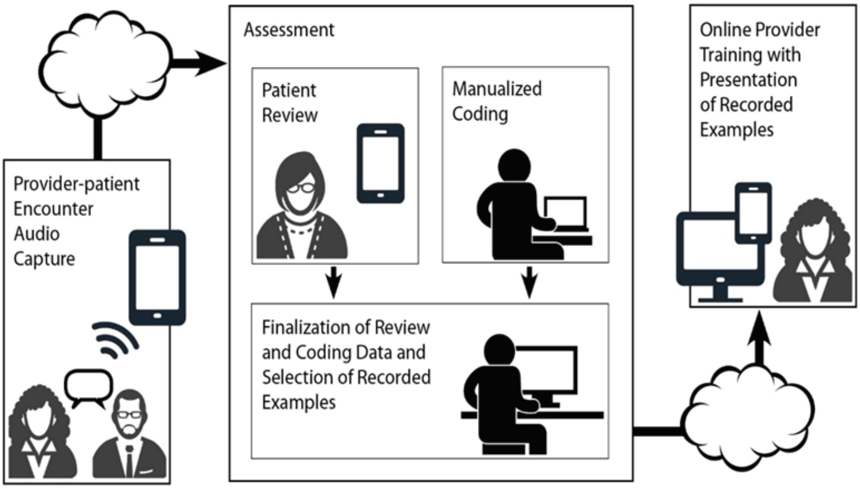

FIGURE 4-1 A computer-aided approach to teaching communication skills.
SOURCE: Presented by Robert Arnold on July 9, 2015.

effect on oncologists' communication skills. Perhaps the bigger challenge, though, is to create the political will to change culture. "Doctors are comfortable doing what doctors have always done, and oncologists do not have it in their DNA to be good communicators," said Arnold. "My view is they either need it in their DNA or they need to get out of medicine. We, as a culture, need to say medicine needs to change."

NURSE TRAINING[2]

Nurses are the frontline of care across disease and settings, and they spend a significant amount of time with family caregivers, providing education and support, said Elaine Wittenberg. When it comes to communicating with patients and families, nurses, unlike doctors, do not need training to initiate conversations because patients and family members typically are the ones who start conversations with nurses. In addition, nurses are often asked to translate what the physician has said or what a patient or family member has read on the Internet, and in fact, one of the key roles nurses play is to educate and promote communication among team members, patients, and family members. Nurses provide an immense amount

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[2] This section is based on the presentation by Elaine Wittenberg, Associate Professor in the Division of Nursing Research and Education at City of Hope Comprehensive Cancer Center, and the statements are not endorsed or verified by the Academies.

of psychosocial support to patients and family members—dealing with emotions is not foreign to nurses—and they often serve as key mediators between patients and family members in making decisions about treatments and about goals for care.

Wittenberg explained that primary training for nurses in palliative care started at the City of Hope with Betty Ferrell's work creating the End-of-Life Nursing Education Consortium (ELNEC). To date, the consortium has provided more than 170 courses to nurses and has trained almost 20,000 nurses in all 50 states, the District of Columbia, and 88 countries. What started as a core curriculum has evolved into different versions for specific nursing subgroups, such as pediatric, geriatric, and critical care nurses. Health literacy holds an important place in these curricula because nurses are often asked to translate complex medical words, abbreviations, and procedures, and to describe medications and teach patients and family members how to use medications at home.

Health literacy affects quality of care, said Wittenberg. Patients with compromised health literacy, for example, have a hard time adhering to medication regimens. She noted that the seriously ill patient population and their caregivers are aging, which increases the health literacy challenge. She also said she thinks of health literacy as including oral literacy, which refers to a person's ability to speak and listen. Lower listening skills, she explained, complicate the ability to understand and recall complex oral information and have a negative impact on medication management. Family meetings are common in palliative care, but her research has found that not all patients and families are comfortable communicating in a small group, let alone a large one that includes the entire health care team. Regardless, the health care system puts a great deal of pressure on oral literacy skills because the most common method for getting information from patients and family members is by asking them to provide the patient's medical history orally.

Over the past 5 years, Wittenberg has been working with Debra Parker Oliver at the University of Missouri to record hospice teams talking with patients and family caregivers and measure caregiver outcomes for anxiety and quality of life. One finding from this work was that as the grade-level talk in the conversation increased, so too did the anxiety level of caregivers (Wittenberg-Lyles et al., 2013a), which in turn led to confusion among caregivers about how to properly provide pain medication at home. Another finding was that hospice team members used six times as many medical words as caregivers (Wittenberg-Lyles et al., 2013b). "Yes, we do have caregivers who can learn how to present to an attending physician, but those are few and far between in our family caregiver population," said Wittenberg. The majority of the medical words used were drug names, which sometimes were brand names, other times generic names, and 75 percent of the medical words were not explained to the caregivers. Moreover, the parts of the conversations that had the most medical words proceeded at a faster pace, giving caregivers little time to respond and understand.

According to the National Library of Medicine, the appropriate level of educational health information should range between a sixth and seventh grade reading level, which Wittenberg acknowledged, based on her experience with her sixth grade daughter, is not easy to achieve. Nonetheless, training for nurses in palliative care is needed to develop this communication skill, and toward that end, she and colleagues Joy Goldsmith, Betty Ferrell, and Sandra Ragan have developed the COMFORT communication curriculum (Wittenberg-Lyles et al., 2015). This curriculum is based on seven core principles of palliative care communication: communication, orientation and options, mindful communication, family caregivers, openings, relating, and team. The modules on communication, for example, emphasize clinical narrative practice. The orientation and options module teaches nurses to describe the big picture of a diagnosis, summarize the disease path, and share options for treatment and care in plain language and with sensitivity to a patient's and family's cultural background. One of the tools they have developed is the plain language planner for palliative care, which translates the 20 most commonly used medications and symptoms into plain language at the sixth grade level based on five readability indices. The planner includes such plain language essentials as using the active voice, using the patient's and doctor's names, speaking in the second person, limiting jargon and defining new words, and keeping sentences to 15 words or less as a means of limiting the amount of information provided at one time.

The initial research with the planner compared the written responses from 155 nurses recorded before and after the planner was introduced and used by the nurses (Wittenberg et al., 2015). The nurses were asked to explain a medication and symptom to a patient, and results showed they were able to integrate and use plain language after attending an educational session on the planner. Most importantly, said Wittenberg, the amount of jargon decreased and the use of active voice increased.

In January 2015, the COMFORT communications team launched its first training efforts, including instruction on how to use the plain language planner, for 30 hospital-based palliative care teams across California. Wittenberg and her colleagues have more recently trained 100 nurses nationwide, with plans to train another 100 in October 2015. To help further disseminate the planner, her team has created a pocket guide and integrated it into an app called Health Communication for Apple devices. She and her colleagues are also adding additional information on oncology symptoms and medication side effects to the planner at the request of some of the providers who have participated in their studies. They are also translating the planner and the app into Spanish. In closing, Wittenberg mentions that the *Textbook on Palliative Care Communication*, which has five chapters on health literacy, would be published in October 2015.

DISCUSSION

To open the discussion, moderator Renee McLeod-Sordjan asked the two panelists to talk about how the medical profession is preparing the next generation to be better communicators and produce the necessary culture change. Wittenberg said she is excited, not dismayed, about the future because the stage has been set to determine what palliative care communication should look like and how it should be delivered given what has been learned through research over the past 15 years. The challenge, she said, is to develop tools for health care providers to use. She noted the decision aids and question prompt lists that Thomas Smith spoke about as good examples of the kind of tools that are needed. "Some specific disease areas, such as oncology, are already developing those tools, but from a palliative care perspective, we do not have palliative care decision aids per se," said Wittenberg. The next step, she said is to conduct quality research on communication strategies that can be used to train providers in all areas of medicine. She also said interprofessional education should be prioritized as a key component of this effort to drive home the point that it is the entire health care team's responsibility to provide information to patients and family members at the appropriate health literacy level. "There is a team process piece that has to be accounted for when we think about training providers about communication," she said.

Arnold said that medical schools are doing more today to teach communication skills. Vital Talk, for example, is working with cardiologists, nephrologists, and neonatologists, and he has heard that a course for pediatric cardiologists is being developed as part of physician training. To him, there are two big challenges facing the next generation of health care providers. The first is to ensure that once they train to be good communicators that they move into an environment that rewards them for that skill. "Are they going to be in an environment in which a 10-minute conversation is 5 minutes too long because they have too many other things to do that the health care system says are more important than communication?" asked Arnold. Second, he said, it is important not to just add more cognitive material to the training the next generation receives because decisions are not made entirely on the basis of facts. He mentioned emotional intelligence as being important. "We need to think about what will help clinicians have emotional resiliency to have these hard and sad conversations," said Arnold.

McLeod-Sordjan said that was an excellent point and asked the panelists about their expectations for health literacy given that health care providers are no longer getting trained in silos. Arnold said that interprofessional communication training is a good idea, though he had no idea how to do it. "We do not even know how to make sure that doctors and nurses have good communication skills let alone how to put them together so that they do not conflict with one another," said Arnold. This is particularly true, he added, given that in today's health system the same nurse and doctor rarely work together on a regular basis. He used a school band as an analogy. "It would be like every week having a different band because you took kids from different schools and put them together every week and expected them to play well." Though there are many opportunities, he said, the health care enterprise still needs to figure out which systems will work better for patients and how to create a health care system that better meets patient needs.

One advantage of working with a palliative care team, said Wittenberg, is that its members stay fairly constant. "If you have everybody using the same language and practicing together in a team-based approach, that is going to initiate cultural change at your institution," she said. "It is also going to help patients and families when they hear the same message and the same language from the palliative care social worker as they do from the palliative care nurse and palliative care physician." Toward that end, she encourages palliative care teams to work together to develop unified definitions and explanations that are specific for the patient population they serve, as well as culturally appropriate metaphors. She also believes that if every member of the palliative care team is consistent in the language they use with patients and families, then patients and families are going to have expectations of consistency and express that to other providers they encounter. That, she said, will further the culture change that needs to happen.

Winston Wong from Kaiser Permanente asked Wittenberg if she knew of any curricula that were being developed for interdisciplinary training for nursing and medical schools. Wittenberg replied that she does not know of any standardized communication training programs that are available today, though ELNEC is developing an undergraduate nursing curriculum on communication that will be tested online in four states in the upper Midwest. Arnold added that the Macy Foundation has funded a number of initiatives in this area. The University of Pittsburgh, for example, offered a course that nurses and medical students took together when they took care of patients in long-term care. What is not clear from studies of these efforts is how well the different professions give consistent information to patients, as opposed to how well they get along with each other and understand what each other does. Most of the work, he said, has focused on measuring the latter. McLeod-Sordjan added that schools need to move away from teaching nurses and doctors how to break bad news to patients and then move on to teaching them more broadly how to have difficult conversations about chronic disease.

Wilma Alvarado-Little noted that the presentations have focused on adult palliative care, and she asked if any considerations have been made regarding pediatric palliative care. Arnold said that there are a number of ongoing efforts in that area. A program at Johns Hopkins Medicine, for example, trains neonatologists to talk to parents about their critically ill infant, and the University of Pittsburgh has a program for pediatric intensivists. The University of Indiana is teaching pediatric oncologists how to talk with parents and children, and Vital Talk has a group of individuals who are beginning to do work in pediatrics. Wittenberg said that ELNEC is working with its core curriculum to develop one specific for pediatrics.

Cindy Brach from the Agency for Healthcare Research and Quality (AHRQ) commented that while there have been several mentions of the need for culture change, the two panelists both spoke about stand-alone interventions to intervene with specific clinicians, which she said does not sound like a recipe for culture change. She then asked the panelists if either of them had any experience trying to change an entire institution or health care system and sustain change. Arnold said that the first step that he has taken at UPMC Health System has been to measure how many seriously ill patients there are at each of the system's hospitals and to then measure how many of these patients have a documented discussion about goals of care. He is now developing metrics that he can take back to the chief medical officer of each hospital and the heads of each service line to document the scope of the problem. Starting in 2015, UPMC is conducting 1-day courses for practicing clinicians—the fellows already take courses—and the heads of every service line have agreed that every clinician will take this course. The course will use simulated patients to illustrate how to talk about goals of care.

His next move, he said, will be to enact policy that will forbid any medical student or intern to have this conversation with a patient, given that they have not been trained to do so. "We do not let medical students or interns put in Swan-Ganz catheters, and any intensivist will tell you that it is harder to have a conversation about goals of care than it is to put in a Swan-Ganz catheter," said Arnold. In his opinion, what is more important than establishing these systems and rules in the hospital is to develop programs for use in the home care and ambulatory-based setting to really produce culture change. The goal, he said, should be to have these conversations with people before they need to be treated in the hospital.

Wittenberg remarked that the first national nurse communication training program just started in 2015. Nonetheless, some of the participants in this program have already been recognized in their institutions as being leaders in communication training and being initiators of culture change. One of the goals of her program, she said, is that the nurses will themselves become trainers when they go back to their institutions and implement some sort of cultural change. She noted there is a competitive application process to be accepted into the course, and one of the requirements is to identify three goals for when the applicant goes back to his or her institution. As part of the evaluation of the communication training course, she and her colleagues follow up at 6 months and 12 months to find out what the trainees have done since returning to their institution with regard to how many people in how many disciplines they have trained and what new systems they have implemented. Part of the COMFORT curriculum, in fact, includes supplemental resources to initiate change, including research-based decision aids, question prompt lists, and tools to measure and evaluate the communication skills of the providers that they then train.

Michael Paasche-Orlow from the Boston University School of Medicine applauded both speakers for talking about culture change and pushing that conversation forward. He also noted the parallel focus on communication between health literacy and palliative care. He then asked the panelists to comment on how they think about the problem in a broader cultural context rather than in terms of one institution or health care system at a time. Arnold said that he would like to see more emphasis on community and public education and getting to the public before they enter the health care system. Part of this effort will be to train patients and caregivers to expect something different from the health care system than the promises that the next miracle is right around the corner. He commended the Center to Advance Palliative Care for its efforts in public education, and also called out newspapers and science reporters for their role in touting the next promising cure.

Wittenberg said that she would like to see the topics and scope of communication training broadened. As an example, she said she would like all health care providers to receive spiritual care communication training and more interprofessional training. She would also like to see training for family caregivers and noted that ELNEC is about to run a trial that offers a communication guide for caregivers that aims to ease the burden placed on caregivers to relay hard news to, and mediate among, family members. “We need to pay more attention to this communication task that family caregivers take on and provide some training and support for that as well,” she said, adding that nurses are in a good position to help support caregivers with that task.

Bernard Rosof closed the discussion for this panel with the comment that it is time to stop teaching medical students as individuals and start teaching them as part of a health care team, perhaps with patient advocates such as Beverly Alves involved in that team. “The real opportunity to address these challenges is to do it with the team and not with the individual,” said Rosof. He noted that there are, in fact, medical schools that are taking this approach, and his prediction is that they will be more successful training physicians to be good communicators and team members.

5

Integrated Care Teams

The afternoon's first session included four speakers presenting different perspectives on how to provide palliative care. Reverend Richard Freeman, Sr., a member of the Pastoral Team at the University of Pittsburgh Medical Center (UPMC) Children's Hospital and Senior Pastor of the Resurrection Baptist Church, discussed how to integrate spiritual care into palliative care. Carol Levine, Director of the United Hospital Fund's Families and Health Care Project, provided a family caregiver's perspective, and John Cagle, Assistant Professor at the University of Maryland School of Social Work, spoke about the role that social workers play in palliative care. Ginger Marshall, National Director of Palliative Care for Hospice Compassus and President-Elect of the Hospice Palliative Nurses Association, then addressed the role of nurses in providing palliative care. An open discussion moderated by Yael Schenker, Assistant Professor in the Division of General Internal Medicine, Section of Palliative Care, and a member of the Clinical and Translational Science Institute at the University of Pittsburgh, followed the four presentations.

