

# A Better Way: *Dealing with Serious Illness and End of Life Care*

BY STEVEN PANTILAT, M.D., PALLIATIVE CARE PROGRAM, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

“The hospital is all stainless steel. Palliative care is the human touch.”

—Susan, wife of a 68-year-old man with lung cancer, hospitalized with pain and shortness of breath who received palliative care.

## An All-Too-Common Story

Mrs. Mei was an 82-year-old woman with ovarian cancer that had spread throughout her abdomen. Chemotherapy had stopped working months earlier and she was gradually getting weaker. Mrs. Mei was living at home with her family, surrounded by her daughter, son-in-law, and three grandchildren. A few days earlier, she had stopped eating and drinking. She became sleepier and spent all of her time in bed. One morning, Mrs. Mei's daughter awoke to find that her mother was not able to speak or even open her eyes and seemed in distress. She was moaning and breathing quickly. Feeling panicked, her family called the paramedics. The paramedics arrived within a few minutes. They put an oxygen mask on Mrs. Mei and rushed her to the hospital.

On arrival in the emergency department, Mrs. Mei did not respond to talking or touch and was not able to make her wishes known. The emergency physician and nurse asked the family, “Would you like us to do everything possible?” Of course her family responded, “Yes.” Everyone does and everyone would.

The emergency physician and nurse did not clarify what Mrs. Mei's family meant by “everything possible” and did not explore what the goals were for Mrs. Mei. They assumed that Mrs. Mei's family really wanted all possible interventions done.

The nurse placed an intravenous catheter and drew blood. The physician quickly called the intensive care unit (ICU) team to come and care for Mrs. Mei, who appeared very sick and near the end of her life. Within 20 minutes of arriving at the hospital, Mrs. Mei had large catheters in her neck, a tube down her throat with a machine breathing for her, monitors and machines beeping and humming, and medicines flowing into her body. Even though she was not responding when she arrived at the hospital, she was given medications to sedate her to make sure she did not experience



Too often patients nearing the end of life end up in the intensive care unit receiving treatments they do not want and from which they cannot benefit.

the discomfort and pain associated with these treatments. Mrs. Mei was admitted to the ICU where she was allowed only two visitors at a time.

Mrs. Mei's story is played out every day in hospitals across the country. Acting with the very best of intentions, physicians and nurses provide patients with serious and life-limiting illness care that they may not want and from which they cannot benefit.

We must ask ourselves:

- Is this the care that Mrs. Mei would have wanted?
- Is this *really* the care that her family wanted for her?
- Assuming that it is technically excellent, is the care that Mrs. Mei received quality care?
- Finally, is the care that Mrs. Mei received the kind of care any of us would want for ourselves or our loved ones in the same situation?

## Common Shortcomings in Care for the Seriously Ill

As happened with Mrs. Mei, clinicians often fail to properly elicit and heed the wishes of patients, and the dominant hospital culture of cure and save at all costs leads to care that may be technically excellent but adds to suffering rather than relieving it. Mrs. Mei's case

highlights several challenges to our current healthcare system and great opportunities that exist in the hospital to meet these challenges and improve care.

One important response to the challenges posed by Mrs. Mei and the millions of patients like her with serious, chronic illnesses such as cancer, heart disease, and those near the end of life is palliative care. Increasingly, hospitals are adopting this approach to care to better match treatments to patient preferences. Palliative care provided simultaneously with

optimal medical management has been proven to improve care for people like Mrs. Mei.

## What Is Palliative Care?

Palliative care is: “comprehensive, interdisciplinary care focusing primarily on promoting quality of life for people living with a serious, chronic, or terminal illness and for their families, assuring physical comfort and psychosocial support. It is provided alongside all other appropriate medical treatments.”<sup>1</sup>

Examining this definition in more detail reveals a great deal about what kind of care people need when faced with serious illness and as they approach the end of life. The definition begins by stating that palliative care is “comprehensive” and “interdisciplinary.” When patients and their families are asked about what they need from the healthcare system when faced with serious, chronic, or life-threatening illness, they say that they don't want to be in pain or short of breath; they want to be comfortable; they want to talk with their doctors, nurses, social workers, and family about the experience and what the future holds; they want help make decisions that are consistent with their values and their goals; and they want to be supported. In particular, they want to know who will take care of them and where and how they will be cared for, and they want

1 J Andrew Billings, “What Is Palliative Care?” *Journal of Palliative Medicine*, Vol. 1, No. 1 (1998): 73–83.

to talk about emotional, psychological, and spiritual questions and concerns.

