



Advanced Illness Management Strategies: Engaging the Community and a Ready, Willing and Able Workforce Part 2

December 2012

A report from the AHA Committee on Performance Improvement:

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Association**

The Committee on Performance Improvement's first report in 2012, *Advanced Illness Management Strategies*, can be found at:
<http://www.aha.org/aim-strategies>

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The Committee on Performance Improvement's first report in 2012, *Advanced Illness Management Strategies*, can be found at: <http://www.aha.org/aim-strategies>

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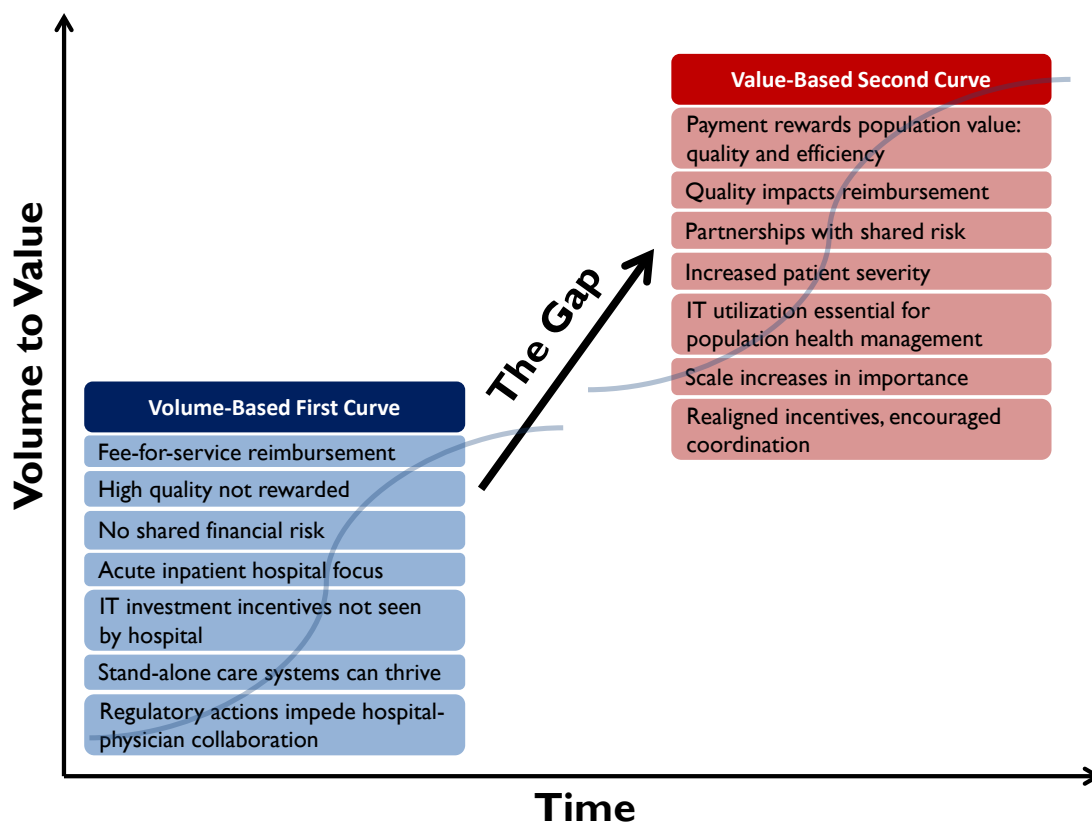
The Appendix identifies a number of valuable resources, including the accompanying August 2012 AHA Committee on Performance Improvement report, [Advanced Illness Management Strategies](http://www.aha.org/aim-strategies), found at <http://www.aha.org/aim-strategies> and AHA's Circle of Life Award found at www.aha.org/circleoflife.

Executive Summary

The American Hospital Association (AHA) Board's Committee on Performance Improvement (CPI) was created in 2010 to support performance improvement across the AHA membership and to align with the AHA's strategic platform, Hospitals in Pursuit of Excellence. The inaugural 2011 CPI report, *Hospitals and Care Systems of the Future* (found at: <http://www.aha.org/about/org/hospitals-care-systems-future.shtml>), conveyed that hospitals and health care systems in the United States are facing unparalleled pressures to change because of multiple and intersecting environmental forces—from the aging population to the unsustainable rise in health care spending as a percentage of national gross domestic product—that will transform health care delivery and financing from volume- to value-based payments over the next decade. These anticipated conditions are driving health care leaders to address the economic incentives that influence patient, provider and payer behavior.

Economic futurist, J. Ian Morrison, premised that as payment incentives shift, health care providers will go through a classic modification in their core models for business and service delivery. In his “first-curve-to-second-curve” framework, he defined the *first curve* as an economic paradigm driven by the volume of services provided and fee-for-service reimbursement while the *second curve* is concerned with value such as cost and quality of care necessary to produce desired health outcomes within a particular population. Conclusively, this framework illustrates that the most significant issue for hospitals and health care systems is establishing the transition rate from the two economic curves, which is referred to as *life in the gap*.

First Curve to Second Curve



Source: Hospitals and Care Systems of the Future Report, AHA CPI, September 2011, www.aha.org. Adapted from Ian Morrison, *The Second Curve*, Ballantine Books, 1996.

Managing Life in the Gap

Because progressing from the first curve to the second curve is a vital transition for hospitals, the first CPI report in 2012, *Advanced Illness Management Strategies* (found at <http://www.aha.org/aim-strategies>), focused on a particular approach that supports the imminent shift in business, care and service delivery models. The report geared its attention to **advanced illness management (AIM)** since hospitals are uniquely positioned to implement best practice strategies and integrate them into the normal continuum of care.

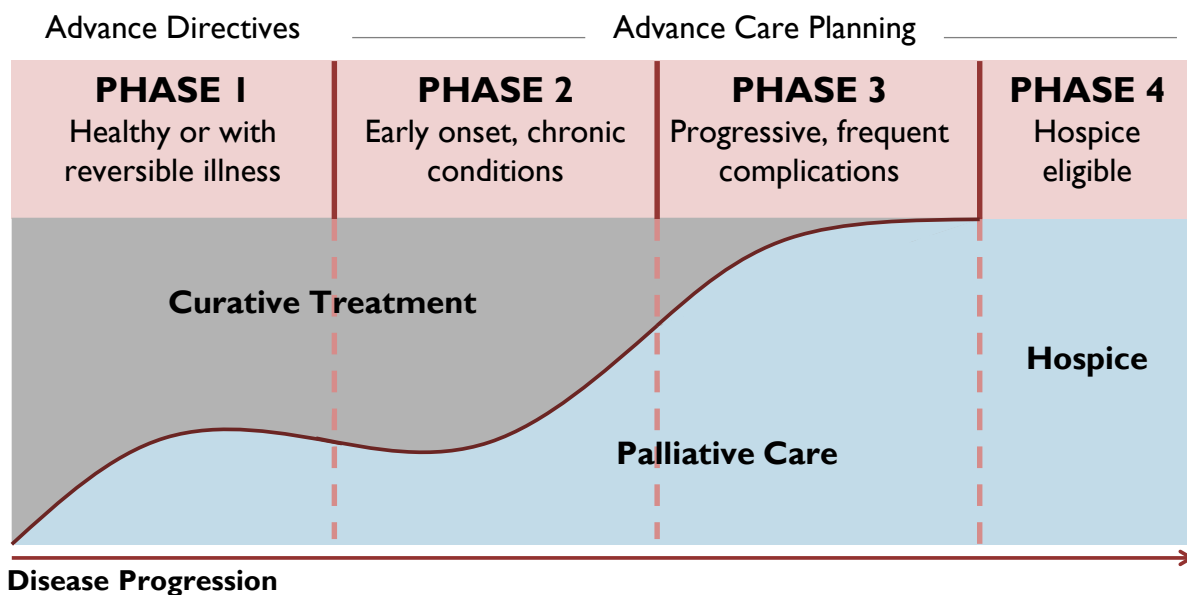
Why AIM?

The Coalition to Transform Advanced Care (C-TAC) defines advanced illness as one or more conditions serious enough that general health and functioning decline and treatments begin to lose their impact. Even though the trajectory of advanced illness leads to death, many studies show that well-developed AIM programs improve quality of life, lower utilization of clinical treatments and hospital admissions, increase patient and family satisfaction and reduce aggregate spending.

Three Key Strategies to AIM

The first CPI report framed AIM as a four-phase process—incorporating (1) advance directives, (2) advance care planning, (3) palliative care and (4) hospice care—and illustrated that integration of each segment results in successful initiatives. While hospitals have made significant strides incorporating these components, there are opportunities for improvement in both the number and coordination of AIM programs.

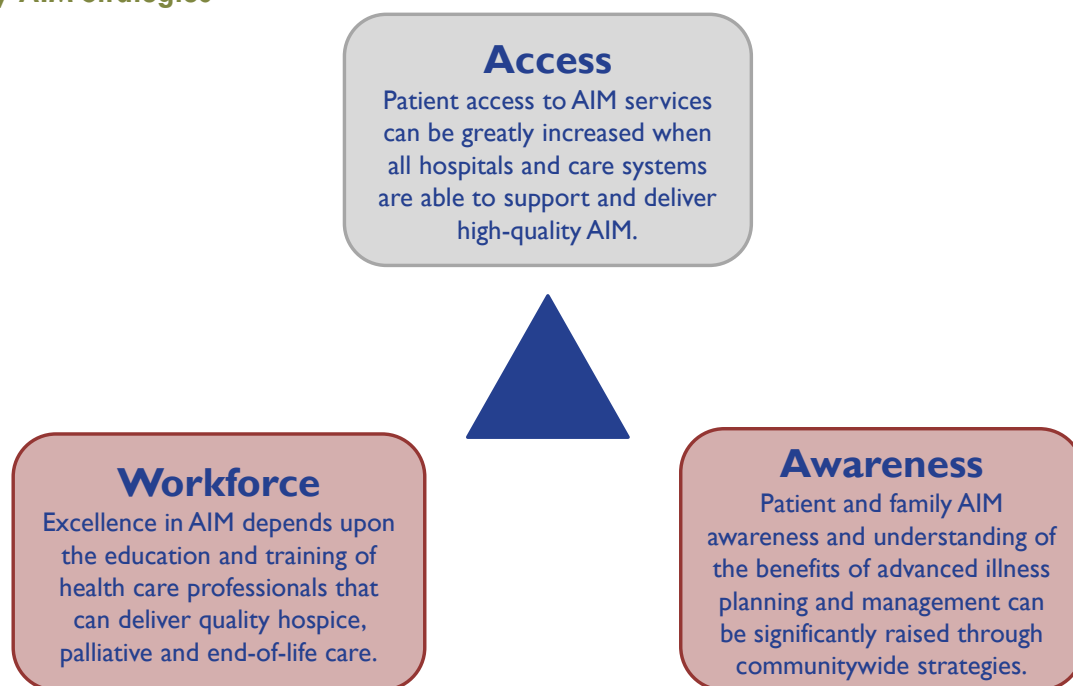
Phases of AIM



Source: AHA CPI analysis, 2012, with contributions from 2012 C-TAC data and 2011 Center to Advance Palliative Care data.

Three key strategies were also introduced in the push toward AIM's second-curve goals: *access*, *workforce* and *awareness*. They are connected and should be emphasized with equal value. When all strategies are at play, increasing demand from the public should be met by a supply of AIM structures, systems and services whose workforce can elicit informed end-of-life preferences and deliver consistently high-quality services with benefits that continue to expand community awareness, engagement and demand.

Three Key AIM Strategies



Source: AHA CPI, December 2012.

The [first CPI report](#) examined in depth how hospitals can increase **access** to AIM programs thereby changing the way medical services are utilized to improve outcomes and honor the wishes of patients and families. This second and follow-up report reviews the three key strategies and concentrates on two: patient and community **awareness** and engagement; and ready, willing and able **workforce**.

The “Strategy Implementation Checklist” table provides a list of salient implementation steps that can ensure success in each of the three strategies.