HOW TO BRING SPIRITUAL CARE INTO PALLIATIVE CARE[1]

"I believe that the essence of what we do in palliative care, what we do in spirituality, is tending to the broken heart," said Richard Freeman as

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[1] This section is based on the presentation by Reverend Richard Freeman, Sr., a member of the Pastoral Team at the University of Pittsburgh Medical Center Children's Hospital and Senior Pastor of the Resurrection Baptist Church, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

an introduction to his presentation. His hope, he said, was that his remarks would help the workshop attendees gain an appreciation for the imperative of spiritual care, increase their personal posture of attending to patients' spiritual needs, and develop a better repertoire of resources to aid in meeting the needs of patients. He also noted that palliative care is a "heart thing—it is moved by what drives us at the core of our being. If the core of our being is not engaged in this work, we will not move forward." His challenge to the workshop was to not overintellectualize what the human spirit cannot comprehend and to not fall back to the position of developing another tool.

Freeman said that he was impressed with the field's efforts in teaching and building what he called brand new hammers. "But my challenge is we have to build better carpenters, and we do that by dealing with the continuum of care and with the heart of people," he said. The one thing that has been missing from the day's presentations, he said, is any mention of a person's life before they became ill. To truly understand patients and their needs from the health care system, it is necessary to understand the histories that are integral to them, explained Freeman. He used the story that Diane Meier told about Mr. R. and his need to speak to his son, talk to him about the burdens of his soul, and ask for forgiveness from his son. It was only then that he was able to find peace and die.

Freeman then talked about the synthesis of humanity as a meshing of body, mind, and spirit. Health care providers, he said, do well with the body and mind because they believe they can fix them when they are broken, but they do not do as well with a person's spirit, which he defined as the repository of meaning making. Dealing with this last piece of humanity, he said, is where his responsibility as a pediatric chaplain lies, adding that the way these three pieces fit together is shaped by who each person is. He noted that he is also trained as a psychotherapist, and during his training he was forced to develop a keen sense of introspection to understand his own motivations. If he had one wish, he said, it would be for every clinician to go into therapy to truly understand what drives them to do what they do. "When they come to terms with that, they will no longer be exercising it in the context of being a caregiver," said Freeman.

He then told a story of a mother who was tending to her son at Children's Hospital. As is his practice, he came into the room, introduced himself as the manager of the pastoral department, and let her know that he was available to help. Later that day, he got a phone call from the boy's nurse who said this woman wanted to talk to a psychologist—she had sequestered herself and was crying profusely. When he came to her son's room, she said to him that she had asked for a psychologist, but that he would do, and she abruptly stopped crying. She then informed him that she was Jewish, and that she did not believe in Jesus Christ. He said that was okay, that he did, and asked if they could talk. He recalled that she then started laughing when she realized he was not there to convert her but just to be with her, and for the remaining week and half that she was in the hospital before her son was sent home to die she talked to him every day. "That is the spiritual part that I am talking about," said Freeman.

He then challenged the workshop by arguing that not doing spiritual care may in fact be unethical. The major tenets of ethics, he said are autonomy, nonmaleficence, beneficence, and justice. "If you don't know my spiritual journey, how can you say you are allowing me to work autonomously?" he asked. "If you don't know what vexes my spirit when you offer me a treatment that is going to prolong my life, but is never going to improve my lot and you are telling me I cannot go be with my God, you might be doing something that is maleficence. If you don't know what drives and motivates me, you may be keeping me from the very thing that gives meaning to my life," he said.

How then is it possible to avoid this ethical quagmire? Informed consent, he said, is a governing principle of patient interaction. Although often implied, there is another principle operative in medical delivery that he called informed treatment—that a patient gets what they desire. Spirituality, said Freeman, must be considered when determining what medical services are dispensed.

Returning to the idea of building a better carpenter, Freeman listed a few steps to take to be prepared to care for all of a patient's needs. It is important, he said, to identify personal hot buttons, the situations that takes someone out of their sphere of comfort. Most hot buttons, he said, are a by-product of a person's construct of likes and dislikes and are informed by personal histories. It is important, too, to recognize that every caregiving experience is a learning experience that can help hone individual best practices. "Understand your value system and be acquainted with your nonnegotiables," said Freeman. "Distinguish those values that are your essence from those that are just important, and safeguard those values that you esteem as your essence." Lastly, he said, it is critical to have spiritual integrity, the ability to differentiate one's values from those of a client without a compulsion to reshape the spiritual beliefs of the client. "Nurturing spiritual integrity requires searching for the questions that vex your spirit and that give meaning to you and you alone," said Freeman. "Once you have gotten those answers, find peace with it, and then leave it alone. It is not to be dealt with in the context of a caregiver."

It is important for health care providers to nurture spiritual integrity because they will be more empathic in their approach when their issues are not their patient's issues, he explained. "We become more tolerant of differences that are apt to be discovered when working with the dying," said Freeman. He noted that spiritual integrity is not the same thing as religious training. Although religious traditions inform spiritual identity, religion is not the sum total of a person's spiritual essence, he explained. It is possible to feel that one's spiritual essence is seriously threatened, and when that happens one should appeal to other members of the care team and perhaps even step away as a caregiver if the situation dictates.

Freeman ended his presentation with two suggestions on how to enhance the delivery of spiritual care. The first is to be curious, to recognize the humanity in every patient as a common starting point from which to ask interesting questions. The second is to be courageous and ask potentially difficult questions. "This is not easy," said Freeman. "Sometimes you are going to have to ask somebody about their spiritual journey and the meaning it gives them. It is a question that affirms the individual's humanity, and if we do that we have been good caregivers."

A FAMILY CAREGIVER'S PERSPECTIVE[2]

Carol Levine approaches the subject of palliative care from the dual perspective of someone who directs a project that works with family caregivers and who for 17 years was the caregiver for her late husband, who suffered a traumatic brain injury that left him quadriplegic and with a severe cognitive impairment. She said that when she was listening to Beverly Alves and Diane Meier, she could feel anger welling up inside her as she remembered all the things she dealt with during her years as her husband's caregiver and saw that the situation for family caregivers has changed little over the past 20 years. She recounted that the attitude 20 years ago was that the wife would take care of things. "Some people go to the hospital and lose their eyeglasses," she said "I lost my identity. I became the wife." That personal experience, she said, combined with her 20 years of professional experience in the field, colors what she had to say at the workshop.

The person who is health literate, said Levine, needs to understand not only the medical situation, what the treatment might be, and how to make choices, but also understand bureaucratic language, insurance language, and institutional arrangements. From her perspective and experience, health literacy is not a problem solely of poor people, those with low education levels, or of any ethnic or racial group. Depending on the circumstances, anyone can be health illiterate as it is impossible to be completely up to date on all knowledge pertaining to health and health care. To make that point, she told the story of an ambulatory clinic administrator who asked her to explain the difference between hospice and ambulatory care. "Here is a per-

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[2] This section is based on the presentation by Carol Levine, Director of the United Hospital Fund's Families and Health Care Project, and the statements are not endorsed or verified by the Academies.

son in the health care system and she did not know," said Levine. "We have to assume that at some point, every one of us will need more information and better explanations." In her opinion, she added, understanding services may be harder than understanding basic health information.

When she started her journey she expected the health care system to be a maze and expected that taking her husband home from the hospital was not going to be simple. "Nurses and the social worker waved good-bye to me from the rehab facility and said 'You are on your own now, dear,' and I was," she recounted. She figured, though, that being smart and having accomplished much during her life that she could figure out how to get the services she needed to care for her husband. What she encountered, though, was not so much a maze as an abstract painting with no clear path and nobody to guide her. There were individuals who could help her navigate one little section of the journey, particularly with regard to the hospital experience, but there was nobody to help her once she was in the community.

There are several reasons, said Levine, that palliative care is hard to understand. To start, it is hard to spell and pronounce, and there is the confusion between hospice and palliative care. Health care professionals do not even share the same definition. There are palliative care doctors, who offer specialized medical care. Home care nurses think they are providing palliative care but they are really providing ordinary care for sick people. Long-term care staff believe they are providing palliative care when they are keeping residents quiet and comfortable. "If providers have different definitions, how can the patient and the family caregiver understand it?" asked Levine. She noted that there is much to be unlearned about palliative care before new information is presented to patients and families. Contrary to common belief, palliative care is not just for dying, it is not a program to save the government money, and it does not require hospitalization. Palliative care does not mean giving up hope, nor does taking pain medication lead to addiction. Most people believe that insurance will not cover palliative care at home, which may or may not be true, and it is common to assume that palliative care means the doctor is abandoning the patient and family.

From the perspective of the family caregiver, there are special challenges, said Levine. There is an intense emotional component, and it is important for clinicians to recognize that and confront it directly. Levine suggested that the simple statement, "I understand this is a difficult and emotional time for you," can mean a great deal coming from members of the health care team. A challenging role that the family caregiver takes on is making health care decisions either with or for another person, which is not only difficult but can cause conflict within the family. Levine noted that there are often people within a family who each perceive they have an equal role to play in decision making yet come to the table from different perspectives and with different information about and understanding of the family member's medical situation.

Often, family caregivers feel excluded from the health care team. Levine recounted that when she was caring for her husband, she repeatedly asked to have a meeting with his health care team. It never happened even though she knew there were team meetings. Affordability is a major concern of family caregivers, and Levine noted that Medicaid Managed Long-Term Care may no longer cover all of the services the caregiver may want for their loved one. Family caregivers also worry about being able to provide complex care at home. "Palliative care as it is practiced today is not chicken soup and a pillow," said Levine. Family caregivers are not getting the proper training to manage a morphine drip, a peripherally inserted central catheter, and other complicated procedures, and Levine questioned how that was acceptable practice.

United Hospital Fund's free *Family Caregiver Guide to Hospice and Palliative Care* (United Hospital Fund, 2013) is an attempt to provide this kind of information, and it includes a chart comparing hospice and palliative care (see Table 5-1). Levine said both the English and Spanish versions are the most frequently downloaded guide to palliative care. It is also available in Chinese and Russian. Its popularity, she added, suggests that family caregivers are not getting information from health care providers.

Caregiver assessment can be used as a guide to discussion, but Levine suggested that it should not be done in the manner of a formal medical exam. Start by acknowledging that the caregiver has much to learn about palliative care and how it will affect the patient, and learn about the caregiver's situation and who will do what for the patient. Ask the caregiver about his or her other responsibilities for an honest assessment of their limitations, and probe for worries and concerns, which is often the most revealing part of the assessment and can provide answers that range from the mundane—can I get home in time to pick up my child from school?—to the existential—why is this happening?

The most important thing to do for family caregivers, said Levine, is to involve them at every stage of the patient's care and decision-making process so nothing comes as a big surprise. Start the discussions early, not when a crisis situation develops, and be available to offer support and training. Levine reminded the workshop participants about the importance of dispelling myths and answering questions as often as needed using clear, simple language. In conclusion, Levine described the four habits approach to effective communication (Frankel and Stein, 1999), which are to invest time at the beginning of the process to develop trust and learn about the patient's and family caregiver's perspective early rather than when a crisis arises. Demonstrate empathy, both in words and body language, and invest in the end by summarizing what was heard and what the next steps will be.

TABLE 5-1 United Hospital Fund's Comparison of Hospice and Palliative Care

	Palliative Care	Hospice Care
Goals	To assess and treat the patient's pain and other physical, psychosocial, and spiritual problems.	To keep the patient comfortable, as free as possible from pain and symptoms, and allow him or her to maintain a good quality of life for the time remaining. Hospice accepts death as an inevitable outcome for a patient with a terminal (end-stage) illness. In hospice, both the patient and the family are the focus of care.
Patients	Palliative care accepts patients who have complicated or advanced medical disease. There is no time limit in terms of life expectancy—patients may or may not be dying. Patients can get treatments intended to cure. They also can participate in research studies.	Hospice only accepts patients who are near the "end of life" (meaning they have a terminal illness) and are likely to die within 6 months if the disease runs its normal course.
Where care occurs	Palliative care is usually given in hospitals. Sometimes it takes place at nursing homes or assisted living facilities. Palliative care at home is possible but not readily available.	Most hospice care happens at home, although it can also be given in other settings as well, such as the hospital, nursing home, or assisted living facility.
Who provides the care	Palliative care is a medical subspecialty. This means that doctors and nurses who practice palliative care extra training about ways to manage symptoms. They work with a team of other professionals.	Hospice care is a team approach, led by doctors and nurses with special training. Specialists may provide spiritual, psychosocial and other care. Hospice care may require a lot of time and effort from the family.
Paying for services	There is no special insurance benefit for palliative care. The patient's health insurance generally covers palliative care services.	Hospice is a Medicare (federally funded) program. Many state Medicaid plans and private health insurance plans pay for hospice. A patient who chooses the Medicare hospice benefit agrees to give up treatments meant to cure disease. This is in return for other types of support and supplies.

SOURCE: Presented by Carol Levine on July 9, 2015.

A SOCIAL WORK PERSPECTIVE[3]

John Cagle, who was a hospice social worker for 10 years before assuming his current position, said he is ready for the culture change some of the speakers had discussed. "I would love to see what we have been practicing in the field implemented sustainably across the country," said Cagle. He then gave his working definition of palliative care as being patient- and family-centered, interdisciplinary, focused on quality of life, and can take place either inside or outside of hospice. Social work, he said, is part of the interdisciplinary team that addresses the multidimensional needs of patient and family (see Figure 5-1). He noted that there cannot be palliative care without the family or a truly interdisciplinary team addressing these multidimensional needs.

The different disciplines involved in true palliative care each bring a unique set of skills, though there is overlap. Cagle sees the interdisciplinary team as a Swiss Army knife for palliative care, with social functioning as the can opener because social workers get people to open up. Social care has to be integrated into palliative care given that socioeconomic factors account for as much as 40 percent of the determinants of health, while health care accounts for only 20 percent (see Figure 5-2). In fact, he views medical care much like water for a plant—it is important and good, but too much can be a bad thing.

The role of social workers within palliative care is to attend to many of the nonmedical social, emotional, behavioral, and environmental aspects of care. Social workers also provide a comprehensive psychosocial assessment of a patient and family, help patients and families navigate complex health care systems, and negotiate transitions across settings. Social workers can help foster coping and minimize psychosocial distress, provide emotional support, and facilitate decision, often by leading or coordinating family discussions about care goals. He said there is a belief that social workers are not conducting these family meetings but in fact they are (Meeker et al., 2014; Sharma and Dy, 2011). Other roles that social workers play include improving access and adherence to treatment and connecting families to needed resources available in the larger community.

Health literacy, palliative care, and social work intersects in five places, said Cagle. These include

- Careful attention to language
- Addressing myths and misperceptions
- Advocacy for social justice and vulnerable populations

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[3] This section is based on the presentation by John Cagle, Assistant Professor at the University of Maryland School of Social Work, and the statements are not endorsed or verified by the Academies.

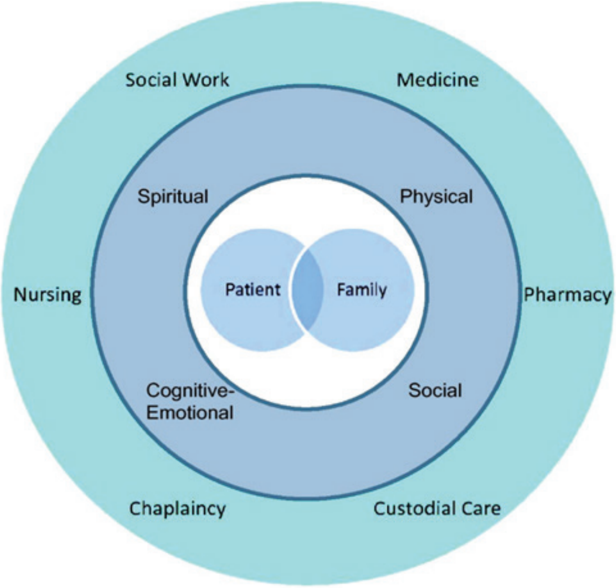

FIGURE 5-1 A graphical representation of the multidimensional nature of palliative care.
SOURCE: Presented by John Cagle on July 9, 2015.