### The Needs of Hospitalized Patients with Serious Illness<sup>2,3</sup>

- Relief of pain and other distressing physical symptoms
- Relief of anxiety, worry, and depression
- Communication about treatment and what the future holds
- Support for themselves and their families
- Help with emotional, psychological, and spiritual concerns

Even a brief review of this list of patient needs reveals that no single member of the health-care team—not doctors, nurses, social workers, or chaplains—working alone can possibly address all of these important issues. Palliative care, by its very nature and design, is interdisciplinary so that it can be comprehensive.

Palliative care is focused on improving quality of life. Abraham Lincoln said, “It is not the years in your life, but the life in your years that count.” Whether life is measured in years, months, weeks, or days, and regardless of whether patients are pursuing curative treatment, the central focus of palliative care is to help patients achieve the best possible quality of life, as *the patients* define it, for as long as possible.

“It is not the years in your life, but the life in your years that count.”

—Abraham Lincoln

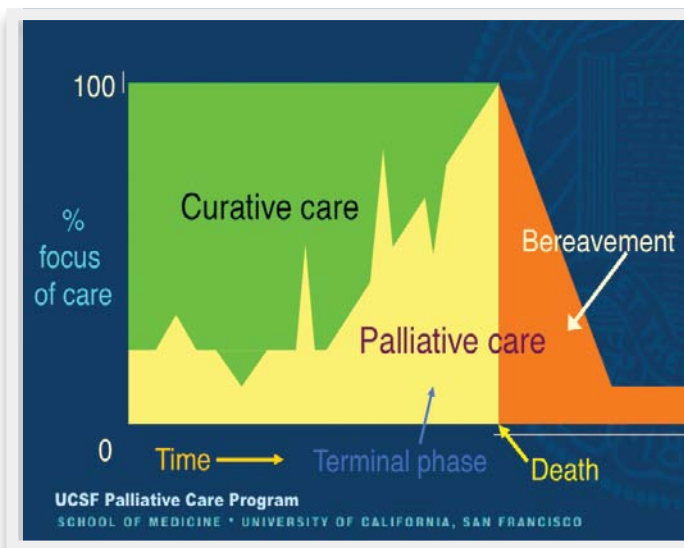
Palliative care is appropriate for any person living with a serious illness—cancer, heart failure, lung disease, dementia, liver disease, and kidney disease—regardless of stage of illness. At all stages of illness people have physical symptoms that need treatment, either from the disease itself or from its treatment. Too often that suffering goes untreated, either because the medical team lacks the expertise or because the sole focus on cure means that the medical team fails to adequately assess and manage symptoms. In addition, regardless of stage of illness, patients with serious illness have emotional concerns such as anxiety,

depression, and worry about treatments and what the future holds. They also have spiritual concerns about the meaning of the illness and what illness means for relationships and faith. These issues are rarely addressed in the hospital but are routinely addressed by a palliative care team.

In the normal course of a chronic, serious illness there will be times when the greater focus of care will be on cure, and times when the major focus will be on palliation. Over time, palliative care may come to play a larger role in the care of the patient, either because curative-intent treatment is no longer available or because the patient no longer desires it. At this point in a patient’s care, palliative care not only helps relieve physical and psychological symptoms, but helps to match treatments with patient preferences and values, providing the best care possible. The key to providing optimal care is for patients to receive the best of what medicine can offer of curative treatments and managing disease alongside the best we can offer of expert palliative care. (See **Exhibit 1**.)

Palliative care also provides support to the family. Serious illness and the end of life create stress and worry for patients and their loved ones. While medical management focuses on treatments for the patient, palliative care recognizes the critical role of the family and loved ones in caring for the patient. It also recognizes the fact that serious illness impacts the entire family, not just the patient. The palliative care team—the social worker, chaplain, nurses, and physician—have the time and expertise to support the family and loved ones in addition to the patient. Palliative care even extends to bereavement support for loved ones. This support from the palliative care team reduces depression and post-traumatic stress symptoms in loved ones.<sup>4</sup>

**Exhibit 1: Current Model of Palliative Care: Best Care Possible**



### The Difference between Palliative Care and Hospice

Palliative care is the universe of care focused on improving quality of life for people living with a serious illness. There are many ways to provide palliative care. Hospice is the most common way to provide care focused on quality of life, and is for patients nearing the end of life with a prognosis of six months or less. The vast majority of people who receive hospice care do so in their own home. Nearly every community in the U.S. has a hospice agency and overall, 41 percent of Americans use hospice at the end of life. While hospice is palliative care focused on the last six months of life, palliative care is appropriate to patients at any stage of illness, regardless of prognosis. Hospital-based palliative care teams can see patients from the time of diagnosis through the end of life. Hospital-based palliative care teams increase referrals to hospices; close coordination between the hospital palliative care teams and hospices helps to ensure that patients receive palliative care after discharge.