Table 1. Strategy Implementation Checklist

Strategy Implementation Checklist	
Access to AIM Services	
Patient access to AIM services can be greatly increased when an infrastructure of organizational services (1) is in place to deliver and support high-quality, coordinated, advanced illness care across settings and (2) is supported by the structure and incentives of public and private payment systems.	
	Develop a multidisciplinary care team with leadership buy-in
	Identify qualifying patients through evidence-based protocols
	Think beyond the traditional four walls of the hospital to promote AIM collaboration throughout the surrounding community
	Use a performance improvement framework to measure, monitor, evaluate and adapt the program between disease states and throughout time
Patient and Community Awareness and Engagement	
Communitywide strategies can significantly raise patient and family awareness in advanced illness planning and management.	
	Increase patient accessibility to information about end-of-life care by developing awareness and “conversation-readiness” among health care professionals; work with stakeholders on the importance of conversations, advance directives and early decision making; provide effective language assistance services; and address low health literacy
	Launch community development strategies that spread awareness of cultural diversity and support partnerships with local leaders and organizations that cater to the patient population’s demographics, education levels, culture and language
	Develop a workforce that embraces diversity to address the needs of patients and their families from different backgrounds and is equipped with the skills and knowledge necessary to support and guide those facing end of life
	Implement internal systems strategies such as collecting information on communication needs, tracking performance of patient engagement programs and ensuring that a strong advocate for patient-centered communication programs is present in the organization
Ready, Willing and Able Workforce	
The success of AIM programs is contingent upon the education and training of health care providers as the demand grows for managing multiple chronic conditions, as well as palliative and end-of-life care. There are not enough health care professionals who are ready, willing and able to manage advanced illness with patients and their families, and there is a constant need to engage in conversations and provide guidance to more expert resources.	
	Develop educational programs that offer ongoing training for health care professionals to learn the necessary skills and competencies to engage in sensitive conversations; train health care providers on the role and impact of spirituality in end-of-life care
	Use a multicultural guide/spiritual toolkit to support understanding and meeting diverse patient needs
	Launch collaborative strategies that create an environment for the multidisciplinary team to improve communication, leverage patient family advisory councils in communicating sensitive messages and provide or make available, to the palliative care workforce, comprehensive training in educating patients and their families during end-of-life care interactions
	Create a solid program infrastructure to sustain a successful palliative and end-of-life care program

Source: AHA CPI, 2012.

Introduction: Advanced Illness Management Strategies

This report explores two essential cornerstones for managing advanced illness: (1) patient and community awareness and engagement and (2) a health care workforce that is ready, willing and able to engage with patients and provide the spectrum of services that uphold dying comfortably and well. To begin, this report briefly recaps background information and defines terminologies associated with AIM, connecting content to an earlier companion report.

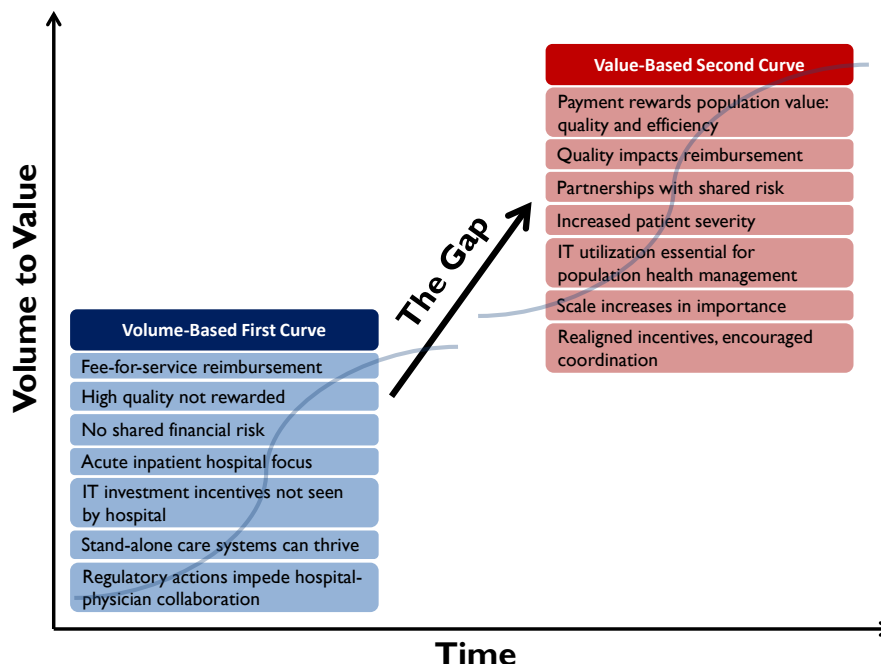
Terminology

According to Joanne Lynn, MD, director at Altarum Center for Elder Care and Advanced Illness, leaders in the care of frail elders and people with multiple chronic conditions or advanced or life-limiting illness are still exploring an appropriate language for serving those nearing the end of their lives. These and other overlapping terms are used to categorize the set of services needed for patients and families during the course of illness whose trajectory leads to death. For purposes of this report and its earlier companion,¹ AIM is being used as the overarching term. C-TAC has defined advanced illness as “occurring when one or more conditions become serious enough that general health and functioning decline, and treatments begin to lose their impact. This is a process that continues to the end of life.”²

Background

The AHA Board’s Committee on Performance Improvement (CPI) was created in 2010 to support performance improvement across the AHA membership to align with the AHA’s strategic platform, Hospitals in Pursuit of Excellence. Its inaugural 2011 report, [Hospitals and Care Systems of the Future](#), is based upon economic futurist J. Ian Morrison’s “first-curve-to-second-curve” framework (Figure 1).³ It describes the shift in payment incentives that impact health care providers’ core business models for care and service delivery and demonstrates why progressing from the first curve to the second curve is a vital transition for hospitals.

Figure 1: First Curve to Second Curve



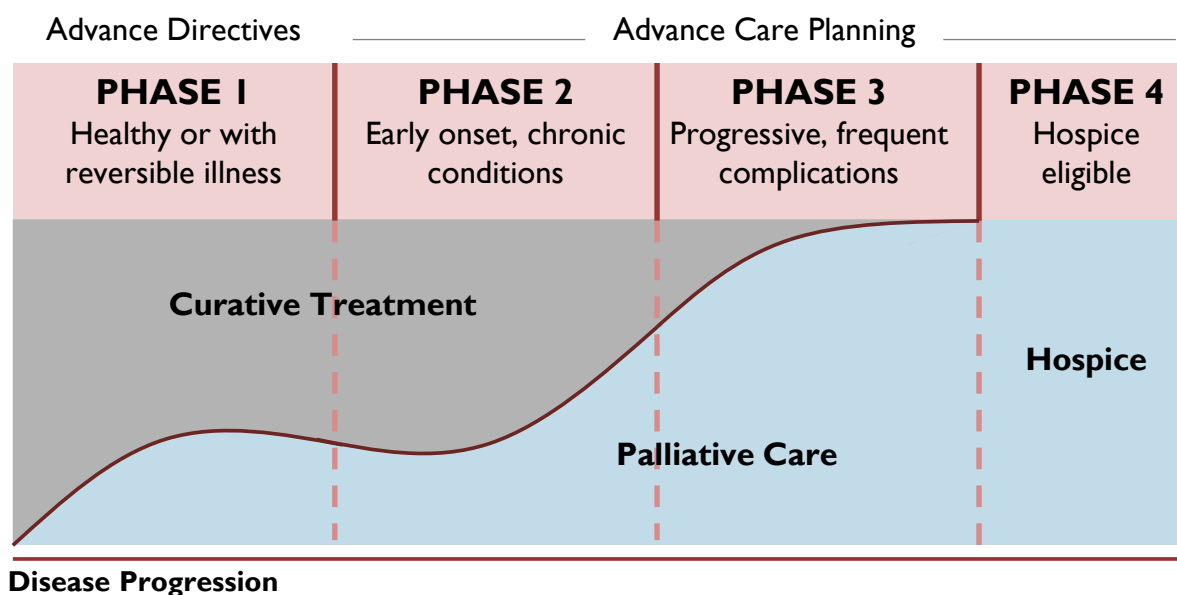
Source: Hospitals and Care Systems of the Future Report, AHA CPI, September 2011, www.aha.org. Adapted from Ian Morrison, *The Second Curve*, Ballantine Books, 1996.

In the August 2012 report, CPI focused on approaches to managing the transition period between the first-curve and second-curve economic markets, specifically in advanced illness management. Hospitals are uniquely positioned to implement best-practice strategies that integrate AIM into the normal continuum of care and ensure that the wishes of the patient and his or her family are carried out by the entire multidisciplinary team throughout disease progression.

Phases of AIM

There are four phases to AIM (Figure 2)—advance directives, advance care planning, palliative care and hospice care. Successful AIM programs integrate these phases into a continuum of care in which the treatment plan will increasingly be guided by the goals and decisions of the patient and family members, shifting from curative to palliative treatments and becoming more weighted toward psychosocial, relational and spiritual needs.

Figure 2: Phases of AIM



Source: AHA CPI analysis, 2012, with contributions from 2012 C-TAC data and 2011 Center to Advance Palliative Care data.

In the first phase, people are healthy and can recover from reversible illness. Those who stay ahead of the curve engage in advance care planning and have conversations with trusted friends and family members about their values and preferences should they become incapacitated. They document these conversations, sometimes in advance directives, and share or discuss their preferences with their health care provider(s), if they have the capacity and time. Some patients may already be well aware of their options, while others receive guidance from providers who will translate their preferences into available care options.

A person in the second phase typically has manageable, early or stable chronic condition(s) for which palliative care may begin to supplement disease treatment as part of maximizing quality of life. Palliative care relieves symptoms, complications of illness at any stage and side effects of medications or other treatments. It is independent of a prognosis and can be offered within or outside of a hospice structure and/or delivered at home, in a hospital, nursing home, residential hospice facility or other venues. While it is primarily focused on the alleviation of physical symptoms, palliative care encompasses social, emotional and spiritual needs and facilitates patient autonomy, access to information and choice.⁴

The second phase morphs into the third phase when the clinical condition (or conditions) continues to progress, producing more complications and placing increasing limits on the patient's activities, independence and quality of life. The third phase then evolves into the final phase when a person is deemed hospice-eligible. This is to say that the patient has a prognosis of six months or less. Hospice services provide comprehensive biomedical, psychosocial and spiritual support to patients and family members through multidisciplinary teams (consisting of a physician, registered nurse, licensed practical nurse, social worker and spiritual counselor, to name a few) and provides bereavement support to the family during the year following death.⁵

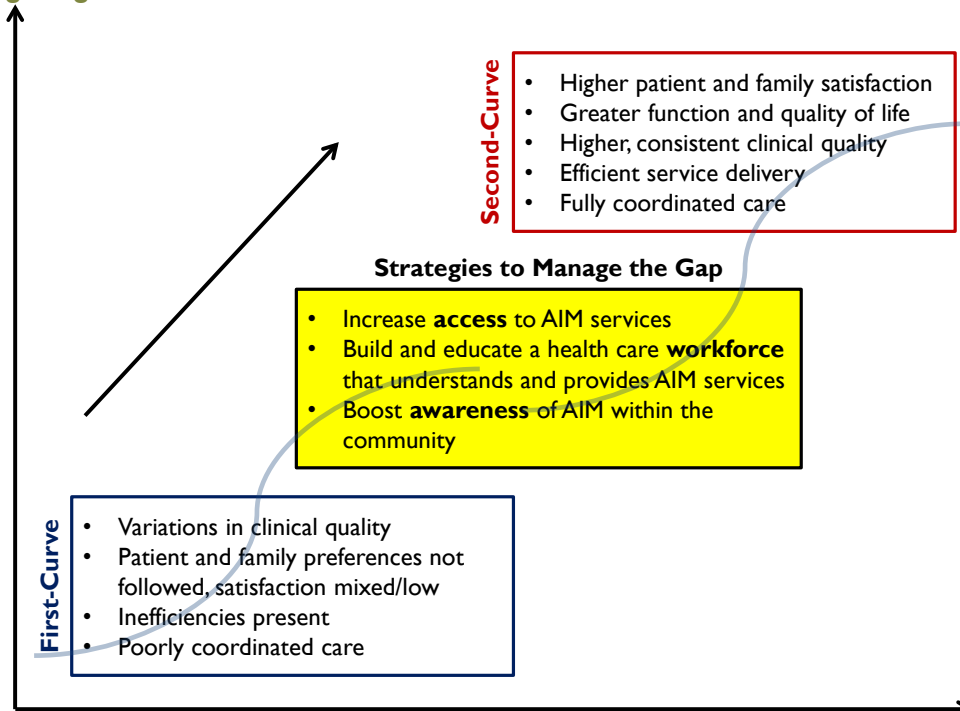
Goals and Strategies

AHA's CPI identified four goals or outcomes of AIM:

- Better and more consistent clinical quality
- More efficient service delivery
- Full coordination of care throughout the continuum of care
- Higher patient and family satisfaction.

In 2012, CPI commissioned a pair of reports. The first report, *Advanced Management Illness Strategies*, framed AIM as a four-phase process to be addressed through three strategies (Figure 3)—**access**, **workforce** and **awareness**.⁶ It examined in depth how hospitals can increase **access** to AIM programs so that they may change the way medical services are utilized to improve outcomes and honor the wishes of patients and families at the end of life.