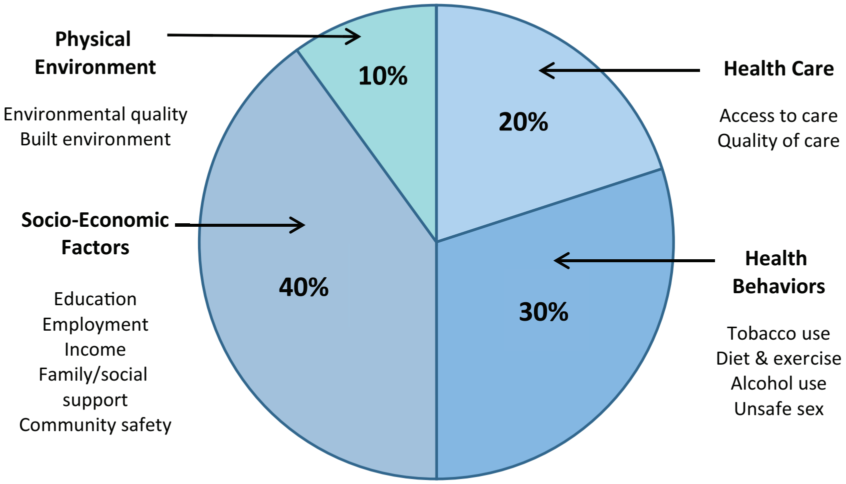

FIGURE 5-2 Social determinants of health.
SOURCE: Presented by John Cagle on July 9, 2015.

- Facilitating coping and minimizing distress
- Acknowledging uncertainty and change

Schools of social work focus on communication and family dynamics, part of which involves paying close attention to language. Language is how people make sense of the world, yet the health care system fails repeatedly to use appropriate language. The potential pitfalls and missteps include using medical jargon, acronyms, and Latin phrases. Basic terms such as *oncologist* do not make sense to many people, said Cagle. The volume of information given to patients and families is often overwhelming, and as an example, he said he has seen families receiving 2-inch-thick stacks of information at hospice admission. "We cannot expect them to retain all of information," said Cagle. Individuals on the health care team often lack the time to solicit information from and provide proper explanations to family members, suggesting the need to better manage the way team members work to meet family needs.

Metaphors may seem useful and are well intended, but metaphors such as "fighting against cancer" can put patients in a position where they feel they are fighting against themselves, producing an intrapsychic dilemma. Moreover, when a patient reaches a point where they are going to succumb to their illness, they can feel that they did not fight hard enough, producing subtle blame on the patient. Cagle also said that absolutes need to be avoided—instead of saying there is nothing more to do, say it is time for palliative care and expert pain and symptom management, which are not doing nothing. It may seem that there are few options when therapy fails, but the truth, he noted, is there is much that can be done, such as paying attention to quality of life and dignity; exploring and defining the family role from that point on; mobilizing social, emotional, and spiritual supports; and strengthening relationships. It is also important, he added, to be attuned to culturally specific terms. As an example of the latter, he has found in his own research that the term *good death*, which is used often in the medical setting, is not a term found in the Hispanic lexicon, and Hispanics are more likely than members of other ethnic groups to describe death as bad rather than good.

"We need to choose our words carefully because the way we frame decisions affects how decisions are made," said Cagle. "It is important to recognize our own biases, our own perspectives, our own prejudices so when we go in to talk to the patient and family, we understand our own frame of reference." Paying attention to body language is also imperative. "If we ask a question and we are nodding our head, we might be prompting a yes answer," he said as an example.

Cagle agreed with Levine that it is important to educate patients and families and to address myths and misperceptions. He noted that only

20–30 percent of Americans have heard the term *palliative care*, and while 85 percent have heard of hospice, nearly two-thirds do not know that hospice requires patients to forego curative treatment. When he and his colleagues administered a true-false test related to hospice, the mean score was 78 percent, a C plus grade. Common misconceptions about hospice include it is only for cancer patients, it is a place, it is only for the patient, it is expensive, and it stops after 6 months. Patients and family members also overestimate the likelihood that treatment will succeed and underestimate the risks and costs of therapy even though many of the best interventions have low rates of success and high rates of burden, said Cagle. He is particularly concerned, he said about the disparities in understanding and utilization among African Americans and Hispanics, as well as among other high-risk populations. He noted that an estimated 40 percent of patients who qualify for hospice care never receive it (Harrison et al., 2005).

It is also vital, said Cagle, to address the emotional and psychological factors, such as shock, denial, anger, blame, depression, and anxiety that can impede the ability of a patient or family member to process health-related information. Helping patients and families dealing with uncertainty and change is another important consideration for the health care team. The truth, said Cagle, is that there are many unknowns when it comes to serious illnesses and the potential effects of treatment, yet health care professionals most often focus on facts. “We need to have frank conversations about what we do not know,” he stated. Regarding change, health literacy and preferences may change as a result of medication side effects, disease progression, and emotional capacity.

In conclusion, said Cagle, health illiteracy is invisible and requires vigilance on the part of the health care team. It is important to assess for it, to start where the patient and family are when they enter the health care system. Communication is key to addressing health literacy, and while it is impossible not to communicate in some way, not all communication is effective or appropriate, he emphasized. Health care team members need to pay attention to nonverbal cues and the way they communicate expectations. Empathy is vital, as is involving the family whenever possible, including in team meetings. Greater transparency with regard to health care costs is badly needed, he said, and paying attention to individual preferences is paramount. “I think that should be the prime directive for palliative care, and whatever metrics we develop to measure the success of palliative care should account for patient preferences,” said Cagle. To illustrate that last point, he told the story of a patient whose pain was registering 8 on a scale of 10 but did not want pain medication because the pain made him feel alive even though he was dying.

A NURSING PERSPECTIVE[4]

Ginger Marshall started her presentation with a "connect-to-purpose" story involving a recent clinical encounter during which she and a medical resident met with young woman to discuss treatment goals for her mother, who was unable to make decisions because of confusion she was experiencing. The resident began explaining some of the medical issues confronting their mother, using terms such as *hepatic involvement*, *renal insufficiency*, *encephalopathy*, *head CT [computed tomography] consistent with malignancy*, and *resuscitation*. Marshall, whose own anxiety level was rising with each piece of jargon, saw the daughter's face reflect fear, frustration, and boredom as the explanation continued. The resident finished and asked the daughter if she had any questions, but before she could respond, Marshall asked the daughter if it would be helpful if she summarized a few of the points the resident had made. She explained to the daughter that her mother had colon cancer and it had moved to her liver, and because of that, her liver was not filtering out toxins in her blood as well as it used to, causing her confusion and affecting her kidneys. She also explained the special X-ray that had been done on her mom's brain and that it had found a new site of cancer.

Marshall then talked more specifically about what her mom would want done if her heart stopped or if she stopped breathing, and she explained that she understood the huge responsibility involved with making those decisions for her mother. Marshall also encouraged her to allow her mother's voice to speak through her to be able to make decisions, not on what she felt would be best but what her mother would say if she was there with them. When she finished, she asked the daughter if she had any questions and she asked Marshall if she could give the same information to her brother and sister, who would be arriving shortly. Marshall replied she would be happy to, and as she and the resident turned to leave the room, the daughter leaned forward and said to the resident that it was okay for him to be there when her siblings arrived, but that she wanted Marshall to do all of the talking.

Turning to the subject of her talk, she cited Terri Ann Parnell's definition of health literacy (Parnell, 2015): "The relationship between the skills of persons receiving care or treatment and the professionals or systems that are providing the care and treatment." She favors this definition because it emphasizes the intersection of how well the patient takes in information with how well that information is delivered. That intersection, she said, is

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[4] This section is based on the presentation by Ginger Marshall, National Director of Palliative Care for Hospice Compassus and President-Elect of the Hospice Palliative Nurses Association, and the statements are not endorsed or verified by the Academies.

what enables patients and families to exercise their autonomy in making decisions.

Marshall noted that more than 80 percent of older adults suffer from at least one chronic condition, and nearly 90 percent of deaths involving patients over age 65 are directly associated with one of nine chronic illnesses: cancer, chronic liver disease, chronic lung disease, congestive heart failure, coronary artery disease, dementia, diabetes, peripheral artery disease, and renal disease. Rarely, she said, does she see a patient with only one of these illnesses. Chronic disease is tied to health outcomes, she added, by health literacy because, "If patients with chronic disease are not able to understand what we need them to do to achieve their goals, either because they do not have the ability to understand or we have not done a good job explaining, there will be a significant impact on their health outcome," said Marshall. Moreover, she added, when a patient's condition requires palliative care, health literacy also affects autonomy and a patient's ability to give informed consent regarding what they want and do not want in terms of care.

Nurses, said Marshall, provide patient education and care for a diverse population across the life span in multiple health care environments. As of June 2015, there are close to 4 million nurses working in the United States, with more than 120,000 nurses working in Virginia and the District of Columbia alone (Henry J. Kaiser Family Foundation, 2015). It is difficult, she said, to determine how many of these nurses are working in palliative care or hospice, but the Hospice & Palliative Nurses Association has more than 11,000 members, and approximately 14,000 nurses are board certified in hospice and palliative care, including advanced practice nurses, registered nurses, pediatric registered nurses, and licensed practical and vocational nurses. Hospice and palliative nurses provide care in the acute setting, outpatient clinics, skilled nursing facilities, assisted living facilities, hospice facilities, at home, parish nursing, prisons, and community centers.

A study (Roter, 2000) found that patients recall and understand as little as half of what they are told by their health care provider. Marshall said her expectations are lower, and she tells patients and families that she anticipates they will retain 20 percent of the information she provides them, which is why she repeats information every time she encounters them. The reasons for such poor retention, she said, include the fact that patients and families are often experiencing emotional instability, which can impair information processing (Wittenberg-Lyles et al., 2013a), and that patients and family members may not all be on the same page or there may be family dynamics that prevent consensus. Interdisciplinary team communication and poor communication across the care continuum, which can stretch from the emergency department to a long-term care or hospice facility, also contribute to poor information retention. Nurses, given their frontline presence in hospice and palliative care, can play a role in alleviating poor information retention and improving patient autonomy by becoming more involved in patient education. Appropriate patient teaching, said Marshall, reflects a patient's developmental stage, age, culture, spirituality, preferences, and health literacy considerations.

Health literacy, she said, has to become as automatic for nurses as is hand washing. "It would be wonderful if every time we had a conversation with a patient, we would be asking ourselves if we are conveying information and if we are reading the patient correctly that they are understanding things," said Marshall. She believes that nurses can be on the frontline of watching for jargon and alerting other members of the health care team when their explanations are missing the mark with patients and families. Nurses, she added, can be advocates for health literacy across the entire spectrum of care. In fact, said Marshall, the Hospice & Palliative Nurses Association's Advancing Expert Care initiative emphasizes health literacy. It has created patient and family teach sheets, many of which are available in Chinese, English, and Spanish, as well as tips sheets for nursing assistants and quick information sheets for nurses that provide brief overviews of diseases that can be shared with patients and families. This initiative also offers online learning courses, and both education and research scholarships in health literacy. Marshall noted that being a member of this association has provided a wonderful opportunity to be mentored in her role as a leader of health literacy in her organization. It also provides resources, such as special interest blogs that she has used as a source of information to help patients. She recounted an example in which she had a patient with a calciphylaxis, a painful wound condition that can accompany renal disease. This patient did not want to take pain medications because she was the household member who balanced the checkbook, so she turned to one of the association's special interest blogs and learned about topical opioids. With some further research, she was able to provide information to the inpatient pharmacy, which created a topical formulation that took the patient's pain score from 10 to 3 within 48 hours.

Marshall then described two palliative care programs. The Carolinas HealthCare System's inpatient, outpatient, and virtual care programs have been able to have all of their patient education material reviewed and approved by the system's health literacy committee. To improve the cultural relevance of health information and care, the Carolinas system created a website, Culture Vision, that enables any employee to enter, for example, "end-of-life care for patients who are practicing Buddhists" and get information on how to better care for those patients. The Carolinas system has also created a 7-hour compassionate care course, based heavily on the End-of-Life Nursing Education Consortium course, and has educated more than 900 nurses about primary palliative care. Marshall noted that each member of the Carolinas HealthCare System's interdisciplinary teams meet in a morning huddle to decide which skill set on the team can best meet a patient's need for that day.

She then discussed the Hospice of the Western Reserve in Cleveland, which participated in the Family Caregiver Project run by the City of Hope. This 18-month national education pilot project focused on assessing oncology caregivers needs, developing an education program to meet those needs, and then evaluating caregiver confidence and satisfaction. Marshall said this pilot program determined that teaching instrumental caregiver skills, such as how to turn a patient in bed, assess if a patient is in pain, and assist with activities of daily living, improved caregiver confidence by 75 percent. It also revealed the importance of educating hospice nursing assistants to be able to identify a caregiver's learning type and how to use adult learning principles to teach caregivers essential skills. Through education, hospice nursing assistants have been able to take information developed initially for the caregivers of cancer patients and use it with caregivers regardless of their patients' diagnoses.

In closing, Marshall recommend that nurses, physicians, and other hospice and palliative care team members receive communication training, and that such training should be extended to all health care providers regardless of their role or specialty. Current materials and resources related to health literacy should be revised to include content related to chronic illness and end-of-life care. She concluded her presentation by reading from a thank-you card that she received when she was director of the University of Utah Palliative Care Service. "Your team answered our questions before we knew we had them," read the card. That comment, she said, was a sign that health literacy was front and center in the health care team's interaction and that as a result, she and her team had done a great job in caring for that family. It is messages like this, she said, that do wonders for her after a rough day at the hospital.

DISCUSSION

Yael Schenker started the discussion by referring to Freeman's comment about needing to nurture the soul and spirit of patients and families and asked the panelists if they had thoughts about how to nurture the soul and spirits of the palliative care team. A simple answer, said Freeman, is to find the things that give meaning to life. "If you like playing golf, go do it. Relax. Do what is necessary to bring peace to yourself," he said. "It is really as simple as that." Another piece of advice he offered is to talk about work with colleagues, who understand the trials and tribulations of working with seriously ill patients better than family members. He holds gripe sessions and cry sessions in his office to help staff make it through the hard moments. "We are but human," said Freeman. "Do whatever nurtures your humanity."

Schenker then asked Marshall if she had any ideas about how to work more effectively in teams to extend the impact that palliative care can have given workforce shortages that exist in health care systems. Marshall referred to Freeman's comment about tapping into passions with regard to letting team members work on tasks that may be outside the boundaries of their professional assignments but for which they have a passion. Incorporate personal goals into team assignments, she added. "We have to think outside the box," said Marshall.

Cindy Brach from the Agency for Healthcare Research and Quality (AHRQ) asked the panelists to comment more on the inclusion of patients and caregivers in teams, but not as information conduits between family members. Carol Levine said that teams need to do some self-reflection on why they are resistant to including patients and family members as teammates. She believes that one reason is fear—teams are afraid they will not be able to talk about hard things because the patients or family members will get too emotional. Another reason is that teams have no clear picture of what each team member's responsibilities are, and so there is no clear structure for the team into which patients or family members can fit. She added that patients and family members should have the option, not obligation, to be part of the team, and noted that while there is no *I* in *team*, there is a *U* in *team* when you are a family caregiver, as in "You do it," and you get told what to do. "The reason to involve someone in the team is not to give them instructions but to listen to them," said Brach. "That is part of the culture change we need."

Marshall made the point that she believes palliative care consulting teams do a great job of incorporating patients and families into the decision-making process. "I have never worked with a palliative care team that makes a plan outside of the presence of a patient or family members, and that does not give patients or family members control over who gets to help with the decision-making process," said Marshall. As an example, Marshall recounted a case in which she saw a patient in a pulmonary clinic and the social worker who was working with her picked up on the fact that Marshall had missed the patient's concern that her daughter, who was living with her, would be involved in decision making. "She did not want the daughter involved but was not able to tell her that," recalled Marshall. The social worker was able to mediate the conflict and start the discussion.

Cagle added that Debra Parker Oliver has used video links in the home to bring caregivers into team meetings so they do not have to leave home but can still participate in the discussion. He noted, though, that the paternalistic settings with strong hierarchies in place in many health care settings can create challenges to including patients and caregivers on teams.