### The Current System for Caring for People with Serious Illness Is Broken

Advances in medicine have helped us to live longer with a better quality of life, but they have also created the reality that most of us will live for years with serious illness, experiencing periodic worsening and hospitalizations. These advances have contributed to a

2 Peter A. Singer, Douglas K. Martin, and Merrijoy Kelner, “Quality End-of-Life Care: Patients’ Perspectives,” *JAMA*, Vol. 281, No. 2 (1999): 163–168.

3 Karen E. Steinhauser et al., “In Search of a Good Death: Observations of Patients, Families, and Providers,” *Annals of Internal Medicine*, Vol. 132, No. 10 (2000): 825–832.

4 Alexi A. Wright et al., “Associations between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment,” *JAMA*, Vol. 300, No. 14 (October 8, 2008): 1665–1673.

culture and medical system that see illness as failure and death as optional. While we may not be able to avoid serious illness, through palliative care we can significantly reduce the suffering that accompanies it.

Advances in medical care have also led to our spending more money on healthcare than any other country in the world, in terms of total amount spent and percentage of gross national product. The costs of care are especially high in the last year of life. The 5 percent of people in Medicare who die each year consume 27 percent of all healthcare expenditures. And while we might wince at this massive expenditure, cost is really not the issue. We might reasonably expect that we would spend more money on healthcare for people in the last year of life when they are the most ill. The largest study of care for hospitalized people at the end of life found that 40 percent of people had moderate to severe pain in the last three days.<sup>5</sup> Another study found that nearly one in five people with cancer receive chemotherapy within two weeks of death when it cannot help.<sup>6</sup> The real tragedy is that for all we spend, we get very poor quality and bad value. Teams that are skilled in talking with patients

about their values and preferences can ensure that they receive care consistent with those preferences; this can improve the quality of care, reduce costs, and increase the value of healthcare.

Instead of hope, dignity, compassion, and caring, our current system provides treatments that people do not want and that not only fail to make them better but also become a source of suffering. There is a better way through palliative care.

### The Benefits of Palliative Care

Palliative care provides many benefits to patients, families, healthcare providers, and hospitals.<sup>7</sup>

#### Proven Benefits of Palliative Care

- Relieve pain, shortness of breath, and other distressing physical symptoms<sup>8</sup>
- Relieve anxiety, worry, and depression
- Improve quality of life
- Increase patient satisfaction with care
- Ensure that patients receive care consistent with their values
- Reduce unwanted invasive treatments
- Reduce hospital readmissions<sup>9</sup>
- Support family caregivers and reduce depression in caregivers after the death of their loved one<sup>10, 11</sup>
- Improve survival
- Support physicians and nurses and increase satisfaction and retention
- Reduce ICU length of stay
- Reduce hospital costs

#### Palliative Care Relieves Pain and Other Distressing Symptoms

Studies show that patients who receive palliative care report improved pain, less shortness

of breath, less fatigue, and relief of other symptoms. Palliative care teams include physicians and nurses who are expert at assessing and treating symptoms. They take the time to fully understand the cause of symptoms and have the expertise to bring to bear many modalities to relieve symptoms.

#### Palliative Care Relieves Anxiety, Worry, and Depression

Studies demonstrate that patients who receive palliative care experience less depression and anxiety. Palliative care teams are expert in talking with patients to understand their worries and have the time and the expertise to address the worry.

#### Palliative Care Improves Quality of Life

Patients who receive palliative care report a higher quality of life than those who receive standard medical treatment. Quality of life is defined by the patient and involves many areas of life, including physical well-being, emotional well-being, and ability to find pleasure and satisfaction in life. By addressing a broad range of issues that are important to patients, palliative care teams can help patients achieve a better quality of life.

#### Palliative Care Increases Patient Satisfaction with Care

Patients who receive palliative care are more satisfied with their care. Patients who are more satisfied are more likely to keep appointments and take their medicines. Hospitals routinely measure patient satisfaction and physicians and nurses are evaluated on the satisfaction of their patients. It is especially notable that palliative care can increase patient satisfaction since patients who receive this care are some of the sickest in the hospital.

#### Palliative Care Ensures that Patients Receive Care Consistent with Their Values

By having the time and expertise to fully explore and understand patient values and preferences, palliative care teams help align care to be consistent with patient preferences. When offered realistic options many patients may choose less invasive care that is focused on improving their quality of life instead of more invasive treatments that may add to suffering.

#### Palliative Care Can Reduce Hospital Readmissions

Increasingly, hospitals are faced with the need to reduce readmissions. Readmissions are costly and can be a sign of poor quality, a marker for lack of coordination, and can reduce quality of life for patients. Palliative care teams are expert at coordinating care and developing plans for continuity. By working with partners outside of the hospital, including



5 A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), The SUPPORT Principal Investigators, *JAMA*, Vol. 274, No. 20 (1995): 1591–1598.