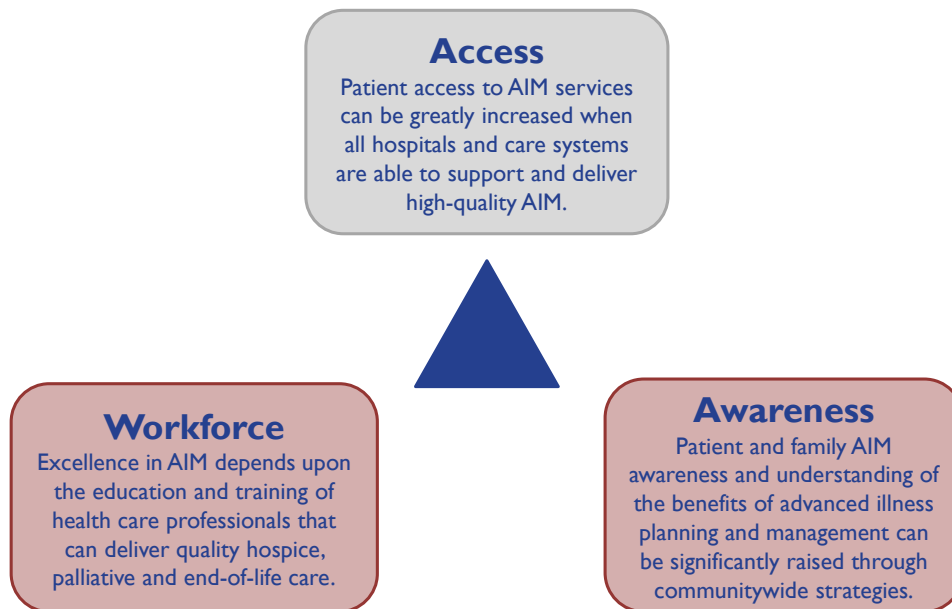
Figure 3: Navigating AIM



Source: AHA CPI analysis, 2012.

Following the CPI mandate to focus on the other two strategies (Figure 4)—**workforce** and **awareness**—this follow-up and second report expands and explains more precisely all three strategies, which could also be deemed cornerstones of late-life care.

Figure 4: Three Key AIM Strategies



Source: AHA CPI, 2012.

- **Access to AIM services:** An infrastructure of organizational services must be in place to deliver and support high-quality, coordinated advanced illness care across settings. Additionally, it must be supported by the structure and incentives of public and private payment systems.
- **Patient and community awareness and engagement:** To attain the best quality of life and support for psychosocial and spiritual needs, patients and family members should become aware of their options and understand the benefits of all phases of advanced illness planning and management. This will in turn drive the demand for AIM services.
- **Ready, willing and able workforce:** All health care professionals should be ready, willing and able to (1) have informed conversations with their patients about advanced illness and their evolving goals of care, (2) provide the basics of palliative care and (3) guide patients and families to more expert resources. Concurrently, the supply of ready, willing and able geriatricians, palliative care specialists and palliative care and hospice nurses must expand to meet the accelerating demand for managing chronic and often multiple conditions as well as palliative and end-of-life care.

When all three strategies are working synergistically (Figure 4), increasing demand from the public should be met by AIM structures, systems and services whose workforce can elicit informed end-of-life preferences and deliver consistently high-quality services with benefits that continue to expand community awareness, engagement and demand. The fourth and missing cornerstone in this dynamic—and the *sine qua non* of excellent late-life care and dying well—is the rethinking, reevaluation and restructuring of work that is needed to value and support family caregivers.

Expanding Patient and Community Awareness and Engagement Strategy

Most people want to die at home. Literally or metaphorically, the phrase encapsulates the imagery of “dying well” at home, comfortably surrounded by familiar people and things that evoke a lifetime of memories in an environment that can be more or less controlled and is the antithesis of the clutter, anonymity and intrusiveness of hospitals and nursing homes. Less than 25 percent of people die at home; most people die in institutions, where their symptoms are not managed well. Many are in pain. Some terminal illnesses are not painful, but most involve deteriorating mobility and uncomfortable, sometimes scary, sometimes serious complications. For example, limited movement and parchment skin make people vulnerable to pressure ulcers. Breathing and swallowing may become more difficult. Most of these symptoms can be prevented or alleviated, but often they are not. The staggering gap at the physical/biomedical level alone provides opportunities for radical improvement.

Whatever the venue, dying comfortably and well doesn’t just happen. Many factors contribute to end-of-life care, which requires the active involvement and participation of both health care providers and users. The former will need the necessary infrastructure of systems and supportive services designed to care for people as they become increasingly less able to tend to themselves. This includes palliative care units and hospices by which late-life care and complications are managed and overseen by a workforce skilled in providing this service. Meanwhile, the latter will need to engage and clearly articulate their needs so that providers can objectively translate and deliver the desired care. This involves becoming aware of the range of options for managing their symptoms and care and engaging with their late-life psychosocial, relational and spiritual needs and support.

Awareness is the first step in becoming informed of possibilities and options in end-of-life care. However, knowledge that palliative care units and/or hospice exists should not suffice. Appreciating the benefits and partnering with them sooner rather than later can make the utmost difference between “dying well” and “dying badly” and should be the draw to managing advanced illness and engaging with one’s mortality.

Sooner Rather than Later

When patients and families receive information about their prognosis, it affects their choices. Early discussion of and planning around end-of-life issues are linked to better outcomes for both patients and families. Advance care planning results in superior quality of life, increases the likelihood that individual wishes are followed, reduces hospitalization or admissions to the intensive care unit (ICU), and emotionally prepares families to better cope with the situation and the decision making involved in end-of-life care.^{7, 8, 9} Leaders in hospice and palliative medicine strongly recommend that hospitals make effective training programs widely available and professionals who care for people with complex and life-threatening conditions are trained and able to demonstrate competency in having such conversations.¹⁰

According to the National Hospice and Palliative Care Organization (NHPCO), in 2010, 75 percent of Americans did not even know that hospice care could be provided at home.¹¹ Although the percentage of patients with terminal illness who elect this service is steadily growing and the mean number of days their care is overseen by hospice is increasing, patients’ time in hospice care is still short: for a third of patients, it is a week or less.¹² One of the implications is that most of the care is physical and directed at managing the myriad symptoms that arise not only from the primary illness but also from bodily systems that are shutting down. As a result, many hospice patients and their families do not receive the full multidisciplinary benefits that come from partnering with hospice sooner rather than later.¹³

Developing Engagement

Friends and family members need to discuss, address and develop their preferences with health care providers and properly document them so that their wishes are likely to be carried out throughout the care continuum. Several efforts have been taken at the national and state levels to ensure that patient preferences are addressed. One example is Aging with Dignity, a nonprofit organization based in Tallahassee, Florida. This organization began to take steps at the national level to “affirm and safeguard the human dignity of individuals as they age” and “promote better care for those near the end of life.”¹⁴ In 1997, Aging with Dignity introduced to individuals in Florida, and later in other states, the “Five Wishes” document, which informs patients’ families and doctors (1) who can make decisions on their behalf in the event they are no longer able to do so, (2) preferences on medical treatment, (3) preferred comfort level, (4) how they want to be treated and (5) what they want their loved ones to know.¹⁵ Today, Aging with Dignity’s “Five Wishes” document meets legal requirements in 42 states.¹⁶

States, too, are taking the necessary steps to encourage people to complete advance directives and/or living wills. In 2011, the West Virginia state health insurance system, Public Employees Insurance Agency (PEIA), encouraged individuals to think about the kind of care they would prefer should they become seriously ill. PEIA offers a \$4 per month discount off the health insurance premium for signing a living will or medical power of attorney.¹⁷

The MOLST *Glossary of Terms* defines advance care planning as “an ongoing process of discussing and clarifying the current state of a person’s goals, values and preferences for future medical care. The discussion often, but not always, leads to the signing of documents known as advance directives.”¹⁸ In common parlance and practice, this planning process is frequently collapsed into documents (such as health care proxies and living wills as previously mentioned) that could take effect if the person becomes incapacitated.

Most people assume that completing advance directives and living wills takes care of things but this is not the case. Such documents typically deal with only very few options—DNR (do not resuscitate) or not, artificial nutrition or not—and cannot anticipate all the scenarios and decisions that could arise. These documents are frequently ignored or overridden by a family member or a physician. In some cases, the EMT is unaware of them or is being threatened with legal action by a family member if they abide by a DNR order. The MOLST (medical orders for life-sustaining treatment) and POLST (physician orders for life-sustaining treatment) responses in a growing number of states address these and other limitations of traditional advance directives. The six-year MOLST development and roll-out process in Massachusetts makes up an exemplary process. (See Case Study I.)

Written documents are only one aspect and outcome of advance planning. Ideally, people should stay ahead of the curve by having important conversations with trusted family members and friends to clarify their values and preferences regarding potential medical scenarios and end-of-life care. The goal of such conversations is to ensure that preferences are understood and to help those left behind make decisions on the patient’s behalf when the patient is no longer able to do so. The emotional toll on decision-makers when they don’t know what the patient wants can be monumental, and the anxiety and guilt around such decisions can have a lifelong effect.

For people who are able to have those kinds of conversations with friends and family and are aware of their options, they may need only to inform health care providers what they want and why. Others may need their wishes (e.g., to die at home) translated into what needs to be in place for them to be able to carry out those wishes, while providers may provide an educational and a facilitating role. However, many providers do not know how to have or initiate these conversations and may have difficulty receiving and translating the needs of their patients.

Work needs to be done both to stimulate conversations in informal or familial settings and develop capacity among health care professionals to initiate, elicit, receive and build on conversations with patients. Working “both sides of the street” is the aim of The Conversation Project (TCP). In partnership with the Institute for Healthcare Improvement (IHI), TCP develops awareness and engagement among individuals while developing “conversation-readiness” among providers. TCP works at the national and local levels to develop public and personal awareness

of options and possibilities for how patients end their days and tries to narrow or close the gap between what people say they want and what they get. (See Case Study 2.)

Conversations with friends, families and providers can and should continue throughout the care continuum so that people can confirm their wishes or change their minds. As complications, medications, consultations and hospitalizations accelerate and increase, it becomes more likely that patients and families need help navigating the system and becoming aware of the array of options that may be open to them. The compassionate care case management program at Aetna was designed with that objective. The program aims to improve quality of care for members, who are likely to live less than a year, and to support family caregivers with the help of experienced registered nurses who serve as guides and companions. Telephonic case management occurs after reviewing the member's case, patterns of claims and admissions and communication with the physician. (See Case Study 3.)

Other nonprofit organizations have emerged to further guide health care users. Respecting Choices, owned and operated by Gundersen Lutheran Medical Foundation in La Crosse, Wisconsin, designed a program that assists health care professionals guide patients and their families making an informed decision, allows health care plans to be properly documented and updates and ensures availability of these documentations when needed. The Respecting Choices model has demonstrated strong evidence of success and been internationally recognized and replicated. (See Case Study 4.)

Another example is C-TAC, an alliance of diverse organizations and individuals dedicated to transforming advanced illness care. This organization is working to improve the social, policy and health care system environment and norms for quality care, to ensure that patient choice and shared decision making drive care, to improve quality and to promote high levels of patient and family satisfaction. (See Case Study 5.)

Some hospitals are also changing their medical culture and providing optimal patient care by utilizing available resources and their current health care employees. One example is St. Joseph Mercy Oakland (SJMO), a community hospital and member organization of Trinity Health in Pontiac, Michigan. With the help of an interdisciplinary team already employed in the hospital, SJMO established a pain management and palliative care program that provides comprehensive services across the care continuum to individuals suffering from an illness and/or facing the end of life (See Case Study 6.)

Infrastructure of Systems and Supportive Services

Patient-centered communication is often described primarily as individual clinician-patient interactions.¹⁹ With the increasing diversity of the patient population, hospitals and health care systems can foster and encourage patient-centered communication by finding innovative ways to address cultural differences, linguistic barriers and varying literacy levels. This can include creating an infrastructure of systems and supportive services.

In a study conducted in eight hospitals by the American Medical Association's Ethical Force Program and the Health Research & Educational Trust (HRET), several recurring themes were identified as "promising practices" for hospitals and other health care systems to support patient-centered communication strategies:²⁰

- **Encourage passionate champions throughout the organization**
A passionate champion can serve as the most significant catalyst for change in launching patient-centered communication initiatives and guaranteeing their long-term sustainability.
- **Collect information to demonstrate needs**
Collecting information—e.g., in the form of surveys or interviews—to identify current gaps in communication will allow hospitals and health care systems to assess the needs of patients, staff and the community, which can then be transformed into programs and initiatives that will cater to the patient population.

- **Engage communities**
Planning community engagement initiatives requires acknowledging and understanding the demographics, education levels, culture and languages of the population being served. Engaged communities can provide an opportunity to share resources and information as well as work collaboratively and form partnerships.
- **Develop workforce diversity and communication skills**
Hospitals and health care systems must maintain or acquire a workforce that reflects and understands their diverse patient populations.
- **Involve patients every step of the way**
Patients must be educated about their health and care in a manner that they can comprehend.
- **Be aware of cultural diversity**
Cross-cultural communication is effective when hospitals and health care systems have a workforce that is culturally competent (explained in further detail later in this report), a welcoming environment, and interpreters who will conduct outreach in the community, assist patients in navigating the health system and facilitate cross-cultural discussions.
- **Provide effective language assistance services**
Studies show that qualified language interpreters can provide “better-quality care, order fewer unnecessary tests, and most likely decrease medical errors and the potential for lawsuits.”²¹ In addition, providing access to effective language assistance services empowers and enables patients who would not have been able to communicate in the common language to participate in their own care.²²
- **Be aware of low health literacy and use clear language**
Health care illiteracy can affect both English and non-English speaking patients, especially if they are facing a life-threatening illness and experiencing a lot of stress and discomfort. To engage patients in their care, staff must be able to detect signs of misunderstanding, avoid medical jargon and strive to communicate in clear and simple language.
- **Evaluate organizational performance over time**
To defend and demonstrate the value of patient-centered communication initiatives in hospital and health care system budgets, the initiatives must be continuously evaluated to show that they can have valuable impact on patient outcomes and deserve continuous funding.