Organizational support from system leadership is essential for creating true teams, said Cagle. "We are seeing many watered-down versions of interdisciplinary teams out there," he said.

Freeman commented that some health care systems do not value all of the potential members of a team, such as social workers or chaplains. "They do not value those nonreimbursed entities in hospitals," he said. He also noted that if a health care system does not start engaging every employee—the chaplains, social workers, environmental service people, cafeteria workers, and others—in the holistic care of the entire family, it will sow the seeds of its own destruction because another health care system will do those things.

Steven Rush from UnitedHealth Group commented that the definition of health literacy used for this workshop focuses on getting and understanding information to enable appropriate decisions, and he wondered if there is a role for the palliative care team to help people make appropriate decisions. Freeman replied with a statement that he acknowledged might be controversial: that rather than following the Golden Rule of doing unto others as you would have them do unto you, the paradigm for medical care should be to do unto others as they want done to them. "We have to challenge ourselves to say that we want to give you what you want," said Freeman. "This top-down hierarchical structure, believing we understand what everybody needs and wants, is a flawed paradigm." He then recalled a time when Robert Arnold came to his hospital and asked staff how many of them wanted to be on a ventilator—nobody raised their hands. When he asked how many would want to be on a ventilator for 1 week and then be fully recovered and a few hands went up, but when he asked how many wanted to be on a ventilator if it were just for a few hours and then be completely restored, every hand went up. The lesson of this exercise, said Freeman, is that what people want depends on the real circumstances, and to know what they want in a given circumstance requires asking them. "If we do not do a good job of asking, we are just dictating and we have a problem," Freeman said.

In Marshall's experience, every time one of her teams gets asked to participate in a consult to assist with a discussion about treatment goals, the reason is that there is a problem with health literacy. She believes that palliative care has a large responsibility to address this issue, but she also agreed with Arnold's statement that it would be ideal if the palliative care specialty did not need to exist. "Every one of the medical providers should have the ability to recognize when there are challenges involved with understanding." Cagle cautioned against giving advice to patients and family members based on what they, the team member, would do. "As soon as we start talking about the role of the team in leading patients to make decisions about appropriate care, the question becomes whose definition of appropriate care," said Cagle. That decision, he emphasized, has to be centered on the patient. Rush seconded that statement. Freeman recalled an incident where an oncologist told him not to mention death or dying if there was a 75 percent chance of a cure, and his response was that if a patient wants to talk about death and dying, that is what he will talk about with them. Though the oncologist was not pleased then, he has come around to realize that Freeman was right—those decisions are about the patient's journey, not the doctor's.

Jennifer Cabe from the Canyon Ranch Institute said she appreciated the "delicious morsels of hard truth from this panel," and said that one thing that she holds to be true is that health literacy is about advancing self-efficacy and empowerment. "It is a two-way street between the people we call patients and the people we call health professionals," said Cabe. One idea that has intrigued her is the need to increase public awareness about the concept of pain management. Marshall replied that while she supported that idea, she thought that providers need to be educated first. "Any type of education about pain management to increase their autonomy and help them make good decisions is a wonderful idea, but I think it has to be balanced with educating health care providers about services that may not be available everywhere," said Marshall.

Cagle thought that it would be difficult to conduct a broad-based public education campaign on pain management but that targeting people who are in pain or caregivers that are caring for patients in pain can be effective. He cited a recent study that he and his colleagues conducted on addressing barriers to pain management and hospice with family caregivers (Cagle et al., 2015). They saw improved caregiver efficacy related to pain and symptom management and improvement in patient pain within 2 weeks after the intervention. "I am optimistic about targeted approaches such as this," said Cagle. The problem with a larger public education effort is that the information may not be needed for a number of years and is forgotten, "but if you get the people who are dealing with it right then, there are ways to open the door," he noted.

Jennifer Dillaha from the Arkansas Department of Health's Center for Health Advancement asked about other disciplines that would be helpful to bring into palliative medicine, and Levine replied that pharmacists need to be involved. It is important, she said, to have someone on the team who truly understands what medications do and do not do, how to prescribe them, and if there are alternate methods of delivering them. In addition, many patients get better information about their medications from pharmacists than they do from their doctors. Cagle said that hospital aides play a vital role in caring for patients and often they develop intimate relationships with patients and family members. He noted his surprise that aides are not heard from more in forums such as this workshop. He also thought that perhaps someone who is technologically savvy could be part of the team.

Marshall seconded Levine's statement about pharmacists and said they are often skilled at education and teaching. Another addition might be to have people skilled in complementary medicine disciplines such as acupuncture or Reiki. "It does not matter if as a provider you feel there is a need for that expertise on the team, but it is about what our patients feel they need," said Marshall. She also remarked that she worries about pushback from hospital administrators who are concerned about the effect on budgets of creating bigger teams.

Michael Paasche-Orlow thought the panelists were being too polite about the dominance that physicians have in creating teams. As a physician, he felt he could state that "there are a lot of people who have power and who are not sharing it." He noted that one reason that physicians may be reluctant to have patients and family member on their teams is that they will then have to stop using jargon and communicate more clearly even in that environment, not just at the patient's bedside. He admitted that on occasion he uses made-up acronyms in meetings with his medical colleagues just to see if anyone will admit that they do not know something, and nobody does. "Communication at the team level has to be improved, too," he said. "There are many hierarchies that need to be unpacked."

Wilma Alvarado-Little asked the panel how interpreters were used in their teams when patients or families members have a primary language other than English or if they are hearing impaired, and if they were briefed before being in the room with patients and family members. Marshall said that in the best-case scenario, an organization has interpreters available. In her organization, it is standard practice to meet with the interpreter to make sure they have a good understanding of what will be discussed with the patient and family. In smaller communities and in smaller geographically located communities, she added, it is not unusual for those interpreters to know the patients, and in that case it is important to make sure that the interpreter will not have a problem interpreting for someone they know. In the end, though, the mandate is to use interpreters. "It should never be acceptable to have a family member interpret and make them responsible for delivering difficult news," said Marshall. Brach quickly noted that AHRQ has a curriculum on working in teams with specific modules, including video demonstrations, on how to integrate an interpreter into a team.

6

Health Literacy in Palliative Care Programs

The workshop's final session presented four examples of how health literacy and palliative care can be integrated into a successful program. Stacie Pinderhughes, Director of Palliative Medicine at Banner-University Medical Center in Phoenix, Chair of the Division of Palliative Care at Banner Health, and Clinical Associate Professor of Internal Medicine at the University of Arizona, described some of the ways in which health literacy plays out in Banner Health's palliative care program. Dana Lustbader, Clinical Professor Critical Care and Palliative Medicine at Hofstra North Shore–Long Island Jewish (LIJ) School of Medicine, Department Chair of Palliative Medicine at ProHEALTH Care Associates, and Medical Director of ProHEALTH Care Support, then discussed a program for providing palliative care at home. Anne Kinderman, Director of the Supportive and Palliative Care Service at San Francisco General Hospital and Assistant Clinical Professor of Medicine at the University of California, San Francisco, showed how her service helps patients navigate difficult decisions in the hospital, and Reverend Tyrone Pitts, co-chair of the Interfaith and Diversity Workgroup at the Coalition to Transform Advanced Care, Ecumenical Officer and General Secretary Emeritus of the Progressive National Baptist Convention, and President and Chief Executive Officer of Bridges International LLC, described a faith-based movement to transform health disparities. An open discussion moderated by Marian Grant, a nurse practitioner and assistant professor at the University of Maryland School of Nursing, followed the four presentations.

Grant, while introducing the panel, remarked that the workshop so far had addressed some difficult topics and highlighted some opportunities for progress. It was her hope that the four presentations would be "little pools of light that will ultimately become beacons and that all of us will work to together to make this type of care more widely available in the United States." She also acknowledged what she called a "brave move on the part of our government yesterday," when the Centers for Medicare & Medicaid Services announced that it was going to propose billing codes that would allow providers to bill for advance care planning conversations. Recalling the days when some pundits were raising alarms about death panels, which she considers an example of health illiteracy, she called this announcement the start of a brave new day. "I am hoping that the fact that in the last 23 hours since the announcement was made that we have not heard about death panels is a sign that maybe those days are behind us," said Grant.

HEALTH LITERACY AND PALLIATIVE CARE IN A LARGE HEALTH SYSTEM[1]

Stacie Pinderhughes started her presentation with a story about Mrs. W., a 61-year-old Navajo American woman who she met in the intensive care unit (ICU). Mrs. W., who had a history of autoimmune hepatitis, hepatocellular carcinoma, and hepatitis B, was nearing the end of her life and had many of the complications common among critically ill patients in the ICU. Mrs. W. was on dialysis, on a ventilator, and in septic shock, and was so ill that she had been removed from the liver transplant list. The ICU director had called Pinderhughes when the ICU staff had reached an impasse with the family regarding what their goals were for Mrs. W.—the ICU staff thought that Mrs. W. should have a do-not-resuscitate (DNR) order, but the family did not. When Pinderhughes arrived at Mrs. W.'s room, she was struck by how this tiny woman was connected to so much machinery, and she remembered that she did not even see her husband through all of this equipment until she went around to the other side of the bed.

Pinderhughes pulled up a chair, sat down, and introduced herself to Mr. W. and asked him what the best way of honoring his needs were regarding his communication style. For many Native Americans, talking directly about death and dying is taboo, but Mr. W. told Pinderhughes that he wanted her to be direct with him and give him the facts about what was occurring with his wife. First, though, she asked him to tell her

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[1] This section is based on the presentation by Stacie Pinderhughes, Director of Palliative Medicine at Banner-University Medical Center in Phoenix, Chair of the Division of Palliative Care at Banner Health, and Clinical Associate Professor of Internal Medicine at the University of Arizona, and the statements are not endorsed or verified by the National Academies of Sciences, Engineering, and Medicine.

about his wife. He said they had been married for more than 20 years and had many children, and she was an independent, vibrant, and easy-going woman who liked having pedicures and manicures. When asked about his faith and spirituality, Mr. W. said that his family believes in the creator, and when asked what he thought was happening to his wife, he paused for a moment and then said it looks like she is dying. After another quiet moment, he told Pinderhughes that his wife had been in another hospital's ICU 6 years earlier, connected to multiple machines, and the doctor then had told them she was probably going to die, just as they had now. He then said that when people die, they go out into the galaxy, past all the planets and the stars, to be with their ancestors in a place filled with peace and love, and 6 years ago, his wife told him that was where she was, and that when she looked back she saw the earth as a tiny insignificant speck. At the time, her family was holding a ceremony with the tribe's medicine man and he was blowing an eagle bone whistle, a sacred religious musical instrument used in ceremonies to call the spirits. Mrs. W. told her husband that when she heard the eagle bone whistle, she knew it was not her time to die and she described to him that she then moved rapidly past all of the galaxies and planets to Earth and her body. "That was a very powerful story," said Pinderhughes. "We were silent for a minute—you cannot fill that space up with words."

Pinderhughes then said to Mr. W. that it sounds like he needed to go back to the reservation, hold a ceremony for his wife, and blow the eagle bone whistle. Mr. W. agreed, and Pinderhughes told the ICU director what was going to happen and to continue providing critical care in the meantime. Much to its credit, said Pinderhughes, the ICU team supported that decision. A few days later, Pinderhughes was called down to the ICU because Mrs. W.'s room was full of people. When she arrived, she sat down with Mr. W., who told her that they had held the ceremony, blew the whistle, and his wife did not come back. At that moment, the family decided it was time to focus on comfort and dignity measures.

Pinderhughes shared that story because she believes that it illustrates how palliative medicine is a natural fit for health care literacy. "I think the key elements of palliative care service delivery creates an environment that allows health literacy to emerge," she said. "It is an intervention focused on aligning with patients around their goals and values and what matters most to them." The conceptual model that she follows, which comes from Diane Meier, is that palliative care is a dedicated team of professionals with different skill sets who spend the time and focus with patients and their family members to make decisions, have a clear picture of a patient's values, and then create a plan aligned around those values. The application of this model at Banner Health is done through the combined efforts of a large educational team and the palliative medicine team.

Banner Health, Pinderhughes explained, is a large health care system comprising 28 hospitals in seven states, including the recently acquired University of Arizona Health Network. The Banner Medical Group includes more than 2,500 physicians, and the Banner Health Network includes 19 graduate medical education resident and fellowship programs training more than 290 residents and fellows per year. Banner Health views its palliative care program as a systemwide program that operates across all of its facilities, with a high-level executive support and strong support from the organization's chief executive officer. The program works, she noted, as a dyad partnership with the medical directors of each facility. Banner Health's vision, added Pinderhughes, is to expand the program's involvement in inpatient care from 8 hospitals to 12 by 2016 and to expand into the ambulatory setting. Currently, the palliative care program has a home-based program and is creating two large ambulatory programs. It also has a new fellowship residency program that accepted its first two fellows in July 2015.

One area of emphasis going forward is to improve education of providers, and toward that end Banner Health has created a new palliative care clinical consensus group, joining the 22 other consensus groups in the system. These consensus groups, explained Pinderhughes, develop evidence-based clinical practices that affect patient care for the entire Banner Health system. She believes that by working collaboratively with the other 21 clinical consensus groups, the palliative care group will be able to affect health care literacy. Banner Health System Education team, through its patient education resource center, is creating standardized content, written at a fifth grade reading level and approved by a council of community members, that providers can use with their patients. The System Education team is also instructing providers on how to use these materials in conjunction with teach-back methods. Pinderhughes noted that all new registered nurse hires receive teach-back education and that clinical education teams engage all nursing staff with regard to teach-back methods. One result of involving every nurse in health literacy training is that health literacy now starts at a patient's admission and continues every day until a patient is discharged. "It is an integrated process to ensure that our patients are able to understand and process the information we give them, take it with them from the hospital, and then implement it when they are home and when they are in the community," said Pinderhughes. In closing, she said the palliative care program has prioritized equipping providers with the tools to deliver primary palliative care in a health literate manner.

A HOME-BASED PALLIATIVE CARE PROGRAM[2]

For the past year, Dana Lustbader and her colleagues have been creating ProHEALTH Care Support, a home-based palliative care in the New York market. From her experience over the past year of having conversations in the familiar environment of a patient's living room, with family members and the dog sitting on the couch, she has learned how different it is compared to having the same conversation in the ICU at midnight when everyone is exhausted and stressed. As an example, she told the story of Sarah, a 45-year-old with metastatic cancer, malignant ascites, and pain. Her care is comanaged with the oncology practice, and she still comes into the clinic weekly for intravenous chemotherapy. She also has 10 to 15 liters of abdominal ascites drained weekly, either by the palliative care team or by a home health agency nurse.

Lustbader explained that the ProHEALTH Care Support team is attempting to break down the silos that currently exist in Sarah's care. The team supports her during her visits to the oncology clinic and provides support to her family during home visits. For pain management, the team uses long-acting opioids combined with short-acting agents for breakthrough pain that Sarah experiences because her oncologist is not comfortable prescribing the high doses of opioids that she requires. They work collaboratively with the visiting nurse to comanage Sarah's care, such as when she needs additional fluid withdrawn at times when her abdomen is particularly distended. The ProHEALTH Care Support team provides 24-hour-per-day access to either a nurse or a doctor and conducts secure video virtual visits using telemedicine with the patient and her family members. In one instance, Lustbader conducted a virtual visit at night with Sarah and her son to evaluate a leg cellulitis. She prescribed oral antibiotics from a pharmacy that was able to deliver them to the house within 2 hours, protecting Sarah from having to go to the emergency room or urgent care center.

ProHEALTH also has a volunteer department with 15 individuals who do massage therapy, Reiki therapy, or just sit with patients and listen. Sarah, for example, gets Reiki therapy during her chemotherapy from one of the program's newest volunteers. The goal, said Lustbader, is to have a high-touch model of total care so patients get many touches, not just medical treatments. Her team, she explained, is doctor lean and nurse, volunteer, and social worker heavy.