6 Craig C. Earle et al., “Aggressiveness of Cancer Care Near the End of Life: Is It a Quality-of-Care Issue?” *Journal of Clinical Oncology*, Vol. 26, No. 23 (August 10, 2008): 3860–3866.

7 Areej El-Jawahri, Joseph A. Greer, and Jennifer S. Temel, “Does Palliative Care Improve Outcomes for Patients with Incurable Illness?: A Review of the Evidence,” *The Journal of Supportive Oncology*, Vol. 9, No. 3 (May–June 2011): 87–94.

8 Jennifer S. Temel et al., “Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer,” *The New England Journal of Medicine*, Vol. 363, No. 8 (August 19, 2010): 733–742.

9 Glenn Gade et al., “Impact of an Inpatient Palliative Care Team: A Randomized Control Trial,” *Journal of Palliative Medicine*, Vol. 11, No. 2 (March 2008): 180–190.

10 Alexi A. Wright et al., “Associations between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment,” *JAMA*, Vol. 300, No. 14 (October 8, 2008): 1665–1673.

11 Alexandra Lautrette et al., “A Communication Strategy and Brochure for Relatives of Patients Dying in the ICU,” *The New England Journal of Medicine*, Vol. 365, No. 5 (February 1, 2007): 469–478.



hospice and home care, and uncovering the underlying issues that may lead to readmission, palliative care teams can help patients stay out of the hospital. This collaboration is good for both patients and the hospital.

### Palliative Care Can Help Loved Ones

The comprehensive nature of palliative care means that it includes care for family and loved ones in addition to the patient. Palliative care acknowledges that families are deeply affected by a sick loved one and recognizes the central role of loved ones in the care of the patient. The palliative care team provides support to caregivers that results in less depression, fewer post-traumatic stress symptoms, and reduced grief complications.

### Palliative Care Improves Survival

Contrary to concerns that palliative care shortens life, studies show that palliative care can improve survival for people with serious illness. One study found that patients in hospice lived longer than similar patients who did not enroll in hospice, especially people with heart failure.<sup>12</sup> Another recent study demonstrated that for people with incurable lung cancer who lived, on average, for only 10 months, palliative care provided alongside standard cancer care increased survival by two and a half months. Meticulous attention to symptoms and treating depression can help patients feel better, stay stronger, and continue with other beneficial treatments that can help them live longer.

### Palliative Care Supports Physicians and Nurses

The care of seriously ill patients challenges physicians and nurses. Talking with patients and families about preferences for care and discussing emotionally challenging issues places a strain on them. Having these discussions also takes time, which many busy physicians and nurses simply do not have. It is part of the scope of work of palliative care teams to devote both the time and the expertise to thoroughly addressing these issues with patients and families, and to supporting physicians and nurses in their care of seriously ill patients. Palliative care teams also reinforce the compassion, caring, and humanism that led so many physicians and nurses into healthcare. Finally, by aligning treatments with patient preferences palliative care teams can alleviate the moral distress

that physicians and nurses experience when providing care that they know patients do not want and from which they will not benefit.

### Palliative Care Improves Resource Utilization and Reduces Costs

Rigorous studies of hospital palliative care teams find that costs of care for patients who receive palliative care are reduced by \$1,700 per admission for patients discharged from the hospital, and by \$4,900 per admission for those who die in the hospital.<sup>13, 14</sup> These cost savings are seen in patients with Medicare and Medicaid as well as other insurance, and in patients with no insurance. Palliative care also reduces ICU length of stay and reduces inappropriate utilization of laboratory tests, radiologic studies, and medications. Replacing expensive, unnecessary treatments that patients do not want results in improved care and significant improvements in resource utilization and costs savings. The average 300-bed community hospital can expect to save more than \$1.3 million per year by implementing a palliative care service.<sup>15</sup>

With all the benefits provided by palliative care teams to patients, families, physicians, nurses, and hospitals, for hospitals that do not offer palliative care, the real question is not, why should a hospital start a palliative care service, but how can any hospital afford to *not* offer palliative care?

For hospitals that already offer palliative care, the key questions are:

- How do we improve the quality of palliative care provided?
- What opportunities are there for palliative care to support the strategic vision of the hospital?

Mrs. Romero was an 82-year-old woman with advanced heart failure. She lived at home with her husband who cared for her. She was admitted to the hospital four times in four months for shortness of breath due to worsening heart failure. Each time, she arrived by ambulance anxious, scared, and breathing hard. She would spend hours in the emergency department being evaluated and treated. She would stay in the hospital for four to five days and generally felt much better by the end of her stay. She would receive home care with a couple of visits from a nurse after discharge. Within a month, she would be back in the hospital. Exasperated by her frequent readmissions, the cardiology team contacted the palliative care team for help.