Table 2. Hospital Strategies to Engage and Expand Patient and Community Awareness

Hospital Strategies to Engage and Expand Patient and Community Awareness	
Strategies to Increase Patient Accessibility to Information	
	Develop awareness and “conversation-readiness” among health care professionals providing care to patients with advanced illness. To create demand for AIM programs, health care professionals must be knowledgeable about services available to their patients and prepared to address them with tact.
	Work with stakeholders on the importance of conversations, advance directives, and early decision making in advanced illness management. Opening lines of communication provides an opportunity to discuss and identify all health care options for patients and their families to consider. Transparency of advance directives can also create accountability for all parties involved: patients, family members, health care providers, insurance companies, etc.
	Provide effective language assistance services. Translators can engage patients who would not have otherwise been able to converse due to language barriers.
	Address low health literacy. Patients can be engaged if they are given information that they can understand and comprehend. What is needed is an advocate who can facilitate patients in maneuvering the intricate health system.
Community Collaboration Strategies	
	Spread awareness of cultural diversity. Employing interpreters to carry out outreach programs outside the hospitals walls provides an opportunity to create visibility and network in the community.
	Develop community engagement programs. Developing community engagement initiatives that align with the current patient population’s demographics, education levels, culture and language will provide hospitals and health care systems an opportunity to share resources and work collaboratively with local leaders and organizations.
Workforce Development Strategies	
	Equip health care providers with the skills and knowledge necessary to provide support and guidance to patients and their families facing end-of-life care. Patients and family members often need assistance maneuvering the health care system. It is important to ensure that health services rendered throughout the care continuum are aligned with the patient’s and family’s wishes.
	Develop a diverse and skilled workforce that would cater to the patient population being served. Health care professionals who can culturally relate and converse with patients in their native languages can better address their needs and avoid misunderstanding.
Internal System Strategies	
	Have passionate champions for patient-centered communication programs. Any successful initiatives have a strong and passionate advocate who will see that the program is successfully launched and carried out to sustain in the long term.
	Collect information on communication needs. Identifying current gaps in patient engagement will allow hospitals to launch initiatives that strategically align with the needs of individuals, staff and the community.
	Track performance of patient engagement programs over time. To ensure the viability and fiscal solvency of patient engagement programs, hospitals and health care systems administrators and leaders must continuously measure their performance and impact on the patient population in order to demonstrate that the benefit outweighs the cost.

Source: AHA CPI, 2012.

Case Study 1

The Massachusetts MOLST Program

The MOLST (medical orders for life-sustaining treatment) and POLST (physician orders for life-sustaining treatment) concept began 20 years ago in Oregon, and initiatives of varying scope have now been developed in about 25 states. MOLST is a voluntary process and standardized form used to translate several life-sustaining treatment preferences of patients with advanced illness into valid medical orders that can be honored across all health care settings in Massachusetts. The form is filled out with and signed by a medical provider after discussing the patient's preferences and understanding of the potential risks and benefits of the interventions. The form guides emergency responders and surrogate decision-makers about what to do or not, if and when a situation arises.

Background

MOLST is not an advance directive; it is a medical order and the latter is a legal document. Using the form, a patient can opt in or out for various potentially life-sustaining treatments. The form travels with the patient and can be revoked or altered at any time. It is also valid in every health care setting—outpatient, emergency room, hospital unit, nursing home, rehabilitation facility, etc. Therefore, staff in all these areas requires training to be able to understand the document, how to respond to questions and where to find it in the medical record.

The premise of the MOLST form is that decisions are made following conversations between patient, family and providers, who help the patient understand the prognosis, possible symptoms or complications and potential benefits and risks of various life-sustaining interventions. For instance, resuscitation is rarely successful among frail elders because it may cause serious pain and discomfort and accelerate emotional disequilibrium. In contrast to advance directives, the MOLST form must be signed by the provider—a physician, nurse practitioner or physician's assistant—who will first discuss with patients and families the implications and benefits of their decision.

The format of the MOLST form is particularly significant for EMTs, whose input made a decisive impact on the content and organization of the first page. At a glance, the EMT can view the patient's preferences on four emergency procedures: resuscitation, intubation, ventilator and hospitalization. EMTs consider MOLST an improvement over other documentation tools. To date, EMT training on the document has been the most in depth of any group of health care providers.²³

What They Did

Those who have been working to improve end-of-life care recognized the need for a MOLST-type document and were keenly aware that the needs and wishes of those facing life-limiting illness have often not been expressed, communicated or documented. When such documentation was present, it was often unknown or unavailable to the EMT, the emergency room or other providers who must make medical decisions in the moment or are about how to treat someone who cannot communicate treatment preferences. Previously, Massachusetts' only advance directive was the health care proxy, which identified a surrogate decision-maker but did not circumstantiate the preferences of the person who entrusted that responsibility.

DNR forms deal with only one form of medical intervention. There has been "no standardized way for patients to express life-sustaining preferences in a way that can be readily understood and followed by members of the health care team in all settings of care."²⁴ As a result, providers often feel compelled to provide life-saving/extending treatments that are unwanted by the patient, resulting in increased suffering and decreased quality of life.²⁵

In 2008, the Massachusetts Legislature mandated a MOLST demonstration project directed jointly by the Massachusetts Department of Public Health (DPH) and the Executive Office of Elder Affairs (OEA). From the outset, the approach was developed with the potential for statewide implementation. Therefore, the process was more comprehensive in Massachusetts than in many other states. A steering committee of diversely situated experts with a long history of having worked together was formed to improve end-of-life care at the state and national levels. It was co-chaired by both DPH and OEA staff in partnership with Commonwealth Medicine, the health care consulting arm of the University of Massachusetts Medical School in Worcester, to develop and manage the project.

Two years of iterative development of the MOLST form preceded pilot demonstrations in three nursing homes, two acute care hospitals, two hospices, a geriatric home visiting program and emergency medical services in the greater Worcester area. Based on that experience, conversations continued among multiple stakeholders, professional communities, lay communities, consumer groups, the staff, committee members and work groups to revise the form during the demonstration period prior to the two-year, statewide rollout in 2012.

During four years of development and testing, staff and committee members worked extensively with EMTs to revise the form. They worked with the Massachusetts Medical Society and boards of several health professions, overseen by the DPH. The developers had conversations with providers as well as individuals and groups who had been working on end-of-life care for many years. They also met with nurses, social workers, clergy, emergency responders and medical interpreters. The developers studied other MOLST/POLST forms and decided to broaden their scope. To do this, they held focus groups and worked with many consumer groups including members of the African-American, Latino and Vietnamese communities as well as people of all ages and abilities.

The developers acknowledged many of the concerns voiced by consumers such as: Would patients have adequate time to talk with the clinician? Why had the draft materials not made families more integral to the conversation? They learned from people with disabilities that the doctor spoke to the person who accompanied them rather than the patient. The developers also identified confusion among lay and professional groups about terminology and why both MOLST and proxies were needed. This concern later led to creating a glossary, written in a language that is clear and precise.²⁶ All the information gathered, from engaging a variety of groups, was incorporated into materials that were eventually developed to communicate MOLST and to design the program's website.

Results

The pilot results strongly recommended statewide expansion of MOLST, as did the 2010 report of the Expert Panel on End-of-Life Care under the State's Executive Office of Health and Human Services.²⁷ The goal was to reach every hospital, nursing home, home care agency, hospice as well as other health care entities that care for patients with advanced illness in Massachusetts, so they are aware of MOLST, participate in conference calls and use the implementation toolkit on the MOLST website.

Lessons Learned

From the demonstration sites, staff and work groups learned that:

- It is essential to have a MOLST champion in the institution where it is being introduced as well as the necessary administrative support for implementing the program.
- Each institution must develop policies and procedures so that staff is aware of the form's location, how to complete it and respond to questions and inquiries, and where it is entered in the medical records.
- A task force is needed to oversee the preparation, development, launch and phased implementation of MOLST.
- Health professionals require training, coaching and support during implementation.

With all the changes in health care, having well-versed officials and offices that stay involved during the implementation process has advantages. These participants can identify where and how to bring MOLST into new and emerging programs and organizations.

MOLST provided a tool for starting conversations between attending health care practitioners and their patients with advanced illness, which the state of Massachusetts had legislated for in August 2012. This legislation required conversations with patients regarding their prognosis, their legal rights to pain and symptom management and the "risks and benefits of the various options."²⁸

Massachusetts MOLST

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Case Study 2

The Conversation Project

The Conversation Project (TCP) aims to create a movement that will make end-of-life discussions easier. In partnership with the Institute for Healthcare Improvement (IHI), TCP developed a forum for sharing stories, a marketing campaign, and resources for conversation starters and guides to help people who don't know where to begin end-of-life discussions.²⁹

Background

The concept behind TCP began to take shape after the death of founder Ellen Goodman's mother. Goodman is a Pulitzer Prize-winning syndicated journalist. Following her retirement in 2009, she started to formulate the idea of transforming health care by changing the way people die. Goodman, her colleagues, media, clergy and medical professionals discussed and shared stories and experiences about the culture of death in the United States and learned that more than half of Americans have not communicated how they want to spend the end of life. Prominent health care experts and leaders, Susan Block, MD, and Atul Gawande, MD, also affirmed that even baby boomers are ill prepared to face the death of their parents and their own aging.

The core purpose of TCP became to initiate and facilitate conversations as the first step in ensuring that people's end-of-life wishes are expressed and respected. Goodman believes that "the lever to begin this dramatic change is a willingness to talk as individuals, family members, and a culture about what we want when, as they say, the time comes."³⁰ TCP (1) provides a platform for sharing stories, (2) launches marketing campaigns to promote the conversation movement and (3) provides resources such as conversations starters and guides for those individuals who do not know how and where to begin end-of-life conversations.³¹

What They Did

During the 2009 IHI National Forum, Katherine Sebelius, U.S. Department of Health and Human Services Secretary, addressed to Maureen Bisognano, IHI CEO, the need to lead the charge on end-of-life issues. Today, IHI is a committed partner of TCP, sponsoring and providing TCP's office and activities.

IHI, through its client base of hospitals and clinicians, plans to build a medical community that is conversation-ready and able to fulfill the last wishes of patients facing the end of life. Meanwhile, TCP will work on the "demand" side of the equation, the public. It aims to create a movement that effects social and cultural change on the topics of death and dying. In addition, TCP aims to engage individuals in having conversations about what they want as their life draws to a close or if they are incapacitated. The partnership's premises are threefold:

1. *Reframing dialogue:* To reframe the public dialogue about death and dying in a way that people get what they want and wishes are both expressed and respected.
2. *Tapping readiness:* To tap into the readiness below the surface, creating safe space and permission, providing tools and scripts for how to begin and building critical mass for change. TCP will emphasize the deeper understandings flowing from the conversations rather than the documents. Some of the outcomes and clarifications that arise through conversation need to be documented, but the real meaning of "advance care planning" is the honest conversations among family members that can reveal surprises, foster deeper connections and collectively move dying "well," as defined by one's wishes, into the cultural mainstream.
3. *Creating demand:* For expressed wishes to be fulfilled, change is necessary in both the medical and broader social cultures. The medical culture is oriented to curing, heroics, technology and volume of

interventions. Therefore, TCP believes that change must come from outside the medical arena and originate from the public. While it is essential that physicians and nurses are trained how to initiate these conversations and respond to (rather than negate) patients who take the lead, the heart of the process lies with family and friends at home and not the medical office.

In September 2012, IHI announced it will be working with TCP and 10 pioneer sponsors who have committed sponsorship funds, resources and expertise to develop a “Conversation Ready” change package and with palliative care experts who will develop and communicate innovative ways to engage in difficult and sensitive conversations.³² The pioneer sponsors will first develop and pilot processes and tools that encourage people to express their wishes and engage in conversations with health care providers.³³ After one year of implementation, their change packages will be shared with the rest of the field.

The pioneer organizations are:³⁴

- Care New England Health System (Rhode Island)
- Contra Costa Regional Medical Center (California)
- Qulturum in the Jönköping County Council (Sweden)
- Mercy Health (Ohio)
- North Shore–Long Island Jewish Health System (New York)
- UPMC (Pennsylvania)

In August 2012, TCP launched its website and social and national media campaign. To create public awareness of the benefit of having end-of-life discussions, the website features a conversation starter kit and ways to tell stories. On the horizon is engaging employers who are beginning to realize the amount of time lost due to employee caregiving and the toll and impact on family caregivers such as depression, stress, post-traumatic stress disorder, physical illness and premature death. Employers are beginning to acknowledge the role of HR departments in providing resources and facilitating conversations.