With regard to advance care planning, ProHEALTH Care Support uses New York State's Medical Orders for Life Sustaining Treatment (MOLST)

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[2] This section is based on the presentation by Dana Lustbader, Clinical Professor Critical Care and Palliative Medicine at Hofstra North Shore–LIJ School of Medicine, Department Chair of Palliative Medicine at ProHEALTH Care Associates, and Medical Director of ProHEALTH Care Support, and the statements are not endorsed or verified by the Academies.

form to document DNR and do-not-hospitalize wishes that allow patients to receive end-of-life care at home. However, they leave all the other boxes on the form blank because they are too treatment specific, often leading to an ineffective serious illness conversation. The MOLST form is put in an envelope and taped to the refrigerator door. The MOLST form is not completed at the initial visit with a patient, unless it is appropriate. She noted that one of ProHEALTH Care Support's payers wanted every patient to have a signed MOLST form, but she argued against that as it is most useful for people with serious illness in the final year or so of life. "Everyone who died on our program had had a MOLST so they could have their wishes followed," said Lustbader.

Returning to Sarah's story, the things that are most important to her are to die at home, never go to the hospital again, and to attend her son's high school graduation, which she did. Lustbader said that ProHEALTH Care Support has been working with Sarah and her family for 9 months, and not once has she had to go to a hospital or emergency room.

As another example of how ProHEALTH Care Support uses telemedicine in home-based palliative care, Lustbader discussed the case of Mrs. M., a 77-year-old woman with multiple sclerosis who lives alone and is wheelchair bound. Mrs. M. fell and hit her leg on a radiator, went to the emergency department to have it sutured, and 6 weeks later called ProHEALTH Care Support at 10 p.m. when she developed a fever and was experiencing wound pain. Lustbader had a virtual visit with Mrs. M., and by 11 p.m. she had the appropriate antibiotics delivered to her home, with a follow-up home visit by a registered nurse 2 days later. As a result, Mrs. M. did not have to call 911 and did not have to go to the emergency room, which likely would have led to her being admitted to the hospital given her complex medical situation. "She had perfect care and everything was done within an hour," said Lustbader.

Many of ProHEALTH Care Support's patients have what she called "the dwindles," and do not have a hospice-certifiable diagnosis. In fact, if a person has a hospice-certifiable diagnosis, Lustbader or one of her team members has a phone conversation with the patient, reviews the extra layer of support provided by hospice, and recommends that they get hospice care at home. Typically, ProHEALTH Care Support's patients do not qualify for hospice because they have dementia, two or more chronic conditions, kidney disease, or heart failure (but not with an ejection fraction below 20 percent), or are still getting chemotherapy and other treatments. They have very poor functional status, said Lustbader, and most are homebound.

The ProHEALTH Care Support team comprises Lustbader and 1 other physician, a program coordinator, 5 registered nurses, a licensed clinical social worker, and 10 to 15 volunteers. The reason for the heavy emphasis on registered nurses is that financing is not on a fee-for-service basis but through a shared savings program with payers that delivers the care people want and need. "Our patients do not need a lot of medical intervention, prescriptions, or tests," explained Lustbader. "We are available when that is appropriate, and we leverage our technology to have physician expertise overseeing the registered nurses." She emphasized this is a patient- and family-centered, nurse-driven model of care.

She sees ProHEALTH Care Support's main job as one of treating people with serious or advanced illness at home and tending to the family caregiver. When she first joined the company 1 year ago, she added a caregiver assessment to the electronic medical record (EMR) that it uses because there was no place in the EMR to assess the 90-year-old wife taking care of the 95-year-old husband, she explained. The team works with the patient's other physicians or provides total care to the patient, particularly regarding expert pain and symptom management, and it helps patients and families with advance care planning and facilitates hospice enrollment when appropriate through skilled conversations about serious illness.

Each team, or pod, comprises 3 registered nurses, 1 social worker, and 1 physician working with approximately 200 patients, or 1 registered nurse per 70 to 90 patients. Lustbader explained that she goes to great lengths to select the right nurses, several of which are certified hospice nurses. "They love this sort of work," said Lustbader. ProHEALTH Care Support collaborates with local hospice and home health agencies, as well as with ProHEALTH Urgent Care and community paramedics. It makes heavy use of virtual visits to leverage physician expertise and provide around-the-clock availability.

As an example of the type of collaboration that ProHEALTH Care Support engages in, Lustbader discussed the case of a homebound patient with cellulitis in his legs. Instead of having to bring him into the hospital, his team arranged for him to be taken by ambulance to the interventional radiologist, who placed a peripherally inserted central catheter line for the administration of medication and sent him home. The ProHEALTH Care Support team was then able to administer intravenous antibiotics at the patient's home for 6 weeks. Lustbader noted their program has been garnering support from community paramedics who are interested in not bringing people who are terminally ill and would rather be at home to the hospital. Working with community paramedics, ProHEALTH Care Support has been able to develop a protocol for resuscitating, treating, and releasing patients in their homes. As an example, she recounted a case where an 87-year-old man with dementia, diarrhea, and dehydration called ProHEALTH Care Support at 9 p.m. because he was dizzy. In a virtual visit that included the responding paramedic, Lustbader was able to order 2 liters of intravenous saline, and by 11 p.m. the man was tucked safely in bed. She noted that it is often much safer to protect people from hospitalization, and keep them at home.

Currently ProHEALTH Care Support's parent organization, ProHEALTH Care Associates, sees 800,000 patients in the New York metropolitan area, including all of Long Island. She noted that there are no hospitals in this health system, just 32 urgent care centers, ambulatory surgery centers, 260 outpatient clinics, and ProHEALTH Care Support. She explained that ProHEALTH Care Support is targeting the 2 percent of patients that most concern payers in a Medicare Advantage risk-based payment world. The average spend of this top 2 percent is more than $109,000 per year per beneficiary, compared to an average beneficiary spend of $9,100 per year. "We are able to negotiate with payers for a per member per month rate to pay for home-based palliative care," said Lustbader. "We don't have to worry about billing because we are getting paid a fixed rate every month to cover this kind of care." Her program also has eight shared savings programs that will bring in revenues if it can deliver better care more efficiently as measured by reduced hospital admissions and emergency room visits and increased hospice use. In addition, ProHEALTH Care Support receives a small amount of revenue from the limited fee-for-service billing that exists for this type of home-based, high-touch care, though this fee comes nowhere close to covering the cost of the services provided.

Because ProHEALTH Care Support is in a Medicare shared savings accountable care organization (ACO), it is able to get raw claims data from Medicare. This enables it to find the sickest patients who can most benefit from the program. The results from its first 92 clients show that there was a 50 percent reduction in 90-day spend following enrollment in ProHEALTH Care Support, and a 19 percent reduction in emergency department visits postenrollment. In addition, 92 percent of the patients who died were able to die at home, rather than a hospital setting. "We are in a geographic area where dying at home is very unusual," said Lustbader. "To have a 92 percent at-home death rate is extremely good, and it is a result of our high-touch model. We normalize dying. We don't medicalize it."

Lustbader concluded her presentation by noting there are five elements to making a home-based palliative care program work well. It must be family- and patient-centered, and intervention dosing is key. Some patients, for example, are seen once per month, others three times per week. Some need a nurse, others a doctor, she explained. "We dose the intervention based on need, and since we are not a billing machine, we are not doing this in a fee-for-service model," said Lustbader. Providing around-the-clock coverage through phone consultation and virtual visits is important, and Lustbader said that most of the questions that come in late at night are appropriate. "We want to hear what family caregivers are worried about," she said, adding that her staff reviews all of the questions that come in overnight to see how they could do a better job preparing family members for what happened late the night before. The last key component is to form innovative partnerships. “We try to form new partnerships as we break down health care silos,” said Lustbader.

HELPING PATIENTS NAVIGATE DIFFICULT DECISIONS IN THE HOSPITAL[3]

San Francisco General Hospital and Trauma Center, the place where Anne Kinderman works, is a level I trauma center for the county that cares for anyone at any socioeconomic level in a serious accident. As a result, Kinderman, as a palliative care provider, sees people from the whole spectrum of San Francisco, and even the world, recalling some of the Asian patients she saw who were in an airplane that crashed at San Francisco International Airport. San Francisco General Hospital is also the safety net hospital for the city, providing 80 percent of all charity care in the city and treating a disproportionate number of uninsured and Medicaid patients, with minimal numbers of patients with commercial insurance. It is also the second most ethnically diverse U.S. medical center—in any given month, 140 languages are spoken on the campus.

A large proportion of the immigrants treated at San Francisco General have limited English proficiency, education, literacy, and contact with the medical system, and for many, the U.S. medical system is foreign in terms of how patients interact with health care providers and the way care is compensated. She and her colleagues also see a large number of socially isolated marginalized patients who suffer from mental illness and substance abuse, have limited social supports, are homeless or marginally housed, have limited coping strategies and contact with primary medical and mental health care, are more frequent users of emergency services, and have shortened life expectancies.

What is known about advance care planning in vulnerable patient populations such as these is that low health literacy is associated with less advance directive completion and less certainty about choices, even with targeted interventions, according to research conducted with patients in San Francisco General’s general medicine clinic (Sudore and Schillinger, 2009; Sudore et al., 2010). Latinos and Asians in particular are less certain than Caucasians in choosing their wishes in advance (Waite et al., 2013).

Too often, said Kinderman, providers have the discussion about what patients want at a time when their conditions worsen acutely. The problem is, that is a time when information becomes harder to process and patients

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[3] This section is based on the presentation by Anne Kinderman, Director of the Supportive and Palliative Care Service at San Francisco General Hospital and Assistant Clinical Professor of Medicine at the University of California, San Francisco, and the statements are not endorsed or verified by the Academies.

may have a limited understanding of the implications of the choices they are making in the acute setting and at a time when providers are asking for life-and-death decisions with urgency. "This is a tough situation for anyone, but particularly for those who are starting with low health literacy," said Kinderman.

When seriously ill patients are hospitalized, they experience a culture that is foreign to most people. "We as medical providers forget how foreign the hospital culture is to normal people," said Kinderman. This is particularly true, she added, for the population of patients she sees at San Francisco General. Almost weekly she hears from one of her Chinese American patients that she is taking too much blood, referring to the morning blood draw for laboratory tests. Patients whose primary coping strategy outside of the hospital is to chain smoke suddenly has a nicotine patch instead, in addition to a horrific diagnosis, and all they want to do is go outside for a smoke. In addition, people in the hospital are often disconnected from primary care and other trusted providers in the community, and they face multiple communication barriers, often because of language barriers. Kinderman noted that the check-in desk at the radiology department has a sign in multiple languages informing patients of their right to have an interpreter present, but the type on the sign is so small that it is unreadable even at a distance of 2 feet.

Other factors that cause confusion in the hospital setting arise from the way physicians interact with patients. Too often, as other speakers have noted, physicians present too much information and they use too much jargon. Patients can be overwhelmed, too, by information from multiple providers, some of which may conflict with the information they get from other sources. Conversations with providers often focus on treatment decisions rather than values, and then when the end of life is near, providers turn over responsibility for decision making to the patient or a surrogate under the guise of helping patients be autonomous and in control of their lives.

These factors combine to produce a great deal of conflict, said Kinderman. From the provider's perspective, the patient who has low health literacy and is facing life-and-death decisions may come across as quiet or disengaged, ambivalent or confused about their choices because they cannot recall the information dumped on them at an earlier encounter. Rather than dragging their feet about completing advance directives, patients may merely be overwhelmed. From the patient perspective, providers can come across as impatient or applying pressure about different decisions. Providers may seem redundant, repeating the same information again and again, and uncomfortable dealing with patients.

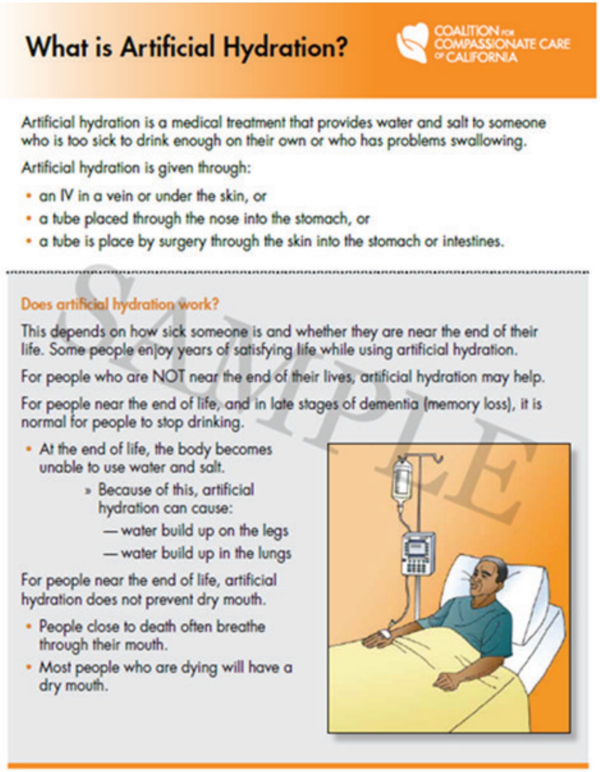
Addressing health literacy in the hospital, said Kinderman, entails a number of communication techniques that optimize conditions and provide support for decision making and advance care planning. With patients of limited English proficiency, it is imperative to have a professional translator present at the time of a discussion and to pay attention to the vocabulary the patient uses. The interpreter can help with this assessment. It is important to address the impact of culture and beliefs on decision making and care preferences, and to empathize and validate a patient's concern rather than being antagonistic about it. It is also important to address communication barriers that patients face when voicing their needs in the hospital. As an example, Kinderman cited the case of a Cantonese-speaking woman who does not speak English and is in pain. How does she communicate that she needs pain medication if there is no interpreter on the floor then?

Reiterating what previous speakers had said, it is important in verbal communication to present information in small amounts, check regularly for understanding, avoid jargon and euphemisms, organize provider input so it is consistent and does not cause confusion, and keep patient values in mind. Presenting information in written form can improve communications. Pictures and diagrams can be helpful, but any written material should be available in multiple languages (see Figure 6-1). Patients also need time to review any materials or to have an interpreter read them and review them with the patient.

It is important, said Kinderman, to optimize cognition. Reviewing medications can help make sure patients are not disoriented because of the medication side effects. Ensuring patients have their glasses and hearing aids available is essential when presenting important information, and it can be helpful to have families present but to also control the conversation so people are not talking over one another. Optimizing the patient's environment by getting the patient on a normal day-and-night schedule can also help improve comprehension.

To support decision making and advance care planning, Kinderman recommended involving surrogates, family members, and other caregivers, as well as trusted providers. It is common, she said, for her socially marginalized patients to bring case managers or other trusted community members to appointments. Also, given how uncertain her patients are about completing advance directives, it has proven important to assess the patients' interests and let them have their way on those, even if they will never fill out an advance directive or a Physician's Orders for Life-Sustaining Treatment (POLST). She did refer, though, to the California Advance Health Directive developed for patients with low health literacy (see Figure 6-2).

Kinderman concluded her presentation talking about some of the quality improvement initiatives at San Francisco General Hospital. One such effort has focused on providing information to family members about what happens after a patient dies, and to help answer the many questions families have at that moment, the hospital developed a brochure, avail-



What is Artificial Hydration?

COALITION FOR COMPASSIONATE CARE OF CALIFORNIA

Artificial hydration is a medical treatment that provides water and salt to someone who is too sick to drink enough on their own or who has problems swallowing.

Artificial hydration is given through:

- an IV in a vein or under the skin, or
- a tube placed through the nose into the stomach, or
- a tube is place by surgery through the skin into the stomach or intestines.

Does artificial hydration work?

This depends on how sick someone is and whether they are near the end of their life. Some people enjoy years of satisfying life while using artificial hydration.

For people who are NOT near the end of their lives, artificial hydration may help.

For people near the end of life, and in late stages of dementia (memory loss), it is normal for people to stop drinking.

- At the end of life, the body becomes unable to use water and salt.
  - Because of this, artificial hydration can cause:
    - —water build up on the legs
    - —water build up in the lungs

For people near the end of life, artificial hydration does not prevent dry mouth.

- People close to death often breathe through their mouth.
- Most people who are dying will have a dry mouth.

什麼是呼吸器?
What is a Ventilator?