The palliative care team met with Mrs. Romero's husband after she said she was too tired to talk. When asked what was hardest about his wife's illness, Mr. Romero said, "The worst part is when she comes to the hospital. She hates it. The hours on the gurney, injections, sticks, tests, and medicines are so hard on her. She gets a little better but then is right back in the hospital." The palliative care team explored these concerns in more detail and asked if he would be interested in a plan that would help him care for his wife at home and keep her out of the hospital. With tears in his eyes he said that would be a blessing to him and his wife. The palliative care team discussed and recommended hospice care.

For the next 13 months, Mrs. Romero was cared for at home by her husband with the help of hospice. Her symptoms were managed at home and she and her husband received both necessary medical equipment and support. When she became too ill for her husband to care for her at home, she was admitted to the hospital, where she was again seen by the palliative care team. She died peacefully five days later.

### Improving Care by Starting a Palliative Care Service

In a hospital without a palliative care team, the most effective and efficient way to improve the care of seriously ill patients is to start a palliative care service. Few other services can provide as much value. With a modest up-front



13 R. Sean Morrison et al., "Palliative Care Consultation Teams Cut Hospital Costs for Medicaid Beneficiaries," *Health Affairs*, Vol. 30, No. 3 (March 2011): 454–463.

14 R. Sean Morrison et al., "Cost Savings Associated with U.S. Hospital Palliative Care Consultation Programs," *Archives of Internal Medicine*, Vol. 168, No. 16 (September 8, 2008): 1783–1790.

15 Center to Advance Palliative Care, *The Case for Hospital Palliative Care: Improving Quality, Reducing Cost* (New York: Center to Advance Palliative Care), 2009.

12 Stephen R. Connor et al., "Comparing Hospice and Nonhospice Patient Survival Among Patients Who Die within a Three-Year Window," *Journal of Pain and Symptom Management*, Vol. 33, No. 3 (March 2007): 238–246.

investment, a hospital can realize all of the benefits listed above and, within the first year alone, recoup the investment through cost savings.

### Hospital Palliative Care Services in the U.S.

The number of hospital palliative care services is growing rapidly. In the U.S., 63 percent of hospitals offer palliative care services overall; for hospitals with more than 50 beds, the number rises to 85 percent. There are nearly 1,600 hospital-based palliative care services in the U.S., an increase of 150 percent over the past decade.<sup>16</sup> Despite this growth, many hospitals still do not offer palliative care services. In particular, smaller hospitals (with fewer than 50 beds), public hospitals, and for-profit hospitals are less likely to offer palliative care services. (See Exhibit 2.)

One of the greatest predictors of success in starting a palliative care program is strong support from a hospital's leadership and its board of directors.

Palliative care services are a marker of excellence and contribute to a hospital's reputation (for example, *U.S. News and World Report's* annual ranking of the nation's best hospitals includes having a palliative care service as a marker of higher quality). Two major national organizations focused on quality of care also endorse palliative care. The Joint Commission recently announced advanced certification in palliative care for hospitals, and the National Quality Forum through the National Priorities Partnership endorsed palliative care as one of eight focus areas for quality.<sup>17</sup> Hospital boards and leadership are increasingly recognizing the importance of palliative care services as critical to providing compassionate, comprehensive care to seriously ill patients, as vital to supporting a reputation for quality, and crucial to promoting fiscal sustainability.

### Getting Started

While palliative care is a billable service, the time needed to provide palliative care and the need to support a team of providers means that billing alone cannot support a service. National guidelines and expert consensus stipulate that palliative care services require an

interdisciplinary team of nurses, physicians, social workers, and chaplains to provide the comprehensive care patients and their families need.

To support this team and allow for the time needed to provide care, palliative care services require financial support in addition to billing. While philanthropy can become a solid source of support, the reality is that long-term sustainability requires ongoing support from the hospital. Fortunately, the savings associated with palliative care services more than covers the costs of the service.