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Case Study 3

Aetna Compassionate Care Program

The Compassionate Care Program (CCP) is a telephone case management program developed by Aetna. Designed to improve the quality of care for members who are likely to live less than a year, the program involves CCP case managers who serve as patient navigators and companions. Candidates are identified proactively through review of hospital admission records, medical history, pharmacy claims, referrals, etc.

Background

Aetna has long offered its members case management services staffed by registered nurse case managers. In 2004, it piloted the Compassionate Care Program (CCP) within a subset of Medicare Advantage and commercially insured members who were struggling with advanced illness. The key component of the new program was a specialized, telephonic case management program designed to improve quality of care for members and help support their family caregivers. CCP case managers serve as guides and companions for members who are likely to live less than a year. Potential candidates are identified proactively through reviews of hospital admissions, history of medical and pharmacy claims, predictive modeling, self-referrals and physician referrals.

For some of the commercially insured, a second program component of benefit liberalization was introduced. Hospice benefits were relaxed to 12 months and could be extended to 18 months, while conventional care could still be provided. Fifteen days per year of respite are now provided for family members. These benefit enhancements could not be offered to Medicare Advantage members without Centers for Medicare and Medicaid Services (CMS) permission. Aetna has proposed to CMS the same enhancements for its Medicare Advantage members at their own risk.

What They Did

After reviewing a member's case and pattern of claims and admissions, the case manager contacts the physician and then the member. Early calls assess the member's physical, familial, psychosocial and home situation. Individual care plans are built around these factors as well as the member's preferences. The case manager may educate patient and family members about the disease process, help them understand and create advance directives, navigate the system, coordinate medical care and benefits and connect them to resources that support both family caregivers and the patient. Caregiver support is a major aspect of the CCP. The case manager can help with pain, symptom and medication management as well as provide psychosocial support.

Aetna's case managers are experienced registered nurses. The CCP selects interpersonally gifted, clinically experienced case managers for four to five days of training in AIM and cultural attunement followed by two to three months of mentoring where they work side-by-side with a training case manager. Many of the CCP case managers have been cancer or hospice nurses and are already or soon to become subject matter experts or master trainers. According to a former team manager, turnover rate for this difficult but rewarding work is very low.

Case management teams include social workers who live in the same geographic territory as those they serve and are familiar with hospitals, physicians and social services in the area, making them better able to direct members to appropriate resources. Teams support each other, and regional teams take turns hosting the Schwartz Center Rounds, a platform that "allows caregivers from multiple disciplines to come together on a regular basis to discuss the most challenging emotional and social issues they face in caring for patients."³⁵

Results

A matched historic control was created for each of the following groups to test CCP: (1) commercially (non-Medicare) insured members that would receive specialized case management, (2) commercial members that would receive both case management and hospice benefit liberalization and (3) Medicare Advantage members that would receive case management.³⁶ The results of the pilot program were dramatic.

- Hospice election increased from 32 percent to 72 percent for the commercial case management group, and hospital days were reduced by 37 percent for the commercial case management group.³⁷
- Increased hospice election, 82 percent decrease in acute days, 88 percent decrease in intensive care days and 82 percent in emergency room utilization for the Medicare Advantage group.³⁸
- High satisfaction among members and their families.³⁹

Since the study was completed, Aetna has expanded CCP making it available to all medical members that are eligible for case management and making benefit liberalization a standard for commercially insured medical members.⁴⁰ In addition, the organization has proposed to CMS that it be permitted to liberalize the Medicare Advantage hospice benefit at its own financial risk.⁴¹

Over the years, Aetna has served 14,000 members through the CCP and not received a single complaint, despite the sensitive nature of the issues being addressed. Results continued to improve as case managers gained more experience in the area. As of 2011:⁴²

- Hospice election rate is 82 percent for Medicare Advantage members.
- Number of days in hospice has doubled, but the mean is still low at 36 days.
- 86 percent reduction in ICU days.
- 82 percent reduction in acute care/hospitalizations.

Lessons Learned

Randall Krakauer, MD, national Medicare medical director at Aetna and champion for the CCP, observed the greater impact to be made on Medicare members, some of whom are dual eligible. According to Dr. Krakauer, there is a greater opportunity to impact quality and costs in this group than those commercially insured because the former is more often associated with significant chronic illness. In addition, the Medicare population, a less affluent group, needs more assistance and will benefit more.

Aetna Compassionate Care Program

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<http://www.aetna.com/individuals-families-health-insurance/sas/compassionate-care/how-it-works.html>

Case Study 4

Respecting Choices in Gundersen Lutheran Medical Foundation

Respecting Choices is a nonprofit organization owned and operated by Gundersen Lutheran Medical Foundation in La Crosse, Wisconsin, part of the Gundersen Health System. The program has designed key elements to promote the adoption of advance care planning as an ongoing process of communication, integrated in the patient-centered care routine and staged to the individuals' state of health.⁴³

Background

In 1991, La Crosse, Wisconsin—composed of a mixed urban and rural population⁴⁴—conducted a random telephone survey of 304 adults and found that only 15 percent of its population reported having had some type of written advance directive.⁴⁵

Major health systems in La Crosse developed and implemented Respecting Choices as a collaborative, systematic and communitywide advance directive education program.⁴⁶ It was designed to assist patients and their families make informed decisions, properly document and update health plans and ensure that they are available to health care providers when needed.⁴⁷

In addition to helping patients and families complete advance directive documents, Respecting Choices is an evidence-based approach that provides a platform for thoughtful conversations with patients over time. The approach is not “one-size-fits-all” and was tailored to meet individual goals and values at a specific point in time.⁴⁸

What They Did

The premise of the program model is that a single document and discussion about health care plans cannot capture all possibilities. Effective advance care planning involves a process of communication that (1) allows individuals to understand their care options; (2) reflects the personal goals, values, religious and personal beliefs of individuals; and (3) supports conversations between individuals and physicians, health care agents and their family members.⁴⁹

Respecting Choices adopted three distinct stages of health when assisting individuals and families:⁵⁰

- **For healthy individuals**, it promotes basic planning. This includes creating a power of attorney with specific instructions for health care plans in the event that severe or permanent brain injury or disease occurs that could change treatment goals—shifting from prolonging life to providing comfort.
- **For individuals with progressive and advanced illness**, the program provides disease-specific planning, which includes specific instructions should a devastating complication arise from the illness, altering the goals of care.
- **For individuals facing end of life in the 12-month period**, it substantively opens communication about specific treatments documented on the POLST (physician orders for life-sustaining treatment) form.

Results

The Gundersen Health System along with other health care organizations in the La Crosse region have continued to monitor the outcomes of the program. Data collected in 2007 and 2008 on 400 deaths at all health organizations in La Crosse County over a seven-month period showed that:⁵¹

- Prevalence of care plans among adults who died in health care organizations in La Crosse County was 90 percent.

- Care plans were available in the medical records of health organizations in 99.4 percent of patients that died.
- 99 percent of the time, treatments provided were consistent with the care plans.
- 67 percent of individuals had a POLST form at the time of death.
- 96 percent of individuals had either an advance directive or POLST.

Because of the program's proven results and successful model, there are now more than 80 communities and organizations across the country that have launched Respecting Choices initiatives. In 2002, the program was presented for the first time in Heidelberg, Australia, attracting the attention of the Department of Health and Ageing and gaining political and media support.⁵² Today, the program has scaled up becoming the model for end-of-life care in all of Australia. The program now has expanded to Germany, Singapore and Spain. Respecting Choices has also provided consultation and education for Canadian Health Initiatives.

Large implementations are currently underway in the United States. These include Honoring Choices Minnesota, a project that includes the metropolitan area of Minneapolis and St. Paul convened by the Twin Cities Metro Medical Society; Honoring Choices Wisconsin, a project that will include the state of Wisconsin, convened by the Wisconsin Medical Society; and full implementation of all three stages of advance care planning by Kaiser Permanente of Northern California.

Lessons Learned

For Respecting Choices, living wills and advance directives merely scratch the surface and do not solve the underlying issues. The organization has placed great emphasis on the advance care planning process but also hopes to improve the health care delivery model by:⁵³

- Equipping health care professionals with the skills and competence to facilitate at each distinct stage of health.
- Creating a new role in health care such as the advance care planning facilitator. Advance care planning facilitators are typically health professionals, though they may include other professionals, who are trained using the standardized Respecting Choices curriculum. This curriculum is a blended learning approach that consists of online learning, role playing and coaching.
- Considering and designing new roles and responsibilities, which includes training staff at all levels and holding them accountable for their roles.
- Standardizing ways to document both the interactions of patients and plans that were created.
- Designing medical record systems, including EMRs, that ensure consistency of health care plans and maintenance of health records that are always available to providers. The medical record is also used to help guide the initiation of advance care planning conversations, document all types of care planning and provide a means of writing notes to track all advance care planning encounters.
- Ensuring all process and materials are subjected to evaluation and performance improvement.

The success of the program was also attributed to the support sought from health care leaders, professionals and the community. Local groups were engaged and included in the decision making prior to implementation of Respecting Choices. This type of community engagement established trust and garnered widespread support for the program.

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Case Study 5

The Coalition to Transform Advanced Care

The Coalition to Transform Advanced Care (C-TAC) is a national nonprofit, nonpartisan alliance of patient and consumer advocacy groups, health care professionals and providers, private sector stakeholders, faith-based organizations and health care payers. These groups have a shared vision that “all Americans with advanced illness, especially the sickest and most vulnerable, will receive comprehensive, high-quality, person-centered and family-centered care that is consistent with their goals and values and honors their dignity.”

Background

Patients and family caregivers facing the end of life are often not asked about the care that they want. With little support, they are left to navigate care settings, providers and fragmented information, creating physical, emotional and financial hardships on patients, families and caregivers.

High-performing systems are showing ways toward better care. Some of the most innovative health care providers in the United States have demonstrated that a coordinated, person-centered approach yields better care, greater satisfaction and lower costs.⁵⁴

Building on this experience, C-TAC provides resources, education and visibility aimed to deliver the appropriate care at the right place and time. The alliance is focused on key directives to empower consumers, change the health care delivery system, improve public and private policies, and enhance provider capacity. With a particular emphasis on faith-based and cultural perspectives, these directives are to:

- Identify, design and promote best-practice delivery models that ensure high-quality, coordinated care across all settings.
- Develop and disseminate innovative, interprofessional advance care education to clinicians aimed at improving quality, shared decision making and medical care by cultivating respect, compassion and responsiveness in care delivery.
- Develop and advocate for federal and state legislative, regulatory, judicial and administrative policies as well as private policies to improve care for those with advanced illness.
- Undertake a nationwide campaign of public education and engagement to help patients and their families make more informed decisions and to support delivery system and policy change.

What They Did

C-TAC is aimed at increasing the percentage of Americans who engage in the advanced illness care planning processes. This participation will improve the social, policy and health system environment and norms for quality care, ensure that patient choice and shared decision making drive care, improve quality and promote high levels of patient and family satisfaction.

In the fall of 2012, as part of its public engagement strategy, C-TAC launched its website, which was designed to empower the public to make informed decisions about advanced illness care and provide high-quality resources. For example, the C-TAC website has published a consumer research brief, *Public Perceptions of Advanced Illness Care: How Can We Talk When There's No Shared Language?* which is updated regularly.

As part of its educational initiatives, C-TAC has also identified six core competencies and associated behaviors:

- **Advance care planning:** Facilitate nonbiased, objective discussions between an individual and health care proxy to ensure a better understanding of a person's wishes and goals; actively listen, using communication skills of exploration, summarizing, paraphrasing, validation and open-ended questions.
- **Care coordination:** Link patients with community resources to facilitate uninterrupted care and respond to social service needs; identify patients who are likely to need coordination, as well as the team members who will be responsible for coordinating care.
- **Person-centered care:** Conduct a full assessment prior to providing service; appropriately consider cultural needs; actively promote the well-being of the individual.
- **Communication:** Enable self-management and patient navigation; build and foster healing/therapeutic relationships; coordinate care with other clinicians, health care professionals and health-related agencies.
- **Interprofessional teamwork:** Monitor mutual performance; orient collectively; build the ability to adapt.
- **Clinician resilience:** Cultivate self-awareness; be able to accept personal limitations; maintain effective professional relationships.

By identifying and promoting best practices from across disciplines and diseases, C-TAC assesses existing evidence, increases utilization and applies innovation to advanced illness care such as:

- Developing messages using new and existing consumer research to reach segmented audiences and create strategies and concepts for each key segment and test and refine them.
- Building a website that will feature vetted, curated resources for the public and clinicians.
- Distributing messages via social media, story and editorial placement to motivate and empower consumers to make informed choices and call for and support change in the delivery system.
- Measuring performance and making refinements and adjustments. This includes tracking public perceptions and behavior, which involves establishing baselines, conducting periodic benchmark tracking surveys and adjusting channels and messages accordingly.