COALITION FOR COMPASSIONATE CARE OF CALIFORNIA

呼吸器是幫助您呼吸的一個機器。它可以幫助因重病而無法自行呼吸的病人或需要長期呼吸輔助的病人來呼吸。

- 呼吸器並不能治癒或治療肺部的問題。
- 當醫生嘗試治療呼吸方面的問題時，會使用呼吸器。

呼吸器又可稱為機械通氣。

使用呼吸器時會是什麼樣的情形？
What is it like to be on a ventilator?

- 有一根管子會從口腔插進氣管（氣管插管）。
- 機器會經由管子，將空氣強制打入肺部。
- 為了減輕病人的不舒適，一般會給予藥物使病人昏睡。
- 病人通常是不清醒的，也不能講話或吃東西。

幾天後：

- 醫生會把使病人昏睡的藥量減低，以測試病人是否可以自行呼吸。
- 如果可以自行呼吸，就會拔除氣管插管。

幾個星期後：

- 醫生可能需要在氣管上做個切口，放入管子。這個過程叫做氣管造口術。
- 病人也許需要住進護理之家不然就需要特別的住家護理。

對於將呼吸管經由口腔插入，病人是怎麼感覺呢？
What do people say a ventilator feels like when a breathing tube is placed through their mouth?

當呼吸管穿過喉嚨時，有些人一直是昏睡的，並不記得曾經用過呼吸器。
但是，有些清醒的人可能感覺：

- 一切都好。
- 因插管或強制將空氣打入肺裡所造成的疼痛。
- 害怕，感覺被困住。
- 有吞嚥或咳嗽的問題。

FIGURE 6-1 Two examples of health literate, written information available at San Francisco General Hospital.
SOURCE: Presented by Anne Kinderman on July 9, 2015.

California Advance Health Care Directive

This form lets you have a say about how you want to be treated if you get very sick.

● This form has 3 parts. It lets you:

Part 1: **Choose a health care agent.**

A health care agent is a person who can make medical decisions for you if you are too sick to make them yourself.

Part 2: **Make your own health care choices.**

This form lets you choose the kind of health care you want.

This way, those who care for you will not have to guess what you want if you are too sick to tell them yourself.

Part 3: **Sign the form.**

It must be signed before it can be used.

You can fill out Part 1, Part 2, or both.
Fill out only the parts you want.
Always sign the form in Part 3.

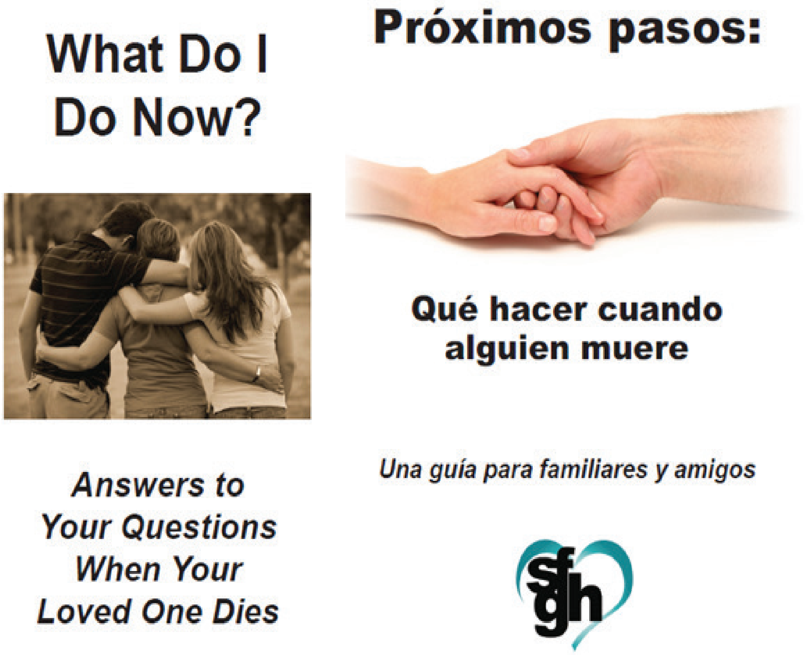
Go to the next page

1

FIGURE 6-2 Instructions for California's low health literacy advance directive form.
SOURCE: Presented by Anne Kinderman on July 9, 2015.

able in Chinese, English, and Spanish, that is handed out immediately after a patient dies (see Figure 6-3). Another project developed cue cards with words and pictures that communicate basic needs and concerns for patients with limited English proficiency (see Figure 6-4). Kinderman, collaborating with colleague Alicia Fernandez, also developed a curriculum for interpreters in palliative care that is designed to help professional health care interpreters negotiate these difficult conversations among patients, families, and health care providers. The materials for this 8-hour training course are available free at www.chcf.org/interpreting. On-demand access to the curriculum for individual interpreters is available for a small fee at learn.hcin.org.

Kinderman said she has learned several lessons from her work at San Francisco General. "We expect a great deal from our patients in navigating



What Do I
Do Now?

Answers to
Your Questions
When Your
Loved One Dies

Próximos pasos:

Qué hacer cuando
alguien muere

Una guía para familiares y amigos

sfgh

FIGURE 6-3 Brochure for family members of patients who have died.
SOURCE: Presented by Anne Kinderman on July 9, 2015.

the health care system, so pacing of how we share information is critical," she said. It is important, too, to consider the patient's emotional readiness to receive information, to adapt communication styles and materials to accommodate the ability of patients to understand and assimilate medical information, and to bring in allies from both the patient and provider side to help with the task of communicating with patients of low health literacy.

A FAITH-BASED MOVEMENT TO TRANSFORM HEALTH DISPARITIES[4]

Tyrone Pitts began the workshop's final presentation with the story of a man who insisted he was ill. After many years, he went to his family and

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[4] This section is based on the presentation by Reverend Tyrone Pitts, co-chair of the Interfaith and Diversity Workgroup at the Coalition to Transform Advanced Care, Ecumenical Officer and General Secretary Emeritus of the Progressive National Baptist Convention, and President and Chief Executive Officer of Bridges International LLC, and the statements are not endorsed or verified by the Academies.

Patient Language Board
SPANISH

I am in pain. My pain level is
0 1 2 3 4 5 6 7 8 9 10
(0 is no pain and 10 is the worse pain in my life.)

Yo tengo dolor. Mi nivel de dolor es
0 1 2 3 4 5 6 7 8 9 10
(0 no hay dolor 10 es el peor dolor en mi vida.)

I feel nauseous.

Yo siento nauseas.

I need to use the bathroom.

Yo necesito usar el bano.

I am thirsty.

Yo tengo sed.

I am hungry.

Yo tengo hambre.

I want to speak to my doctor.

Yo deseo hablar con mi doctor.

Please call an interpreter.

Por favor llame a un interpreter.

Please call/tell my family.

Por favor llame y digale ha mi familia.

FIGURE 6-4 Cue cards for patients with limited English proficiency.
SOURCE: Presented by Anne Kinderman on July 9, 2015.

his family decided he should see a doctor, and they made an appointment for him. He had a physical examination and was found to be in perfect health. Several years later, he died, but before he died he had his tombstone engraved to read, “I told you I was sick.” This story, said Pitts, highlights the reality that individuals who deal with issues of palliative care and advance directive face. This man insisted that he was sick, but his family did not believe him. He experienced symptoms that his caregivers, those who loved him most, dismissed, perhaps because they thought he was a hypochondriac or because they thought he was suffering from Alzheimer’s or some other mental disorder. There also was a gap between the symptoms he experienced, the tests that were administered, and the diagnosis provided by his doctors. Perhaps he was poor and did not have adequate health insurance, or perhaps there was a gap in his communication system where he communicated or did not communicate his symptoms adequately, which is often the case with people whose first language is not English and low-income individuals who do not speak the same medical language as their health providers. This story also provides an example of a person of faith who was determined to have the last word, Pitts added, noting the message he had carved on his tombstone. "It highlights the need for trust between person, his family, and health professionals, and illustrates the complexity of communication with people with advanced illness," said Pitts.

Noting that people often do not receive the care they want and need during advanced illness, Pitts cited the Institute of Medicine report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (IOM, 2014, p. 40) to point out what is needed to close this gap:

> Broad engagement of actors in the health care field, social and supporting services sector, as well as the organizations and institutions on which Americans rely for practical assistance, spiritual support, information, and advice.

The Coalition to Transform Advanced Care (C-TAC) was formed to close the gap between what people want and what they get in advanced illness. C-TAC's vision, explained Pitts, is that all Americans with advanced illness, especially the sickest and most vulnerable, receive comprehensive, high-quality, person- and family-centered care that is consistent with their goals and values and honors their dignity. Powering that vision are more than 120 organizations and leaders who work to empower consumers, change the health care delivery system, improve public and private policies, and enhance provider capacity. He noted when he joined C-TAC 4 years ago, he thought its mission was crazy. "The audacity of a group of individuals saying that they were going to transform advance care in U.S. society is unheard of," said Pitts. "And yet after being at C-TAC for 4 years, it has become clear that there is a movement afoot unlike any other movement in this nation. A cultural change is happening where individuals and groups of networks across this country are coming together to deal with this issue of palliative care and hospice and advanced care." This effort, he added, is built on one simple word: trust.

One of the challenges the medical profession faces is how to deal with diversity and race and how to help the most vulnerable members of society. In the African American community, trust of the medical community has been a problem for years because of a history of inappropriate actions, such as the Tuskegee experiments. Pitts then cited something that Albert Einstein said, which is that no problem can be solved from the same level of consciousness that created the problem. Einstein is also noted for defining insanity as "doing the same thing the same way, again and again, and expecting different results." C-TAC, he explained, is focusing on building bridges and making connections where none now exist.

One thing that C-TAC has found in faith communities is that clergy, imams, rabbis, and other people of faith are the connecting links between people who suffer from serious illness and palliative care, hospice, and advanced care. "It is the clergy and faith leaders who encourage them to seek these avenues of care," said Pitts. Fewer Americans are going to church, he noted, but whenever they have a crisis or are sick, they call their religious leaders.

A series of listening sessions that C-TAC held in 2014 with community members, caregivers, and members of the clinical community identified a key question: Even if you have a seat at the table, do you have a say in the care for your community as part of the health system? The problem, said Pitts, is that there are many people who have seats at the table, but they do not have a voice at the table and they are not empowered to participate at the table. High-level findings from the listening sessions included

- There are latent, underused resources that are not well linked between communities and providers.
- Systematic linkages that integrate clinical and community models would yield outcomes aligned with patient goals, such as reducing unwanted hospitalizations.
- American Africans identified their faith-based organization (FBO) as a trusted resource.
- FBOs need training and partners to serve as a link between the health system and the community.

In response to the messages heard in the listening sessions, C-TAC launched a Community Action Project with health systems and community organizations around the country, including pilot projects in Alameda County in California, Detroit, the District of Columbia, and Rhode Island. Each of these pilot projects, explained Pitts, is bringing together health plans, health organizations, and community members, including clergy and other navigators, with the objectives of fostering partnerships between health systems and faith community organizations to fill critical gaps in care delivery, give each partner tools and knowledge, and help extend existing advanced illness management programs to reach underserved people.

So far, said Pitts, six practical insights have come from these pilots:

1. Advanced illness is already a priority in churches, and every church that was engaged in a pilot program had an intricate network of

individuals working on this issue. The challenge is connecting these networks with the health system and health plans in a way that is collaborative and respects the community.

2. Language is important; clergy refers to patients and persons, and talk about healing instead of curing, the vulnerable instead of the sickest of the sick, the beginning of life instead of the end of life. These are not just Christian, Buddhist, Muslim, or traditional African concepts but universal to all humanity.
3. It is about the money, but it is not about the money, meaning that there is a need for financial support, but people in these communities are perishing for lack of basic aid and services.
4. Like health systems, churches and communities have their own systems, so it is important to engage the community, not just one partner or one church, and to understand the dynamics of the entities within the community.
5. This is an intergenerational issue, where grandparents are caring for grandchildren and vice versa.
6. Ultimately, shared decision making is based on the South African principle of Ubuntu, or the interconnectivity that says "I am because community is, and community is because I am part of the community."

Historically, said Pitts, health and healing went together for places of worship, and the opportunity exists to rekindle that connection to the benefit of the most vulnerable in society. He ended his presentation with the comment that this is not a financial issue, but one of capacity and working together. The problem, he said, lies in the disconnection between what faith communities are doing and what health care systems are doing. "No one can do this on their own," said Pitts. "The good thing is, no one has to."

DISCUSSION

Grant asked Pinderhughes to elaborate on what she meant when she used the expression *teach-back*. Pinderhughes replied that teach-back is a procedure used to engage patients around their understanding of their conditions. It involves asking them to recount what they heard regarding instructions for their care once they leave the hospital or clinic. One approach is to ask patients how they would explain to family members how they are supposed to take their medications. "It is about engaging patients daily through the course of their hospitalization so when they leave they demonstrate a true understanding of the consequences of not taking the medication or not participating in a particular treatment and being able to describe that to others," explained Pinderhughes. Grant commented that having the patient give information back in a different context instead of just repeating it verbatim was a good approach.

Noting the importance of community voice and participation that Pitts highlighted, Winston Wong asked the panelists how their institutions actively engage community in discussions of how advance care needs to change. Lustbader replied that because her program is not affiliated with a hospital, she and her colleagues have even more incentive to go into the community and bring in community volunteers, massage therapists, and Reiki therapists. They have also begun meeting with local church groups and temples and conducting workshops with the Bikur Cholim, the Jewish organization that visits sick people in the hospital, to give them ideas on how they can help those with chronic conditions who receive care at home. "We are starting to try to give these community groups more ideas of how they could be helpful, because I believe many of them would like to be helpful, they just don't know how," said Lustbader. She noted that she and her colleagues have had good success over the past 6 months engaging the temples on Long Island to rally around the critically ill in their communities, Jewish or not.

Pinderhughes said that Banner Health has just started working with various community organizations, particularly senior centers that already have connections with and provide services to the elderly who need help. Kinderman admitted that San Francisco General currently does a terrible job of involving patients in planning. "It is more convenient and easier for us to come up with a solution and then impose it on people," she said. "It does not work well, particularly when talking about advance care planning. The best example of engaging the community, she said, was the community-wide task force on palliative care that was created in the summer of 2014. The task force was broad based, she noted, and the majority of its members were representatives from community organizations, with some representatives from palliative care providers and hospitals.

Pitts described two models for community involvement that he believes have been successful. In what he called the Tennessee model, hospitals have brought in navigators from churches to serve as the link to their communities. The C-TAC model starts in the community, where there is disjointed expertise, and brings in the hospitals to provide help in how to be organized and use that expertise most effectively. In Oakland, for example, the community and Kaiser Permanente have become equal partners in the process of changing how palliative care is provided, with the University of California, Davis, now conducting an evaluation of this program. Pitts explained that the Oakland project was designed to build a relationship between the clinical community and the larger community, and it started with one pharmacist and one surgeon getting involved with the community.

Cindy Brach said that one of the struggles in delivering the right care at the right time and the right place is developing a payment system that rewards those providing services. Traditionally, she said, money has not followed the individual through the system of care but instead it has stayed in the emergency department or the hospital. She asked Pinderhughes and Lustbader if they are beginning to show that the services they provide are producing savings that offset the costs of those services, and if they had ideas on how she and her colleagues at the Agency for Healthcare Research and Quality might think about measures of quality for those services given that there is the unfortunate financial incentive to stint on care or engage in gate keeping to reduce financial risk.

Lustbader replied that ProHEALTH Care Associates has relations with payers to deliver home-based palliative care for a per member per month rate and that there are several metrics they must meet, including admissions per thousand members. For that metric, Lustbader looks at preventing avoidable hospital admissions because most of the family members do not want to go to the emergency department in the middle of the night with their 87-year-old parent or spouse. She noted that admissions per thousand members is both a quality and cost metric. A second metric is location of death in the patient's preferred location, which is most often at home. ProHEALTH Care Associates meets that goal more than 90 percent of the time, she said. Lustbader noted that ProHEALTH Care Associates is developing a first-of-its-kind survey that will enable the patients in its program to rate how well they are doing on pain and symptom management and quality of life, and give caregivers the opportunity to weigh in on the burdens they face and any surprises they encountered.