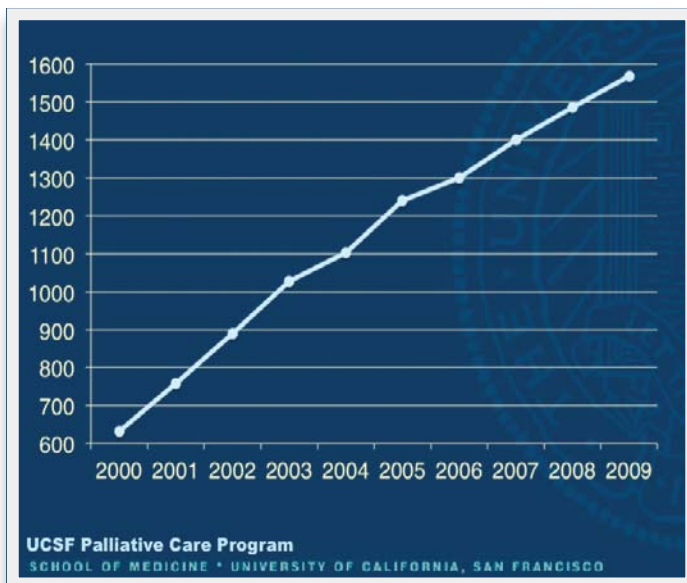
Any hospital planning to start a palliative care service can find ample help. The Center to Advance Palliative Care (CAPC) offers technical assistance through its Web site, publications, and conferences, as well as hands-on training for hospital teams through nine Palliative Care Leadership Centers (PCLCs) across the country.<sup>18</sup> Over 800 hospitals have sent teams to PCLC trainings that include a two-day intensive training followed by a year of mentoring. PCLC training is highly successful, with 80 percent of teams that attend subsequently launching a palliative care service. Hospitals can also find help from other institutions within their system that offer palliative care services or from any other hospital with an established program.

### Overcoming Barriers

Given the many benefits, why are there still so many hospitals that lack palliative care services? There are several barriers, the most important of which is lack of support from hospital leadership. Without financial and moral support for starting a service from hospital leadership and the board of directors, it is very difficult to succeed. Volunteer efforts to provide palliative care nearly always fail as the reality of the time needed to provide good care and the great demand for service quickly overwhelms good intentions. On the other hand, with strong support from hospital leadership and the board, all other barriers can be overcome.

All change is difficult and starting a palliative care service is no different. Physicians,

Exhibit 2: Growth in the Number of Hospital Palliative Care Services



Source: Center to Advance Palliative Care

nurses, social workers, pharmacists, case managers, and others are comfortable with the *status quo* and change, even for the better, is challenging. Strong leadership for the effort, combined with strategic discussions with staff, can demonstrate the overwhelming benefits of palliative care and generate goodwill and support for the new service.

Many teams working to establish palliative care services cite physicians as a major barrier to success. They worry that physicians will not refer patients and that some may actively work against their efforts. Unfortunately, there are still many physicians who misunderstand palliative care and equate it with end-of-life care or with giving up. Careful education about palliative care, combined with providing high-quality care will slowly convince most physicians of the benefits of the service. It is also important to know that even if a few physicians resist palliative care, there will be many physicians eager for the service, which will keep the palliative care team very busy from the start.

A final barrier is a lack of funds. Many hospitals routinely face difficult financial decisions and believe they cannot afford to start any new programs, even palliative care. They may be suspicious of cost savings from palliative care, having heard similar arguments about other services that did not pan out. It is important to note that for most hospitals starting a palliative care service, only a modest investment is required; cost savings are well-studied and proven.

### For Hospitals with a Palliative Care Service: Taking the Next Step

For the 63 percent of hospitals that already offer palliative care services, key next steps

16 Center to Advance Palliative Care, A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals, [www.capc.org/reportcard](http://www.capc.org/reportcard).

17 For more information, see [www.qualityforum.org/Setting\\_Priorities/NPP/National\\_Priorities\\_Partnership.aspx](http://www.qualityforum.org/Setting_Priorities/NPP/National_Priorities_Partnership.aspx).

18 For more information, see [www.capc.org](http://www.capc.org).

are to document and improve the quality of care provided by the service and to consider opportunities for palliative care to support the strategic vision of the hospital.

### Quality of Care

Palliative care teams need to collect data to understand and demonstrate the quality of care they provide. New palliative care teams should incorporate data collection from day one; existing teams should ensure that they collect sufficient data to understand the quality of care they provide. Boards and hospital leaders can reasonably expect palliative care teams to report operational, clinical, satisfaction, and financial outcomes to provide a well-rounded picture of the care they provide.<sup>19</sup> Some basic information includes:

- **Operational data:** How many patients were seen, how many days patients are seen, the diagnoses they have, where they were at the time of the initial consultation (emergency department, intensive care unit, medical-surgical unit, etc.), age, sex, and disposition. These data paint a picture of the amount of care provided and help to highlight opportunities to engage particular patient populations that may not be receiving palliative care.
- **Clinical data:** Use of pain scores and response to treatment; other symptom scores including shortness of breath, anxiety, fatigue, and response to treatment; and spiritual assessment and care. Ultimately, palliative care teams want to know how well they relieve suffering. Collecting and analyzing these data is both practical at the bedside in caring for patients and helpful in the aggregate for understanding their impact.
- **Satisfaction data:** Patients and families can give feedback on care provided by the palliative care team and offer important insights about how best to serve their needs. Satisfaction data can highlight where the team is doing well and opportunities to improve. For example, one hospital found that families were highly satisfied with care in the hospital but experienced a lack of support once they brought their loved one home. Such information can help palliative care teams and hospitals develop strategies to meet the needs of patients and families.
- **Financial data:** Analysis of the financial impact of palliative care teams demonstrates that hospitals can afford to provide

this important service. There are helpful guides to conducting financial analyses, available from CAPC and PCLC, among others. Combined with data on clinical outcomes and satisfaction, a calculation of cost savings creates a full picture of the value of palliative care by considering quality and cost.

Palliative care teams will need help to input and analyze these data and most hospitals have resources to work with clinicians to generate this important information. It is more efficient to have an administrative assistant input data than to ask palliative care nurses, physicians, or social workers to do so; palliative care team budgets should account for this staffing. Incorporating data from electronic medical records (if available) can reduce the burden of collecting data. At the same time, teams should avoid collecting too much data, which can interfere unreasonably with their clinical care duties. However, all teams should collect enough data to be able to describe the work they do and its impact on patients, families, and the hospital.

### Board Certification of Palliative Care Team Members

Certification in palliative care is available to physicians, nurses, and social workers. There is broad consensus that all palliative care teams should strive to have clinicians who are certified and that such certification is a marker of quality. Certification certainly demonstrates expertise in palliative care and is a strong statement of commitment to the practice and field as well as a sign that the clinician is staying up to date. The goal should be for all clinicians on the palliative care team to be board certified. Information about certification is available for physicians ([www.aahpm.org/certification/default/abms.html](http://www.aahpm.org/certification/default/abms.html)), nurses ([www.nbchpn.org](http://www.nbchpn.org)), and social workers ([www.socialworkers.org/credentials/credentials/achp.asp](http://www.socialworkers.org/credentials/credentials/achp.asp)).

### Opportunities

Information from the palliative care team can also identify opportunities to serve new patient populations. For example, data showing that only 10 percent of consultation requests to the



palliative care team are for patients in the ICU reveals an opportunity to reach many more patients who will benefit from palliative care. Similarly, finding a high in-hospital mortality rate among patients referred for palliative care suggests that consultation requests are coming very late in the course of illness and very close to death. This finding should motivate the palliative care team to understand why consultations come so late and work to see patients earlier in the course of illness.

One challenge is that there are many more patients who can benefit from palliative care than the typical palliative care team can care for. While most teams worry about not getting any consultation requests, the typical story is that even new palliative care teams are stretched and working at maximum capacity. Given that most teams are very busy, there is a strong desire to have the greatest impact. Deciding how best to deploy the precious resource of the palliative care team requires discussion with hospital leaders to understand which opportunities are most important. As shown in the case of Mrs. Callahan (see sidebar), a hospital with a very high daily census and a very busy emergency department might decide that having the palliative care team focus on seeing patients in the emergency department will best serve the needs of patients and the institution.<sup>20</sup>

19 David E. Weissman, Diane E. Meier, and Lynn Hill Spragens, "Center to Advance Palliative Care Palliative Care Consultation Service Metrics: Consensus Recommendations," *Journal of Palliative Medicine*, Vol. 11, No. 10 (December 2008): 1294–1298.

20 Michael W. Rabow et al., "The Intersection of Need and Opportunity: Assessing and Capitalizing on Opportunities to Expand Hospital-Based Palliative Care Services," *Journal of Palliative Medicine*, Vol. 13, No. 10 (October 2010): 1205–1210.



**M**rs. Callahan is an 88-year-old woman with dementia who has been living in a nursing home for one year. She was recently hospitalized with aspiration pneumonia and returned to the nursing home a week ago. Her nurse found Mrs. Callahan breathing quickly and in distress, with evidence of another aspiration event. The nurse contacted the physician and together they decided to call an ambulance to take her to the hospital. After Mrs. Callahan was on her way, the nurse called her son and daughter who visited her regularly. They rushed to the hospital and arrived in the emergency department a few minutes after their mother. They met with the emergency physician, who explained that it appeared that their mother had experienced another aspiration event. She was already calm and appeared comfortable but the physician recommended admission for observation and antibiotics. When the son and daughter asked if there were any other options, the emergency physician contacted the palliative care team.