On the horizon, the C-TAC will create public support for policy reform to improve the social and health care system environment and improve norms for quality care. Public and clinician engagement will be integrated into C-TAC's clinical models initiative to ensure that patient choice and shared decision making drive care, improve quality, promote high levels of satisfaction and reduce costs.

Lessons Learned

C-TAC acknowledges that there is a growing body of evidence on the benefits of quality communication and shared decision making among patients, families and clinicians regarding advanced illness. However, clinicians still face challenges as they grapple with difficult questions such as what information to provide and how and when to share it with patients, families and fellow professionals.⁵⁵

While there are evidence-based tools and guides to improve communication and advance care planning, their adoption has not been widespread. Despite the existence of quality solutions, these resources can be hard to find. Some are fragmented, discipline- and disease-specific, and not as accessible or transparent. Much more work is needed in this area, and C-TAC aims to address these issues.

Coalition to Transform Advanced Care (C-TAC)

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Case Study 6

Mercy Supportive Care at St. Joseph Mercy Oakland

Mercy Supportive Care at St. Joseph Mercy Oakland (SJMO), a community hospital and member organization of Trinity Health in Pontiac, Michigan, is a pain management and palliative care program that provides individuals who suffer from an illness and/or are facing the end of life with comprehensive services across the care continuum. SJMO's motto is "dying well is only possible if everyone gets a chance...to live well until they die."⁵⁶

Background

SJMO's Mercy Supportive Care service changed the culture of pain management and palliative care through its multiple programs, services and infrastructure support. The team, led by board-certified palliative-care nurse practitioners in collaboration with an interdisciplinary team and a board-certified palliative care medical director, initiates contact with inpatients and follows a large percentage of them during transitions to hospice or outpatient care settings. Each month, the team provides 300–400 inpatient visits and discusses coordination of care plans during interdisciplinary team conferences.

To create infrastructure support, SJMO's Mercy Supportive Care provided educational training regarding pain management and palliative care programs for employees. To strengthen and foster the change in medical culture at SJMO, a curriculum on pain management, palliative care and ethics was developed for surgical and medical residents. Medical students and residents rotate throughout the pain and palliative care service lines. All medical students are required to participate in special simulations focused on pain management and palliative care scenarios. Meanwhile, nurses and pharmacists receive five hours of pain management education during new employee orientation, and many continue to retake the monthly course offerings.

What They Did

In 2005, SJMO's Mercy Supportive Care created the "No One Dies Alone" program to provide comfort and assistance to inpatients with few or no family members. The program recruits and trains volunteers to be at the patient's bedside at the end of life so that patients can die with dignity and comfort. Classes are offered at least twice a year to train new volunteers. To date, approximately 139 volunteers support the program. Since its inception, more than 554 patients received the service and over 11,779 hours were provided at the bedside. In an effort to expand this service, SJMO's Mercy Supportive Care mentored and assisted more than 85 hospitals to establish their own "No One Dies Alone" program. As a result, in 2010, SJMO received the Hospital Awards for Volunteer Excellence (HAVE) from the AHA for outstanding hospital-based volunteer programs.

Resources are provided to create a peaceful and healing environment for patients facing the end of life. SJMO's Mercy Supportive Care provides portable "comfort" carts for patients that contain a music player, soft listening CDs, homemade "love blankets," bereavement information, community resource booklets, religious books and other inspirational items. Other resources include the ability to conduct a life review; receive massage therapy, healing touch and aromatherapy sessions; and create hand casts of the dying patient for his or her family. Another therapy modality includes a harpist available to play music at the bedside. All of these resources create sacred and peaceful spaces for both patients and families.

Additional end-of-life support programs include the Emergency Department Service for grieving family members. A value-added component involves bereavement follow-ups for those that experienced the loss of a family member at the hospital. A unique miscarriage program was also implemented in the ambulatory surgery center, for mothers who underwent dilation and curettage after a miscarriage. This includes a naming ceremony, bereavement support, information on how to cope with early loss and outpatient perinatal loss support groups. Memorial services are held regularly for both infant and adult loss.

The outpatient palliative care component of the program has evolved over the years and features services such as case management, referrals to outpatient programs, home and hospice care. This service is available 24/7 and

serves as a support system for patients and their families. For example, the outpatient pain management and palliative care center provides the hospital with capabilities to care for complicated chronic pain patients and those facing the end of life within a clinical setting. The parish nurse outpatient service was also developed as a community outreach program. Parish nurses provide education while promoting community engagement and education of patients' rights within a pain management and palliative care setting. In addition, Mercy Supportive Care offers palliative care through the hospital's home care agency.

Results

The high volume of referrals, more than 4,200 patient visits annually, is a testament to the comprehensive services offered at SJMO's Mercy Supportive Care. Since 2001, palliative patients have consistently experienced reductions in pain scores, typically from 10 to 2. Data collected over the last 10 years indicates that more than 95 percent of families who experienced loss at SJMO also consistently reported in satisfaction surveys that they believe their loved one was comfortable at the end of life and felt supported.

Prior to the inception of SJMO's Mercy Supportive Care, resuscitation was attempted in 60 percent of patients who died at SJMO.⁵⁷ Since 2001, this has decreased to approximately 15 percent. This outcome demonstrates that patients and families are well-informed and able to express wishes to decline resuscitation efforts.

Another significant outcome demonstrates SJMO's ability to reduce the length of stay among palliative care patients in the ICU. While reduced length of stay in ICU was a favorable outcome of the program, the analysis justified Mercy Supportive Care as a financially viable and sustainable program. In 2003, the cost-per-case-per-day was \$600 less when palliative care services were involved. In 2011, using the Center to Advance Palliative Care impact calculator, SJMO data indicated that it was able to avoid \$920,000 in costs (based on volume).

The results at SJMO drew the attention of other community hospitals. Since 2005, Peg Nelson, director and nurse practitioner for pain and palliative services, reported that the program has been shared with more than 131 health care organizations, including competing hospitals. Many hospitals sent teams of administrators and clinical staff to observe SJMO'S program so that they might replicate them in their organizations.⁵⁸

In 2012, an important milestone occurred when the program received Joint Commission advanced palliative care certification, the first organization from the Trinity Health system and first of five hospitals in the United States to receive it.

Lessons Learned

The success of SJMO's Mercy Supportive Care can be attributed to the interdisciplinary team involved in the program. Nurse practitioners anchor the service and contact physicians and team members as appropriate.⁵⁹ Because the Mercy Supportive Care team includes pain and palliative care experts from both medicine and allied health occupations, it promotes staff interaction, communication, participation and program support.⁶⁰

While participation of the clinical team is crucial, the program also gained the support of hospital administrators and Trinity Health. All of them played an integral role in the success of Mercy Supportive Care, allowing SJMO to integrate services throughout the hospital rather than providing an isolated service.⁶¹

Mercy Supportive Care at St. Joseph Mercy Oakland

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Ready, Willing and Able Workforce Strategy

To launch successful AIM programs, hospitals and health care systems must have and foster or employ the necessary human capital that can deliver high-quality hospice, palliative and end-of-life care. This involves building a workforce with the knowledge, skills and competency to provide care to patients whose nature of illness leads to death. Health care professionals who are ready, willing and able are needed. But what exist now are serious and growing shortages of health care professionals, medical and nursing training programs that overlook the necessary skills to communicate with patients at end of life, a medical culture that too often regards death as a failure rather than as a natural part of life, and the slow and uneven journey of hospice and palliative medicine to become fully established among the specialties.

Shortages of Clinical Professionals

Baby boomers comprise a significant portion of the health care workforce. About 40 percent are doctors who are over 55 years of age, while one-third of the nursing workforce is over 50.⁶² When these baby boomers retire, there will be a significant shortfall of health care professionals. Coupled with these shortages, the health care community will also face challenges of meeting the needs of an aging cohort as one in five Americans will be over the age of 65 by 2030, according to the 2010 U.S. Census.⁶³

A task force appointed by the American Academy of Hospice and Palliative Medicine (AAHPM) in 2008 concluded that there is an acute shortage of hospice and palliative medicine physicians. Only about 4,400 hospice and palliative medicine physicians are currently practicing and most practice part-time; estimates of their full-time equivalents range from 1,700 to 3,300. If current programs were appropriately staffed, another 2,800 to 7,500 full-time employees would be needed, which translates to between 6,000 and 18,000 individual physicians who practice hospice and palliative medicine.⁶⁴

Aside from physician shortages in hospice and palliative medicine, the nursing shortage is also at crisis levels in the general field of health care. By 2025, it is projected that there will be more than 260,000 unfilled positions for registered nurses.⁶⁵ This shortage intensifies and makes more pronounced the already insufficient number of available nurses to provide care in hospice,⁶⁶ palliative and end-of-life care.⁶⁷ In fact, according to the 2008 *National Sample Survey of Registered Nurses*, only 3 percent of America's registered nurses (3.1 million) identified hospice as their clinical specialty area and 72 percent of them practice in nonhospital settings.⁶⁸

Medical School and Residency

American medical students and residents don't feel prepared to care for the dying, and statistics show that most aren't.⁶⁹ Based on self-reports from 1,455 fourth-year medical students in a major national study conducted in 2003, 296 residents and 287 faculty affiliated with a random sample of 62 accredited medical schools have seen only modest and uneven improvement in their preparation. Less than 20 percent of each group had coursework or rotation or were taught about end-of-life care in the past year. Additionally, only 30 percent of students were taught basic pain management while slightly more than 40 percent of each group did not consider meeting the psychosocial needs of dying patients to be a core clinical competency.

Conclusively, these and other findings suggest that American medical education and residency do a poor job of teaching the clinical aspects of end-of-life care and fail to recognize, let alone teach, the scope and skills of communicative competency required to work with the psychosocial needs of dying patients and their families. On the contrary, using a similar questionnaire, British medical students reported having more training and more experience in palliative care within a medical culture more favorably disposed to it.⁷⁰

Other data suggest that a major contributor to the deficiencies in American medical education is the “hidden curriculum”—mixed and implicit messages from residents and attending physicians that inform the local culture.⁷¹ The cultural milieu documented in the study indicated that end-of-life care is not a faculty competency or priority: residents are not introduced to issues of dying at home or hospice, complex communication issues are ignored, and emphasis is placed on high technology and curing, which reduces the meaning of impending death as being “nothing more we can do.” This concept to “prolong life” is imbued during medical school, suggesting that anything less is considered a failure to physicians. In fact, medical school educators are finding it difficult to teach about dying and death when they themselves were instilled with ideas that would be contrary to their professional oath to save lives.⁷²

The authors of the U.S. study called for structured, systemwide plans that include: (1) integrating palliative and end-of-life care into the curriculum; (2) requiring a rotation in palliative care, hospice and home care/death experience and continuing education for attending physicians; and (3) providing sustained observation and feedback (who is qualified to provide care?) on clinical and communication skills related to end-of-life care. The British study called for “creating robust academic palliative medicine departments to lead and support these advances.”⁷³

Susan Block, MD—a leader in developing hospice and palliative medicine and innovative educational programs and involved in the aforementioned studies—summarized that although there are still huge gaps in medical education, they are otherwise improving. She recounts that there is more integration of classroom-based training in palliative care, exposure to palliative care services, elective opportunities for students and residents, and culture change in some of the large teaching hospitals.

Nursing Programs

Unlike physicians who perhaps spend less than a few minutes per day with the patient, nurses on an 8-hour hospital or hospice shift spend more time on average with patients and their families.⁷⁴ This makes nursing the profession in the most immediate position to provide care, comfort and counsel to patients facing the end of life.⁷⁵

Although nurses are on the front lines, there is a large gap in the education and training of nurses providing end-of-life care. Both nursing and medical schools offer less than one-fifth of a full semester course on end-of-life topics^{76, 77} and when such electives were offered, they were taken only by a minority of students.⁷⁸ In 2005 and 2006, nursing and medical schools overwhelmingly reported having offered educational programs in end-of-life and bereavement issues with more than 90 percent of their students participating.⁷⁹ But despite this topic’s inclusion in the curriculum, an average of fewer than 15 hours was devoted to it.⁸⁰ This allotment merely exposes students rather than provides an in-depth understanding of the subject.