As she noted in her presentation, Lustbader was able to convince payers to not use a metric for MOLST completion because it is not a good metric for the population her organization serves. "We took that metric out because we are at the table and we have a voice," said Lustbader. "It is important the people in this room are sitting at the table as the metrics for these arrangements are outlined because we are the ones doing the work and know what to measure." As an example, one payer in a shared savings program wanted to include a metric that everyone discharged from a hospital has a follow-up appointment at the doctor's office within 30 days. She argued successfully that if a patient has a bone fracture that the orthopedist has repaired, there is little value in having that patient return to the primary care physician in 30 days. A better metric in that case might be that a medically complex person who is discharged should receive a follow-up phone call within 72 hours and touch therapy within 7 days.

Pinderhughes said that Banner Health is still trying to work out payment arrangements and metrics for its home-based program. For the patients who are members of the Banner Health Network, her service has negotiated a per member per month rate. For metrics, she and her colleagues are looking at completion rates for advance care directives, symptoms in opioid and bowel regimens, satisfaction scores, and the percentage of patients that transition into hospice and how long they stay on hospice.

Michael Paasche-Orlow asked if health ministries—a recognized team of people who sponsor regular educational events and experiences that promote well-being—can serve as a vector for health literacy work in the palliative care and advance care areas. Pitts said that most faith-based groups have health care ministries and that C-TAC's model involves, in part, connecting those ministries to the larger health care system. He noted that different faiths have different models for how those health ministries work with the community and the health care system. African American churches, for example, work in hospitals and with individuals who are homebound. Churches that belong to the National Council of Churches have very structured health ministries that belong to a national health ministry network, said Pitts, and the Jewish community has its own unique system for dealing with palliative and hospice care. However, Pitts added, health ministries in other interfaith groups, such as the Bahá'í and African traditional religious groups, are not well connected to the larger community.

Richard Freeman said the challenge is twofold. In his tradition, there is the story of the Good Samaritan, and while the members of his congregation may act like the Good Samaritan, they forget the part about being transformers so the Jericho Road ceases to exist. The Jewish community, he said, has access and the power to make transformational changes more immediately that many of the congregations he works with on matters of social justice lack. What has to happen, he said, is all communities of faith must take an active role in first handling the crisis and then be transformative, which goes right to the heart of the literacy conversation.

Grant noted that in her work as a palliative care nurse practitioner, she has had many amazing experiences in which clergy addressed health literacy issues. In one case, she had a meeting with an African American family that was having a hard time making a decision about whether to provide total parenteral nutrition (TPN) to their loved one, which is an emotional and value-based conversation. The pastor spoke to the family about their church's tradition of fasting, something Grant said she would have never thought of, and in that context the family was able to come to a better understanding of what would be appropriate in this case. In another example, a pastor to an uneducated family from Appalachia served as a translator of sorts, explaining technical words and concepts in a way that they could understand and believe because he was so trusted. She said she often asks families if they are part of a faith-based community because in many cases, clergy have a credibility and relationship that health care providers will never have with their patients. "When you are talking about discussing life-and-death advance directive decisions, we are the wrong people to have that conversation," said Grant. "If you are a person of faith, you have a community that has a point of view on those subjects, and that is the group that is most appropriate to at least consult."

Ernestine Willis from the Medical College of Wisconsin asked Pitts if he had any thoughts on how to overcome the distrust of the medical system that exists in many underresourced communities, including communities of color and many rural communities. Addressing that mistrust, said Pitts, is one of the major areas of focus for C-TAC, and the organization is tackling it in several ways. One is to develop relationships, a critically important step that explains why Ubuntu is so important to C-TAC's efforts. He recounted a story of when C-TAC first started working in Alameda County that illustrated the importance of building relationships. A foundation challenged C-TAC to hold a meeting of clergy and they set up the meeting by opening the Yellow Pages and calling all of the churches listed there. Nobody showed up for the meeting. The people who started C-TAC's pilot instead began working with those in the community that they knew and with whom there was already a relationship and trust and from there built a network that extended throughout the community. They also brought in health partners that had already built trusted relationships with the community, and because there was a shared trust with C-TAC as the bridge, these two groups began to have a dialog and the Alameda County Community Action Project was born.

One of the lessons this program learned regarding trust was that some of the health care organizations in the county were including pastors at the table but only allowing them to make general comments. "They were not included in these institutions' decision-making process," said Pitts. Another observation was that there were people in the institutions who did not look like those they were servicing, and so C-TAC has begun to talk about diversity within the institutional structures that are ministering to people. "The health profession is not a service, it is a ministry," said Pitts, and in that regard, health care institutions need to begin a dialog with clergy and others in the community to talk about issues of language, health literacy, and need, and to build programs that are beneficial to all. In the long run, he added, this will save money and it will save lives. "The reality is if you have fewer people going to the emergency department and better services and more community support that leads to community transformation, what you are doing is not only saving money but saving lives," said Pitts.

Commenting as an African American clinician, Pinderhughes said, "We talk about the mistrust patients have, but in reality the system has been inherently untrustworthy to these individuals for years. There is a history of systemic inequality and lack of access to care that is not a problem of the African American patient or the Latino patient. It is a problem of institutional racism in America." In her opinion, clinicians need to acknowledge what she called the elephant in the room—the inequity that exits, the lack of fairness, the lack of trust—and then go forward. "I cannot fix what has happened, but I can fix what is happening now. I can partner with patients and align around where their values are," she said.

As a closing comment to the discussion, Freeman applauded Pinderhughes's personal approach to addressing inequities and then asked his white colleagues to challenge themselves to address implicit bias, to ask themselves to think about the baggage they bring to the table. "Do I see every African American patient as disadvantaged?" he said. "Let's ask those questions and be honest with our answers."

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Reflections on the Workshop

To end the workshop, Bernard Rosof asked the Roundtable members for their reflections on the main points they heard during the workshop. Michael Villaire from the Institute for Healthcare Advancement remarked that the health literacy component of the day's discussions was not as robust as he would have liked, which he thought was a result of the large chasm that exists today between palliative care and health literacy and the many steps that will have to be taken to marry these two fields. The first step, he said, is to increase awareness of palliative care and what it is. "Before you can understand it, you have to know that it exists," said Villaire. Another step has to be overcoming what he called "the odd culture around death in this country" that makes it such a difficult subject to broach. Another challenge arises from the number of people who have never had health care that now have coverage under the Affordable Care Act and who are even further behind in terms of health literacy and understanding what palliative care is. There also is the issue of access to palliative care and addressing the social justice component of palliative care, he added.

In contrast to Villaire, Cindy Brach was not troubled by the fact that many of the speakers did not use the words *health literacy* in their presentations. To her, the presentations and discussion spoke to the part of health literacy that has to do with reducing demands on patients around navigating the health care system and coordinating care, as well as with addressing the matter of comprehension under difficult circumstances. "The model of care that we imagine for people with advanced illness is a health literate model," she said. Brach then noted that her agency, the Agency for

Healthcare Research and Quality, works on error reporting and patient safety, and to her the difficulties that Beverly Alves recounted—the failure of the do-not-resuscitate order to be in the system, the delays in getting medications at the hospital, the need to continually renew the prescription for pain medication—are errors that should be collected and recorded and counted as failures in the effort to create a culture of safety in the nation's health care organizations. In her opinion, part of the culture shift that needs to occur is to embrace these kinds of errors and work to correct and prevent them. Brach also said she agreed with Robert Arnold's view that palliative care should not be a distinct concept, that it is really about good health care quality.

Margaret Loveland emphasized the need for training physicians in the art of communicating about end-of-life issues with patients and families, given how hard they are to have at times of crisis. Part of that training, she added, should include how to work as part of a health care team, and another component should emphasize the need to acknowledge that patients have a spiritual life. Winston Wong said that he believes that the roles of language and culture are most accentuated at the sentinel moments of life, such as birth, marriage, and death. "I think all the aspects around how to communicate effectively become distilled at those critical moments," said Wong.

He also noted that there is a political component that needs to be acknowledged regarding discussions about palliative care, as illustrated by the opportunistic use of the term *death panels* several years ago to sway public opinion. "There is a point where we have to make sure that people throughout our communities really understand the nature of these conversations and that there is no deviant way to frame these discussions," said Wong. "If we agree on what the nature of those discussions are, we will have made a contribution toward improving health and medicine, and dying and living, for people throughout our communities." Wilma Alvarado-Little agreed with that statement and the importance of recognizing the political component of discussions about palliative care.

Marin Allen from the Office of the Director of the National Institutes of Health voiced her concern that health literacy is thought of as a tactic mentioned along with education, rather than an integral part of the interaction between patient and the health care team, and that treating it as such will not provide the necessary cross-pollination across medical fields. She then added two footnotes. The first concerned the use of interpreters for deaf individuals and their need to be comfortable interpreting medical information for the patient. "It is really the patient that needs to be comfortable with the reputation and language use of the interpreter in deaf settings," explained Allen. Alvarado-Little, who occasionally serves as a spoken language interpreter, added that much of the information given to patients and family members is highly nuanced and that cultural issues play an important role at the intersection of health literacy and palliative care.

Allen's second footnote was on the use of teach-back. She recommended the work of Dean Schillinger at the University of California, San Francisco, who has developed a system that is easy for physicians to use based on the larger communication strategy of feedback (Schenker et al., 2011). In response to a comment from Rosof, Allen said that using the word *person* instead of *patient* was a good idea.

Terri Ann Parnell from Health Literacy Partners remarked that the presentations far exceeded her expectations, and she thought incorporating the thoughts of both the family and the spiritual community broadens the spectrum of the Roundtable's work. One of the strong points for her was the value of having health care providers taking time for self-reflection and looking for unconscious bias that enters into conversations with patients. Robert Logan from the National Library of Medicine noted that several of the presentations argued convincingly that home visitation and community settings provide enormous opportunities to deliver and assess health literacy interventions. He also was impressed with the work showing how home visitation affects health and wellness, quality of life, and health outcomes. From her perspective as a nurse scientist who does informatics research, Suzanne Bakken from Columbia University commented on the gaps that exist in the technological support that could help with clinical decision making and helping consumers better understand the decisions they face.

Alicia Fernandez from San Francisco General Hospital and the University of California, San Francisco, commended the speakers and said she valued the many examples of successful programs that were presented at the workshop. At the same time, she was struck by how poorly prepared the field is to grapple with the increasing fragmented system of care for chronic disease that exists today and the fact that the burden for care is shifting even further to patients and caretakers. Fernandez then made three small comments about unintended consequences. The first was that while palliative care undoubtedly improves care for individual patients, it may at the same time lessen the involvement of the physician in care for those patients. A second unintended consequence results from the fact that once a patient is referred to hospice, insurance will not pay for the patient to go back to the hospital. Perhaps this restriction will be removed as the system begins paying for palliative services instead of hospice, she said. The third unintended consequence is the increasing burden that palliative care can place on caretakers with low health literacy.

The message that Kim Parson from Humana's Innovation Center got from the workshop is the need to remember that this is about the patient's and family's journey, not that of the health care provider, and how important it is to understand where patients are in their journey. This is particularly true, she said, for patients with chronic diseases and multiple conditions that they may have been dealing with for years. She also commented that cost transparency is an important issue for many patients because they worry about the cost of care and the burden that might place on their families and caregivers. Ruth Parker agreed that cost transparency was important. Indeed, she said that there is a wonderful opportunity to think about how to include discussions of cost in the conversation about palliative care, both in terms of how to have that conversation with caregivers as it relates to making choices about care options and with regard to health care costs in the United States.

Laurie Myers from Merck & Co., Inc., noted the importance of recognizing that everyone, regardless of their level of health literacy, knows everything they need to know about their goals and values. The responsibility for getting that information and using it to inform shared decision making rests solely with the health care system. She also commented on the importance of making sure that patients or family members not only have a seat at the table but a voice at the table in team meetings, and that the table should also have a place for pharmacists and medical assistants. Myers seconded the idea that all doctors, nurses, pharmacists, and medical assistants should be trained to use the same language, which she thought could help decrease stress and anxiety among patients and caregivers, and also voiced support for not only talking about pain medications but also antianxiety medications. One question that she had was how to handle family members who think their loved one is giving up when the patient comes to understand and accept that additional treatment does not make sense.

Terry Davis from the Louisiana State University Health Sciences Center in Shreveport wondered how patients get a consistent message when so many people are involved in their care, including all of the members of their families, their faith communities, and their social networks. "Are we talking to each other? Are we using the same language" Are we giving conflicting information?" asked Davis. Though the goal is to put the patient at the center of care, the medical system does not always give them the power to be the team leader and determine who gives them information and how they receive it, which she thought would leave them feeling alone and overwhelmed. Rosof noted a book by retired General Stanley McChrystal, *Team of Teams* (McChrystal et al., 2015), deals with this issue of team leader in a thoughtful, interesting manner.

Christopher Dezii from Bristol-Myers Squibb emphasized the need for accountability, to follow through on all of the points that the speakers and discussion raised so palliative care is at the table when discussing how to create a patient-centered experience and develop performance and quality measures. He suspected, for example, that the health care institutions that Alves dealt with overall had high-quality grades, which suggests that the current measures of quality are unacceptable. "Are we okay with quality as it is, or is the present situation unacceptable?" asked Dezii. "If it is unacceptable, then we have to set up the parameters to reflect that."

Michael Paasche-Orlow commented how the topic of palliative care exposes the cultural struggle that exists between those in health care who care about communication and those who are at war against death. He also remarked how political this topic is, how many social justice issues are at stake, and how complex it is. "I think that is one of the reasons this is such a great topic for the Roundtable on Health Literacy is because it is quite complicated for patients and families, and we can help improve that situation," said Paasche-Orlow. He also noted the lack of data about palliative care and in the end-of-life space in general.

Lindsey Robinson, a full-time pediatric dentist, appreciated the personal stories and the input of the spiritual counselors. "Their voice reminds us that at the end of the day we are tending to the broken hearts of human beings." She then commented on Diane Meier's idea that integrative palliative care is about creating a medical counterculture given that the current system is not set up to work in a collaborative or integrated way. This is particularly true, she said, of dentistry, which worked hard historically to stay out of Medicare and remain separate from the health care system in general. Dentistry, however, is slowly realizing the fault of that "do our own thing" philosophy, and the fact that the American Dental Association has funded her seat on the Roundtable shows the commitment of the dental community to participating in culture change. She noted that oral health plays a large part in overall health, particularly when it comes to chemotherapy, which can produce severe oral health impacts, and she looks forward to identifying opportunities for the dental community to work in this space.

What struck Jennifer Dillaha is the great dysfunction that exists in the health care system, which made her wonder whether the development of palliative care as a discipline is really a response to the low health literacy of the health care system. "It seems that it is a way to shepherd people with advanced illness through the end of their life because the system's health literacy is so low," she said. Catina O'Leary from Health Literacy Missouri commented on how the issues presented at this workshop were more deeply personal, political, and oriented to social justice than is usually the case, and she commended the organizing committee for putting this program together. In particular, she was excited by Richard Freeman's message of how important it is for this group to use its voice to drive change so everyone has access to appropriate care, and by the involvement of community members beyond just those with academic credentials who usually participate in National Academies of Sciences, Engineering, and Medicine roundtables.

Steven Rush thanked everyone who presented and who organized this workshop. In particular, he appreciated the focus on provider issues as opposed to patient deficits and on the concept of patient-centered care as it relates to health communication. He noted that he and Dana Lustbader will be able to take the lessons from this workshop and apply them to the work they are doing with the various advisory councils on which they serve. Rosof then asked Freeman to make the final comment on the day.