The palliative care team met with Mrs. Callahan's son and daughter in the emergency department. They discussed goals of care that Mrs. Callahan would have wanted in this situation. Her son and daughter clearly explained that it appeared that hospitalization was not helping their mother, who was increasingly debilitated and dependent. They said that the last hospitalization was difficult for her and that she is more calm and comfortable in the nursing home. The palliative care team explained that aspiration is a part of advanced dementia and likely will continue to happen. The options for care included focusing on comfort and avoiding future hospitalizations. Mrs. Callahan's children agreed that she would want comfort and no further hospitalizations. They supported a do-not-resuscitate order, a directive not to transfer her to the hospital, and careful hand-feeding and other measures to reduce the risk of aspiration.

The palliative care team physician contacted the nursing home physician to share the above conversation. The palliative care nurse documented a treatment plan for treating shortness of breath and discomfort, and the social worker engaged the children in completing a POLST (physician order for life sustaining treatments) form to document the decision in a legally binding manner. Mrs. Callahan went back to the nursing home where her son and daughter continued to visit regularly.

Established palliative care teams that are collecting data and have demonstrated positive impact can consider other opportunities to improve care for patients. Some hospitals screen all patients to identify those most in need of palliative care. Others target specific populations of patients, such as those with heart disease, or choose to expand into the outpatient setting to provide much needed continuity for patients and families. Once a palliative care team is in place, many

opportunities to improve care for patients will become apparent and palliative care can be engaged to help achieve important hospital goals, including reducing readmissions and improving patient satisfaction.

### **An All-Too-Common Story with a Better Ending**

In the story that begins this article, Mrs. Mei, an 82-year-old woman with advanced ovarian cancer who is nearing the end of her life, ends up in the emergency department. In response to the emergency physician asking her family if they wanted everything done for her, her family said, "Yes." That response precipitated a cascade of interventions that landed Mrs. Mei in the intensive care unit, an environment not well-suited to caring for patients with serious illness nearing the end of life.

The real story of Mrs. Mei was fortunately quite different. In addition to calling the ICU team, the emergency physician called the hospital's palliative care team. The palliative care nurse and social worker met with the family right away and discovered that the family knew that Mrs. Mei was dying. They had even brought new clothes to dress her for her journey to the next life. They wanted "everything possible" done that would help her to be comfortable. The palliative care physician talked with the ICU and emergency physicians and they agreed that moving Mrs. Mei to a palliative care suite with a focus on symptom management and comfort was more appropriate. Mrs. Mei was given medicine for pain and shortness of breath. Her family dressed her in her new clothes in the emergency department and she was moved to the palliative care suite, a large room designed to look more like home, to accommodate patients and families and support a palliative plan of care. All 20 family members were able to be with her until she died several hours later. Mrs. Mei's family was enormously grateful to the nurses, physicians, and social workers who provided such kind and compassionate care to their mother and grandmother.

### **Providing the Best Possible Care**

With the aging of our population and the reality that more Americans will live longer with serious illness, we can anticipate that hospitals will care for more, sicker patients. This reality challenges our current healthcare model and raises the key question of how we will provide the best quality care at an affordable cost. In addition, changes that result from healthcare reform will create a great need for palliative care. As accountable care



Palliative care suite at UCSF Medical Center

organizations develop and consider how best to provide high-quality care to patients with serious illness at reasonable cost, they will look to palliative care teams as providers with the experience of achieving these outcomes.

Palliative care will play a central role in responding to these challenges. Palliative care provides a compassionate, caring, and cost-effective way to care for patients with serious illness and their families, by addressing a broad range of needs and ensuring the crucial alignment of treatments with patient preferences. The evidence is clear that palliative care benefits patients, families, physicians, nurses, and hospitals. Increasingly, palliative care is seen as a marker of quality. The number of hospitals that offer palliative care services is growing rapidly. Hospitals without palliative care services have many compelling reasons to start one and no excuse not to. Hospitals with palliative care services can use data to improve the quality of care these services provide and utilize palliative care to help achieve the hospital's strategic vision.

In a world where healthcare can seem impersonal, where a singular focus on cure leaves many patients and families alone and dissatisfied, and where financial constraints can limit options, palliative care offers a patient-centered alternative, focused on helping patients achieve the best possible quality of life in the time remaining. Palliative care emphasizes the humanism of medicine and allows us to provide the kind of healthcare system we would want for ourselves and our loved ones. ●

*The Governance Institute thanks Steven Pantilat, M.D., professor of medicine, Alan M. Kates and John M. Burnard endowed chair in palliative care, and director of the Palliative Care Program, University of California, San Francisco, for contributing this special section. Dr. Pantilat is a highly regarded and sought after speaker and consultant in palliative care, as well as an accomplished researcher and educator. He can be reached at [stevep@medicine.ucsf.edu](mailto:stevep@medicine.ucsf.edu).*