Medical and nursing schools are in a prime position to educate and provide quality training in end-of-life care. Most medical school deans are in favor of integrating end-of-life care into existing courses or clerkships, rather than as stand-alone programs, because segmenting this topic from the rest of the curriculum detracts from gaining better overall exposure on an important perspective.⁸¹

Other Health Care Professions in End-of-Life Care

There are other key players in end-of-life care. For example, social workers “have unique, in-depth knowledge of and expertise in working with ethnic, cultural, and economic diversity; family and support networks; multidimensional symptom management; bereavement; trauma and disaster relief; interdisciplinary practice; interventions across the life cycle; and system interventions that address the fragmentation, gaps, and insufficiency in health care.”⁸² Social workers offer a unique perspective to advanced illness management. But like physicians and nurses, there are also substantial gaps in their education in end-of-life care even though they are well-positioned to provide psychosocial support.⁸³

As another example, psychologists have the training and exposure to provide mental health treatment to those with major chronic illness.⁸⁴ They bring a unique asset to the field because of their ability “to conduct psychological assessments, build teams, evaluate programs and facilitate communication among the variety of players involved—patients and loved ones, patients and medical staff.”⁸⁵ Not only are they able to provide prescription management and ensure treatment compliance, they are also able to offer pain management to patients using expertise in techniques such as clinical imagery and biofeedback.⁸⁶ There is a high demand for psychologists in advanced illness care, but like the aforementioned health care professionals, they are also scarce.⁸⁷ Nevertheless, the psychological practice is expanding and embracing end-of-life care.

This report highlights several health care professionals in end-of-life care, but the intent is not to overlook other key contributors in the field. These include case managers, dietitians, pharmacists, complementary therapists, caregivers and certified nursing assistants (CNA). All play an integral role in advanced illness management.

An Emerging Recognized Field

Between 1996 and 2006, the American Board of Hospice and Palliative Medicine (ABHPM) certified hospice and palliative medicine physicians. However, ABHPM was not recognized by the American Board of Medical Specialties (ABMS). In 2006, ABMS recognized palliative medicine as a subspecialty of 10 participating boards. Dale Lupu, one of the leaders in this 10-year effort, noted that specialty recognition is a path for codifying knowledge and skills into the curriculum, residencies and fellowships.⁸⁸ Although voluntary, ABMS recognition “is used by the government, health care systems and insurers as evidence of high standards.”⁸⁹

In conjunction with the 10 participating boards, the Accreditation Council for Graduate and Medical Education (ACGME) immediately began the process of accrediting hospice and palliative medicine fellowship training. However, the American Academy of Hospice and Palliative Medicine (AAHPM) task force criticized ACGME’s palliative care requirements for nonpalliative residencies and fellowships as minimal and vague, and the requirements of the Liaison Committee on Medical Education for undergraduate palliative education as shallow.⁹⁰

Changing the Approach

Ninety percent of the American public identified advanced illness care as a top priority for the health care system while 86 percent wanted a public discussion about it.⁹¹ There is consensus to change the current approach of advanced illness care, but a common language is still needed to bridge the communication gap among consumers, health professionals, members of the media and policymakers.

Core competencies for specialists have been put forward and are posted on the AAHPM website.⁹² Basic palliative competencies for nonspecialists are being designed (currently for internists and family physicians). The developers are aiming to define 12 competencies in several domains such as pain and symptom management, psychosocial support, spiritual support and communications.

Foundation: Communicating and Understanding

Empathic, skillful communication is at the heart of palliative and hospice care. Both patients and families have better outcomes when a physician is skilled in communication. “Physician ability to identify and respond to emotion and to effectively share prognostic information” is correlated with better outcomes for both patients and families.⁹³ Proactively intervening to manage symptoms and having family meetings can reduce ICU days and improve bereavement outcomes. “Empathic communication, skillful discussion of prognosis, and effective shared decision making are core elements of quality care in the ICU, represent basic competencies for the ICU physician, and should be emphasized in future educational and clinical interventions.”⁹⁴

Breaking the Bad News: The Prognosis

Critical care nurses and physicians describe communicating a prognosis as “painting a picture” so that families can visualize, comprehend, anticipate and prepare for potential responses including death.⁹⁵ There are two ways of delivering a prognosis: informal and formal communications. For the former, conversations typically occur during medical rounds, when family members are in proximity.⁹⁶ These are often spontaneous and brief.⁹⁷ Meanwhile, the latter occurs when significant negative prognostic information becomes available and needs to be broached to both the patient and the family for the first time.⁹⁸ Research data suggests that the difference between the two forms of prognosis delivery is that ambiguity, expression of hope, and uncertainty are absent in formal communications.⁹⁹

Both critical-care physicians and nurses perceive that it is the physician’s responsibility and role to communicate prognostic information.¹⁰⁰ Even though nurses possess intimate knowledge about patients and their families as a result of their proximity and constant interaction at the bedside, there are “unspoken boundaries” precluded from their domain of practice.¹⁰¹ In a study conducted to shed light on the actual prognostic communication of nurses, physicians did not solicit information from them during a family conference.¹⁰² Despite nurses’ interest in taking part in these conversations, it is plausible that physicians did not want their participation for fear of inconsistent messages being delivered to the family that could confuse or provide a sense of hope and, most of all, detract from aligning and understanding the prognosis and goals for care.¹⁰³

While medical culture does not foster shared responsibility in delivering a patient’s prognosis, communication between physicians and nurses regarding end of life will have a positive impact on quality of care. In fact, active participation of nurses has found to have improved both patient outcomes and nurse satisfaction.¹⁰⁴

During an end-of-life care conference, the decision-making responsibility shifts from the provider to the patient and family. This suggests the reluctance of the former to assume the moral burden for death.¹⁰⁵ In fact, during these conversations, physicians greatly emphasize the statement “you need to decide” or “you need to make the decision.”¹⁰⁶ Despite this shift, providers and other knowledgeable sources still need to translate personal wishes into services and structures through which personal preferences can be met. They will need to acknowledge important dimensions of life including spirituality and cultural diversity of health care users to successfully deliver the appropriate care.

Spiritual Sensitivity

A life-threatening diagnosis has a profound effect on people. Questions relating to identity and self-worth begin to emerge as patients seek to find the ultimate meaning of their lives.¹⁰⁷ Therefore, understanding the role of spirituality in AIM is just as important as adopting a caring attitude and disposition. While sometimes synonymous with religion, spirituality as a broader concept is “the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.”¹⁰⁸

Religious and nonreligious adults overwhelmingly expressed reclaiming and reasserting the spiritual dimensions when faced with death.¹⁰⁹ For this reason, it would be advantageous for health care providers to familiarize with the patient’s spirituality in AIM because (1) it may be a factor in the patient’s understanding of the disease, (2) religious convictions may affect health care decision making, (3) it may be a patient need and a vital coping strategy and (4) it is integral to the entirety of patient care.

As a partner in the therapeutic relationship, “a skillful, caring and compassionate health care professional can be an important anchor in which the patient can find solace and strength to move through distress to peace and acceptance.”¹¹⁰ Of 456 patients surveyed, two-thirds felt that physicians should be aware of their religious or spiritual beliefs while 50 percent desired for spiritual interaction with their physicians in a near-death scenario.¹¹¹

Unfortunately, health care providers are having difficulty defining spiritual care from psychosocial or psychological and emotional care.¹¹² For example, nurses revealed in a spirituality survey the need for clarification in drawing personal and professional boundaries, support in dealing with this issues and guidance and education.¹¹³

To educate health care providers and other caregivers as they provide care and support to patients with advanced illness, programs like the Sacred Art of Living Center (SALC) for spiritual formation, established by Mary and Richard Groves, have emerged. This center offers a workshop for caregivers that acknowledges and incorporates spirituality in clinical care. The two-day workshop, Sacred Art of Living and Dying, provides training and certification programs for health care providers, hospice professionals, faith community leaders and the general public for spirituality in end-of-life care. Program participants explore universal patterns of spiritual and emotional suffering and are taught time-tested ways to relieve them, based upon ancient wisdom traditions with respect to contemporary clinical research. (See Case Study 7.)

Cultural Competence

Although non-Hispanic whites are still the largest race and ethnic group in the United States (64 percent of the population), their growth is much slower (1 percent) in comparison to other races such as Hispanics and Asians, which have relatively higher levels of immigration.¹¹⁴ About one-third of the U.S. population is now comprised of ethnic minorities.¹¹⁵ With this type of racial distribution, it is evident that people will differ in values and beliefs, including preferences about end-of-life care.

Having cultural competence can better equip health care professionals in addressing sensitive matters to patients and their families. This type of competence includes acknowledging diverse attitudes and cultural practices when translating the wishes of patients and their families facing the end of life. According to Searight and Gafford (2005), there are at least three interrelated dimensions to the differences in beliefs and values of racial groups: “communication of ‘bad news,’ locus of decision making, and attitudes toward advance directives and end-of-life care.”¹¹⁶ Below are examples of data that highlight the preferences of various racial backgrounds:

- Asian Americans, Hispanic Americans and African Americans are less likely to complete advance directives.¹¹⁷ For example, about two-thirds of older white patients completed advance directives in comparison to only one-third of older black patients.¹¹⁸
- A majority of Arab Americans indicated a preference to be cared for by family members rather than enter a nursing home.¹¹⁹
- African Americans expressed preference to receive care in nursing homes and hospitals.¹²⁰
- Non-Hispanic whites preferred to die at home but did not believe that end-of-life care was their family’s responsibility; therefore they were open to the idea of hospice care, hospitals and nursing homes.¹²¹
- Both Hispanic and African American men wanted minimal medical intervention while women in both ethnic groups wanted more extensive intervention at the end of life.¹²²

Recognizing and understanding the different racial preferences should not be the only factor in determining how health care professionals approach and deliver care to patients nearing the end of life. It is also important to avoid generalizing and making assumptions based on appearances. While some people maybe be born to a particular culture, they may not necessarily identify with that group and sometimes may identify with more than one.¹²³ Cultural competence should begin with acquiring general knowledge and leaving room for open communication to prevent stereotyping.¹²⁴

Guidelines and Standards

More than 70 percent of large (200+ beds) hospitals report having a palliative care program.¹²⁵ During the past decade, several national forums have drawn upon a broad range of thought and practice leaders to develop a

consensus about guidelines, standards and metrics for palliative care.¹²⁶

- *Clinical Practice Guidelines for Quality Palliative Care* from the National Consensus Project for Quality Palliative Care (NCP 2004; updated 2009) outlines eight domains for palliative care programs: structure and processes, physical, psychological, social, spiritual, cultural, ethical and legal, and care of the imminently dying.
- In 2006, the National Quality Forum (NQF) published *National Framework and Preferred Practices for Palliative and Hospice Care Quality* that identified 38 preferred practices, based on NCP's work, which form the basis for quality metrics.
- In 2008 and 2009, the Center to Advance Palliative Care (CAPC) convened a consensus development process among leaders in the field and published a three-part series of recommendations with additional operational details.

CAPC's first set of 22 recommendations is separated into "must-haves" and "should-haves" in 12 domains. All the groups agree that key "must-have" elements of a palliative care program should include:

- an interdisciplinary clinical team (physician, nurse, social worker, spiritual counselor; others);
- staff trained, credentialed and/or certified in palliative care;
- 24/7 access and responsiveness.¹²⁷

Academic Programs in Palliative Care

In a 2010 position paper, the AAHPM task force of experts drew upon the clinical guidelines work of NCP, NQF and CAPC to develop a set of recommendations to help palliative care faculty and their department chairs, deans and other stakeholders build an administrative and educational infrastructure for viable, high-quality, academic, palliative care programs.

Establishing a new specialty is always difficult, but the task force pointed out why hospice and palliative medicine has distinguishing features that make it particularly challenging: interdisciplinary staffing across multiple settings and the enormous time commitment it requires. Palliative medicine therefore calls for new thinking about organizational structure and how to measure "staffing productivity, compensation incentives, and administrative support."¹²⁸

Palliative care is delivered by interdisciplinary teams. In addition to the team's core members, multiple medical specialists are often involved, as well as nutritionists, physical therapists, occupational therapists and other professionals. Although this teamwork and coordination fit well with health care quality and safety improvement movements, administratively it means multiple reporting lines and financial challenges. Some services are covered by the bed rate and some not at all. Even for reimbursable services, reimbursement rates are inadequate because so much time is expended. Palliative medicine clinicians usually report to administrative leaders whose experience with hospice and palliative medicine is limited.¹²⁹

Clinical care delivery issues—expectations of productivity, incentive plans, billing, business planning, and required interdisciplinary collaboration with other colleagues from other health care disciplines—may also be different from other fields. Colleagues in other specialties or administrative leaders may not appreciate the need for very long consultations, frequent family meetings, the interdisciplinary nature of the work, and the significant emotional impact this work can have on faculty.¹³⁰

Because palliative medicine is taught, investigated and practiced across multiple settings, integrating the diverse continuum of care may be unfamiliar to administrative leaders, resulting in the "underestimation of both the tremendous potential and the unique support needs of a comprehensive palliative care continuum of care."¹³¹

Palliative care also requires substantial investments of time in communication, coordination and ensuring 24/7 continuity across settings. Therefore, conventional productivity expectations and metrics are not a good fit. Palliative care revolves around communicating with and supporting patient and family members, exploring alternatives and negotiating wrenching decisions and bereavement care after death. The scope of care is much broader than biomedical, and the intensity of emotions, decisions, crises and emergencies draws energy and time. “Many consultations are urgent or emergent in nature and must be completed in a timely manner. Palliative medicine specialists require rapid access to disciplines, such as social services, pastoral care, rehabilitation, nutrition, counseling, and advanced practice nursing.”¹³² Care must be coordinated around interacting clinical conditions in a weakening body, across disciplines and settings and with community-based agencies.