Freeman said that he recognizes in the reality of humanity and everything that he does that not everyone approaches life from a deist's view, and he truly honors that reality. Nonetheless, he wanted to close the workshop by connecting everyone's heart in a moment of prayer. "This is a spiritual journey, and every one of you that do it are a spiritual being," said Freeman, who asked everyone to look at themselves and say, "I am spirit, and everything I do touches someone else's spirit." He then offered a prayer:

"By all that is holy, whether we call you Elohim, whether we call you God, whether we call you Yahweh, whether we call you Allah, whether we call you the great spirit, by every name that we hold dear, we come to you now to infuse us with your power. Give us the grace to walk with people who are going through the valleys of the shadows of death. Help us to walk with those who are in pain. Help us to reach out our hearts and our hands to minister in the only way that we know how, how we have been trained. But we also ask that you would challenge us, challenge us to grow to a higher level, to a different place so that we can be even better in the journey that we are in. Now, as we get ready to leave this place, as we go with some fears, some learning, some trepidation, even some prodding, we ask that you be gentle with our learning, be gentle with us as we become better at what we do. We ask these things in your holy and righteous name. Amen."

Rosof then adjourned the workshop.

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A

Workshop Agenda

Health Literacy and Palliative Care

Keck Building, Room 100
Washington, DC
July 9, 2015

OPEN SESSION

8:30–8:45 Welcome, Workshop Overview, Introduction of First Speakers
Bernie Rosof, Roundtable Chair

8:45–9:05 Communication: Palliative Care's Transformational Procedure
Diane Meier
Director, Center to Advance Palliative Care

9:05–10:35 Panel: Interpersonal Communication
Diane Meier, Moderator

9:05–9:10 Introductions

9:10–9:25 Perspectives of a Patient's Wife
Beverly Alves
Patient Advocate

9:25–9:40 Communicating Prognosis
Thomas J. Smith, M.D.
Director of Palliative Medicine, Johns Hopkins Hospital

9:40–9:55 Serious Illness Communication Program
Justin Sanders, M.D.
Research Fellow, Serious Illness Care Program, Ariadne Labs

9:55–10:35 Discussion

10:35–10:50 BREAK

10:50–12:00 Panel: Professional Training
Renee McLeod-Sordjan, Moderator

10:50–10:55 Introductions

10:55–11:10 Physician Training
Robert Arnold, M.D.
Chief, Section of Palliative Care and Medical Ethics
Director, Institute for Doctor–Patient Communication
Medical Director, Palliative and Supportive Institute
University of Pittsburgh Medical Center (UPMC)

11:10–11:25 Health Literacy and Palliative Care: Nurse Training
Elaine Wittenberg, Ph.D.
Associate Professor, Nursing Research
City of Hope

11:25–12:00 Discussion

12:00–1:00 LUNCH

1:00–2:45 Panel: Integrated Care Teams
Yael Schenker, Moderator

1:00–1:05 Introductions

1:05–1:20 How to Bring Spiritual Care into Palliative Care
Rev. Richard Freeman, Sr.
Pastoral Team, UPMC Children's Hospital

1:20–1:35 Family Caregiver Perspective
Carol Levine
Director, Families and Health Care Project
United Hospital Fund

1:35–1:50 Social Worker Perspective
John Cagle, Ph.D., M.S.W.
Assistant Professor,
University of Maryland School of Social Work

1:50–2:05 Nursing Perspective
Ginger Marshall, M.S.N., ACNP-BC, ACHPN, FPCN
National Director of Palliative Care, Hospice Compassus
President Elect, Hospice & Palliative Nurses Association

2:05–2:45 Discussion

2:45–3:00 BREAK

3:00–4:45 Panel: Programs
Marian Grant, Moderator

3:00–3:05 Introductions

3:05–3:20 Health System
Stacie Pinderhughes, M.D.
Chairperson, Division of Palliative Medicine
Banner Health

3:20–3:35 ProHEALTH Care Support: Advanced Illness Care for People at Home
Dana Lustbader, M.D.
Chair, Department of Palliative Care
ProHEALTH Care Associates

3:35–3:50 Helping Patients Navigate Difficult Decisions in the Hospital
Anne Kinderman, M.D.
Director, Supportive and Palliative Care Service
San Francisco General Hospital

3:50–4:05 Community-Based
Rev. Dr. Tyrone S. Pitts
Co-Chair, Interfaith and Diversity Workgroup
Coalition to Transform Advanced Care

4:05–4:45	Discussion
4:45–5:30	Reflections on the Day
5:30	ADJOURN

B

Biographical Sketches of Workshop Speakers and Moderators

Beverly Alves is a retired teacher from upstate New York. She spent most of her career teaching special education in a rural school district and before that she taught math in an inner-city school. Prior to becoming a teacher she was a medical and psychiatric social worker in a large hospital in Newark, New Jersey, and an antipoverty worker. Since her husband, Joe, died from cancer in 2006, she has been an advocate for palliative care and equal access to health care. She was on the steering committee for Single Payer New York and the National Coalition Leadership Conference for Guaranteed Health Care. She is currently on the organizing committee of the Jobs for All Network and is also an advocate for public education.

Robert Arnold, M.D., focuses his research and educational activities on teaching ethics to residents, improving doctor–patient communication regarding palliative care, and changing the culture by developing educational programs in specialties ranging from oncology to critical care medicine. Dr. Arnold is currently developing a structured curriculum on doctor–patient communication for fellows in critical care and trying to better understand the barriers to communication. His clinical activities focus on providing palliative care consults in a tertiary care hospital and providing primary care to HIV-seropositive inpatients. He was the president of the American Society of Bioethics and Humanities and of the American Academy of Palliative and Hospice Medicine.

John Cagle, Ph.D., M.S.W., is an assistant professor at the University of Maryland School of Social Work with a substantive interest in improving care at the end of life. As a translational health services researcher, his efforts have focused on identifying effective models of care and support for dying patients and their families—and implementing those models into routine clinical practice. This includes efforts to minimize financial burden on families coping with life-threatening illness. His research is informed by nearly a decade of clinical work as a hospice social worker. Dr. Cagle completed his Ph.D. from Virginia Commonwealth University where his dissertation thesis explored the needs and experiences of informal caregivers of advanced cancer patients. After being awarded his doctoral degree in 2008, he trained as a National Institute on Aging (NIA)-funded postdoctoral fellow at the University of North Carolina at Chapel Hill Institute on Aging as well as the University of California, San Francisco, Division of Geriatrics. His current research examines financial burden experienced by families during life-threatening illness, disparities in care at the end of life, psychosocial barriers to pain management, and improving palliative care outcomes in long-term care settings. His research has been supported by a number of public and private entities, including the University of Maryland School of Social Work Financial Social Work Initiative, the Hospice Foundation of America, the National Palliative Care Research Center, the John A. Hartford Foundation, the NIA, the Agency for Healthcare Research and Quality, the National Hospice and Palliative Care Organization, and the Foundation for End-of-Life Care.

Reverend Richard Freeman has been a bi-vocational servant throughout his ministry. He has led the chaplain program at Children's Hospital of Pittsburgh for 16 years while concurrently serving as the Senior Pastor of the Resurrection Baptist Church. Rev. Freeman's ministerial passions include teaching and marriage/family enrichment. He has taught in numerous settings on various topics, including Old Testament and New Testament Survey course, The Biblical Standard for Dating, and Building Marriages That Will Last. Rev. Freeman has presented at numerous conference and symposia on topics, including Caring for the Care Giver, Managing a Multi-Generational Workforce, End of Life Care: A Holistic View and How to Bring Spiritual Care to Palliative Care. He is part of a statewide gubernatorial roundtable on public education. He is also president of the Pennsylvania Interfaith Impact Network, a faith-based community organizing organization; putting faith in action.

Marian Grant, D.N.P., R.N., CRNP, is a nurse practitioner dually certified in Acute Care and Palliative Care/Hospice and an assistant professor at the University of Maryland School of Nursing where she teaches courses on communication, evidence-based practice, and end-of-life nursing. She is also on the University of Maryland Medical Center's Palliative Care

Service as a nurse practitioner. In 2014, Dr. Grant was named a Robert Wood Johnson Foundation Health Policy Fellow. Dr. Grant is on the board of the national Hospice & Palliative Nurses Association, is co-chair of the Public Engagement Workgroup for the national Coalition to Transform Advanced Care (C-TAC), and blogs monthly for the *Journal of Palliative Medicine*. Her consistent focus is on raising clinician and public awareness of palliative care and advocating for policy changes to make these services more widely available. Before becoming a nurse, Dr. Grant studied mass communication and worked in advertising and marketing for the Procter & Gamble Company.

Anne Kinderman, M.D., is an Assistant Clinical Professor of Medicine at the University of California, San Francisco (UCSF), and is the Director of the Supportive and Palliative Care Service at San Francisco General Hospital. After completing her Internal Medicine Residency at UCSF and Hospice and Palliative Medicine Fellowship at Stanford, she returned to San Francisco General in 2009 to help develop the Supportive and Palliative Care Consult Service, as its founding Director. Dr. Kinderman's scholarly work has included developing a curriculum in palliative care interpreting for professional medical interpreters, promoting high-quality care for vulnerable patients with serious illness, and expanding palliative care services in safety net health systems. Within the American Academy of Hospice and Palliative Medicine, she helped to create and lead a special interest group focused on the health care Safety Net, which advances collaboration and scholarship among palliative care providers caring for vulnerable patients. In 2014, she was Sojourns Scholars Leadership Award from the Cambia Health Foundation, to support her development as a leader in Palliative Care, and was subsequently named an Inspiring Leader Under 40 by the American Academy of Hospice and Palliative Medicine.

Carol Levine directs the United Hospital Fund's Families and Health Care Project, which focuses on developing partnerships between health care professionals and family caregivers, especially during transitions in health care settings (www.nextstepincare.org). Before joining the Fund in 1996, she directed the Citizens Commission on AIDS in New York City from 1987 to 1991, and The Orphan Project, which she founded, from 1991 to 1996. As a senior staff associate of The Hastings Center, she edited the *Hastings Center Report*. Ms. Levine is the editor of *Always on Call: When Illness Turns Families into Caregivers* (2nd ed., Vanderbilt University Press, 2004); co-editor, with Thomas H. Murray, of *The Cultures of Caregiving: Conflict and Common Ground Among Families, Health Professionals and Policy Makers* (Johns Hopkins University Press, 2004); and editor of *Living in the Land of Limbo: Fiction and Poetry About Family Caregiving* (Vanderbilt

University Press, 2014). In 1993, Ms. Levine was awarded a MacArthur Foundation Fellowship for her work in AIDS policy and ethics. She was named a WebMD Health Hero in 2007. In 2009, Ms. Levine was named a Purpose Prize fellow, an honor for social entrepreneurs over 60 who are using their experience and passion to take on society's biggest challenges.

Dana Lustbader, M.D., is Clinical Professor of Critical Care and Palliative Medicine at Hofstra North Shore–Long Island Jewish (LIJ) School of Medicine. She is Department Chair of Palliative Medicine at ProHEALTH Care Associates, a large physician-run multispecialty group and accountable care organization serving the New York metropolitan area. She created and is the Medical Director of ProHEALTH Care Support, a home-based advanced illness program providing medical care to people with serious illness while supporting their family caregivers. Prior to joining ProHEALTH, Dr. Lustbader worked at North Shore–LIJ where she was the Medical Intensive Care Unit Director, Section Head of Palliative Medicine, and founding Program Director of the Hospice and Palliative Medicine Fellowship. She also served as the Assistant Medical Director for the New York Organ Donor Network providing critical care consultation to intensive care units for optimal donor management. Dr. Lustbader is board certified in critical care medicine, internal medicine, and palliative medicine. She received her medical degree from the University of Wisconsin–Madison School of Medicine, Internal Medicine residency training at New York University Medical Center, and fellowship in Critical Care Medicine at St. Vincent's Hospital in New York. Dr. Lustbader was a founding member of the Hospice and Palliative Medicine Test Writing Committee for the American Board of Internal Medicine.

Ginger Marshall, M.S.N., ACNP-BC, ACHPN, FPCN, earned her B.S.N. from the University of Maryland and her M.S.N. from University of Pennsylvania. She served on the Board of Directors for the Hospice Palliative Credentialing Center (HPCC) from 2007 to 2013, including her role as President in 2010. She is currently serving on the Board of Directors for the Hospice & Palliative Nurses Association in the role of president elect. She is board certified in acute care by American Nurses Credentialing Center and in hospice palliative care by HPCC. In 2011, she was inducted as a Palliative Care Fellow by the Hospice & Palliative Nurses Association. Ms. Marshall has served as the Director of Palliative Care for both the University of Utah Hospital and Carolinas HealthCare System. She recently joined Compassus in the role of National Director of Palliative Care.

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Reverend Tyrone Pitts presently serves as the ecumenical officer and the General Secretary Emeritus of the Progressive National Baptist Convention Inc. He is also the President and CEO of Bridges International LLC, a consultant service with the mission of building reconciliation in international development and global education strategies among churches and civil society. From 1990 to 2010 Dr. Pitts served as General Secretary of the Progressive National Baptist Convention Inc., serving as Chief Operation Officer of the Convention. He is currently serving on the Executive Committee and the Central Committee of the World Council of Churches, with 349 Protestant and Orthodox Church leaders from across the world, and the National Conference of Black Churches representing eight historic American African Denominations, the board of the Baptist Joint Committee on Public Affairs, and the Baptist World Alliance. Dr. Pitts is also a member of the staff team for The New Baptist Covenant spearheaded by President Jimmy Carter.

Justin Sanders, M.D., is an Instructor in Medicine at Harvard Medical School and an attending physician in the department of Psychosocial

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Yael Schenker, M.D., received her undergraduate degree in literature from Harvard University. She completed all of her medical training at the University of California, San Francisco, before joining the faculty of the University of Pittsburgh in 2010. She is currently an assistant professor in the Division of General Internal Medicine, Section of Palliative Care and Medical Ethics, and holds a secondary appointment in the Clinical and Translational Science Institute. She is also an affiliate faculty member in the Center for Bioethics and Health Law, a member of the Biobehavioral Oncology Program at the University of Pittsburgh Cancer Center, and an associate faculty member of Clinical Research Modeling of Acute Illness in the Department of Critical Care Medicine. Dr. Schenker's research focuses on the integration of palliative care services in oncology, surrogate decision making, informed consent, and medical advertising. She has received funding from the National Palliative Care Research Center, the University of Pittsburgh Clinical Research Scholars (KL2) program, and the National Cancer Institute. Dr. Schenker is also a practicing primary care physician and conducts palliative care consults at the University of Pittsburgh Medical Center.

Thomas J. Smith, M.D., is the Director of Palliative Care for Johns Hopkins Medicine and the Hopkins' Sidney Kimmel Comprehensive Cancer Center. Before joining Johns Hopkins, Dr. Smith served as the Medical Director of the Thomas Palliative Care Program and the codirector of the Massey Cancer Center Cancer Control and Prevention Program at the Virginia Commonwealth University. He also holds the first Harry J. Duffey Family Professorship of Palliative Care in the Department of Oncology. Dr. Smith received his bachelor's of science degree summa cum laude from the University of Akron and his medical degree cum laude from Yale University School of Medicine. He completed his residency in Internal Medicine at the

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Elaine Wittenberg, Ph.D., is Associate Professor in the Division of Nursing Research and Education at City of Hope Comprehensive Cancer Center in Duarte, California. She holds a Ph.D. in Communication from the University of Oklahoma. With a focus on hospice and palliative care, she is co-author of several books, including *Communication as Comfort: Multiple Voices in Palliative Care* (Routledge Taylor & Francis Group, 2008), which details the complexities of communication in end-of-life care; and *Dying with Comfort: Family Illness Narratives and Early Palliative Care* (Hampton Press, 2010), both awarded Book of the Year by the National Communication Association. Her latest volume, *Communication in Palliative Nursing* (Oxford University Press, 2013), details the COMFORT communication curriculum that provides nurses with instruction on palliative care communication. Dr. Wittenberg is the lead editor of the *Textbook of Palliative Care Communication*, published in 2015 by Oxford University Press. She is co-founder of the Palliative Care Communication Institute (www.pccinstitute.com), an online resource that provides information on communication training, and offers provider, patient, and family resources developed through rigorous communication research. Dr. Wittenberg and colleagues recently launched Health Communication, a free iOS app that provides easy-to-use communication strategies. She has authored more than 100 peer-reviewed articles on hospice and palliative care communication. Her work can be found in *Qualitative Health Research*, *Journal of Pain and Symptom Management*, *Journal of Palliative Medicine*, and the *European Journal of Cancer Care*.