Because of the complexities involved in developing and managing palliative care programs, the Harvard Medical School Center for Palliative Care (HMS CPC) was established by Drs. Susan D. Block and J. Andrew Billings to serve as a national and international resource for the best practices in palliative care education. The program fosters health care leadership and supports palliative educational programs aimed to alleviate suffering and enhance the care of patients and their families facing severe and life-threatening illness. HMS CPC offers three continuing education opportunities to physicians, nurses and other health care professionals. (See Case Study 8.)

To develop balance between curative treatments and reduce suffering from chronic or life-limiting illness, the Education on Palliative and End-of-Life Care (EPEC) was established. This comprehensive training program is aimed at educating physicians on the clinical competencies required to provide quality and compassionate care to patients facing the end of life.¹³³ Based on adult education theory, the program uses interactive techniques and application of social science principles to change social expectations and behavioral norms. To disseminate its curriculum, EPEC uses the “train-the-trainer” approach to increase physician knowledge. (See Case Study 9.)

Much like the EPEC train-the-trainer approach, there are national educational initiatives that improve palliative care for other health care professionals. End-of-Life Nursing Education Consortium (ELNEC), for example, is aimed at educating nurses to improve end-of-life care.¹³⁴ ELNEC provides palliative care training to undergraduate and graduate nursing faculty, continuing education providers, staff development educators, specialty nurses in pediatrics, oncology, critical care and geriatrics and other nurses.¹³⁵ With a curriculum that focuses on the core topics of end-of-life care, participants teach what they have learned to nursing students and practicing nurses. Since this program was established, trainers have trained more than 390,000 nurses and other health care providers.¹³⁶

Table 3. Hospital Strategies to Create a Ready, Willing and Able Workforce

Hospital Strategies to Create a Ready, Willing and Able Workforce	
Educational Strategies	
	Offer ongoing training for health care professionals to learn the necessary skills and competencies to engage in sensitive conversations with patients facing advanced illness.
	Educate and train health care providers on the role and impact of spirituality in end-of-life care. There is a high demand for acknowledging and incorporating spirituality in health care, especially among patients nearing the end of life.
Toolkits for Multidisciplinary Teams	
	Develop a multicultural guide. Used to assess the cultural beliefs and values of patients and their families, this tool should include questionnaires that clarify preferences for end-of-life care with respect to diversity. The goal is to assist health care professionals in their conversations and interactions with patients and their families. (Examples are Multicultural Care: A Clinician's Guide to Cultural Competence published by the American Psychological Association and A Toolkit for Serving Diverse Communities by the U.S. Administration on Aging.)
	Develop a spiritual toolkit. This tool should complement the multicultural guide. The objective is to delve beyond racial differences—such as the cultural and religious nuances involved—and assist health care professionals in providing care with awareness and sensitivity to the dimensions of life and imminent death. (An example is A Dictionary of Patients' Spiritual & Cultural Values for Health Care Professionals developed by the HealthCare Chaplaincy.)
Collaborative Strategies	
	Create a collaborative environment for the multidisciplinary team to improve communication during end-of-life care. Providing a venue for health care professionals to share ideas and to communicate can increase accountability and maintain consistency of information, thereby impacting the delivery of information.
	Leverage patient-family advisory councils that would mobilize in communicating the message. Advisory councils can be a significant ally in helping patients and their families arrive to a consensus on a health care decision.
	Provide or make available, to the palliative care workforce, comprehensive training in educating patients and their families during health care interactions. The scope of end-of-life care extends beyond the traditional clinical aspect. Health care professionals must integrate a holistic approach in their practice, such as social balance.
Organization and Leadership Strategies	
	Create a solid leadership foundation and program infrastructure to sustain a successful palliative and end-of-life care program. For palliative and end-of-life care programs to thrive, hospitals must acknowledge the value of the continuing education of their leadership, who will not only impart knowledge to the rest of the team but also develop and launch successful AIM initiatives.

Source: AHA CPI, 2012.

Case Study 7

Sacred Art of Living Center

The Sacred Art of Living Center (SALC) for spiritual formation in Bend, Oregon, was cofounded by Mary Groves and Richard Groves, a pastoral counselor and hospice chaplain. Since 1997, they have offered programs for spiritual formation for caregivers.

Background

The flagship workshop-retreat series of SALC, the Sacred Art of Living and Dying (SALD), is the nation's first comprehensive training and certification program for spirituality in end-of-life care. This program explores universal patterns of spiritual and emotional suffering and time-tested ways to relieve them based upon ancient wisdom traditions and contemporary clinical research.

The SALD program series is offered throughout the United States and Canada and in more than 15 countries. Since its inception, more than 30,000 participants have attended, ranging from health care providers and hospice professionals to faith community leaders, from all spiritual traditions and including the general public. The program has drawn 15 percent medical doctors, 22 percent nurses, 21 percent mental health professionals, 19 percent chaplains/clergy and 22 percent of the general public.

What They Did

The SALD program series is taught in seminaries of all faith traditions,¹³⁷ and its nondenominational approach is designed to respect the spiritual path of every participant regardless of religious affiliation. This two-day program is divided into four units: understanding, diagnosing, healing and transforming spiritual pain. Each unit is an interactive learning experience and incorporates a blend of best practices, instruction, personal reflection, hands-on experience, multimedia presentation and creative rituals from great wisdom traditions all over the world. The aim is to train participants to become "contemplative caregivers."

Unit 1: Understanding Spiritual Pain

Participants learn about the rich cultural history and clinically sound practices for detecting and alleviating spiritual and emotional distress at the end of life. Caregivers learn valuable models for addressing death anxiety as the most critical issue for the dying person.

Unit 2: Diagnosing Spiritual Pain

Participants study in depth the time-tested primary diagnoses of spiritual pain: forgiveness, relatedness, meaning and hope. They examine the relationship between ethical and religious-based decision making and enhance their ability to recognize and celebrate the final gifts of growth and transformation revealed at the end of life.

Unit 3: Healing Spiritual Pain

Participants are mentored in a wide range of creative and effective psychospiritual tools for end-of-life care. The spectrum of practices includes art and music therapies, guided imagery, coma work and prescriptive ritual tailored to the spiritual belief of each patient. Holistic therapies are drawn from the world's great spiritual traditions and applied with contemporary scientific skills.

Unit 4: Transforming Spiritual Pain

Based on lessons that the experience of dying teaches the living, this retreat format allows for ample reflection on the meaning of end-of-life ministry. Exercises include meditation, life-priorities evaluation and self-care skills for maintaining a centered, professional presence.

Results

The workshop-retreat series received accolades from multiple health care providers and institutions, religious leaders and authors in the United States and internationally. Mother Theresa of Calcutta described the work as necessary because it takes more than medicine to alleviate human suffering. The San Diego Hospice and Institute of Palliative Medicine lauded the holistic approach of the workshop-retreat series for having introduced a common language for all caregivers in naming and responding to spiritual suffering.

Based on more than 30,000 participant evaluations, the program received ratings of 94 percent to 98 percent in overall program experience, practical usefulness of the series, meeting program goals and objectives, applicability for clinical practice and usefulness for personal/spiritual development.

Lessons Learned

Various factors contributed to the success of the SALD program including:

- Offering a holistic model for healing drawn from great wisdom traditions with respect to contemporary science and depth psychology
- Teaching clinically proven practices
- Presenting a universal language for caregiving not available in most professional training
- Offering a learning model that addresses suffering and loss in transformative ways

Sacred Art of Living

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Case Study 8

Harvard Medical School Center for Palliative Care

The Harvard Medical School Center for Palliative Care (HMS CPC) in Cambridge, Massachusetts, was established by Susan D. Block, MD, and J. Andrew Billings, MD, with the sponsorship of the Robert Wood Johnson Foundation. The center serves as a national and international resource for best practices in palliative care education.

Background

HMS CPC fosters health care leadership and supports palliative care educational programs aimed to alleviate suffering and enhance the care of patients and their families who are facing severe and life-threatening illness.

What They Did

HMS CPC offers three continuing education opportunities to physicians, nurses and other health care professionals: Palliative Care Education and Practice (PCEP), Practical Aspects of Palliative Care (PAPC) and Palliative Care for Hospitalists and Intensivists (PCFHI).

Palliative Care Education and Practice (PCEP)

The field of palliative care is rapidly growing, but leaders in clinical care and education are greatly outweighed by the current supply.¹³⁸ In addition, there are major gaps in physician competence and confidence for providing palliative care. More senior physicians tend to overestimate their palliative care competence¹³⁹ while few faculty members feel prepared to teach end-of-life issues.

To bridge this gap, PCEP, in partnership with the Dana-Farber Cancer Institute, Department of Psychosocial Oncology and Palliative Care (DPOPC), was established “to contribute in the training of leaders and educators who can train the next generation of clinicians, and lead new programs to improve access to palliative care services.”¹⁴⁰

PCEP is a two-week faculty development program for physicians and nurse educators who want to gain expertise in clinical practice, teaching comprehensive and interdisciplinary palliative care and leading and managing palliative care initiatives in their institutions. The educational offering is divided into two segments. The first part is a week-long on-site training followed by a six-month distance-learning component, which supports participants developing a project in their own institutions. The second part is another week of continued experiential learning and training focused on communication, teaching methods, teamwork and leadership.

Practical Aspects of Palliative Care (PAPC)

PAPC is a two-and-a-half-day educational offering that provides basic and advanced palliative care competencies for physicians, nurses, allied health professionals and chaplains who work with patients and families facing advanced illness. The annual review course explores cultural issues, communication, prognostication, bereavement, management of various nononcological conditions, special needs of patients at various stages of the life cycle and ethical, legal and practical issues in the advanced illness setting. The program is designed to address “the assessment and management of physical, psychological, social, spiritual, and existential sources of suffering experienced by patients and their families.”¹⁴¹

Palliative Care for Hospitalists and Intensivists (PCFHI)

PCFHI is an educational offering geared toward palliative care specialists who are providing inpatient care for life-threatening illnesses. Since there is a significant number of hospital-based specialists who are in need of training in AIM, this course provides clinicians with the skills and competencies necessary to offer high-quality care to patients nearing the end of life.

Results

The PCEP course was highly effective in meeting its goal of training clinical leaders in palliative care. Ninety percent of program participants reported launching palliative care initiatives and attributed this success to their participation in PCEP.¹⁴² Participants also described the course as “transformative.”¹⁴³ Program surveys demonstrated a change in the program participant’s teaching approach and practice in caring for patients facing advanced illness after completing the program.¹⁴⁴

Lessons Learned

The success of PCEP is attributed to:¹⁴⁵

- Curriculum design and pedagogy that was based on the adult learning theory.
- Distance-learning component, during the six-month interim that catered to the schedule of busy clinician participants.
- Small group sessions and distance learning that were skillfully used in a complementary manner.
- Encouraging participants to expand beyond personal development to address problems of organizational change and systems-based practice.

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Case Study 9

Education in Palliative and End-of-life Care

Education on Palliative and End-of-Life Care (EPEC) is a comprehensive training program aimed at educating physicians on the clinical competencies required to provide quality and compassionate care to patients facing the end of life.¹⁴⁶

Background

In 1997, the Institute for Ethics of the American Medical Association and the Robert Wood Johnson Foundation developed Education on Palliative and End-of-Life Care (EPEC), a comprehensive training program aimed at educating physicians on the core competencies of palliative care.¹⁴⁷

The program's curriculum is "based on adult education theory that emphasizes interactive techniques and the application of social science principles that can lead to changes in social expectations and behavioral norms."¹⁴⁸ To disseminate the curriculum, EPEC uses the "train-the-trainer" approach to increase physician knowledge. The program is structured so course participants can teach others what they have learned in their own institutions.¹⁴⁹

What They Did

To educate physicians on the clinical competencies necessary to provide quality and compassionate care to patients with life-limiting illness, EPEC identified specific goals. First is defining the skills required for end-of-life care.¹⁵⁰ The project staff and 56-member advisory group, consisting of leaders in end-of-life care and education, established the educational needs that the program would address, and the principles that they identified guided the development of the EPEC curriculum. These principles are:¹⁵¹

- The program would be built around the palliative care framework that is to cure, prolong life or have total focus of care.
- The content would include expert opinions about the core competencies of the general practicing physician.
- The program design would cover the entire scope of end-of-life care and address general physician education in comprehensive materials.

The EPEC curriculum that was later developed addresses the medical education gap and teaches critical communication skills essential for end-of-life conversation.¹⁵² It also teaches fundamental skills in ethical decision making, palliative care, pain and symptom management, and other end-of-life issues.^{153, 154, 155} Today, the EPEC curriculum provides a combination of didactic sessions, video presentations, interactive discussions, and practice exercises.¹⁵⁶ The program also offers various versions of its curriculum adapted for specialties such as oncology, emergency medicine, and the care of veterans.¹⁵⁷

EPEC's second goal is to use the train-the-trainer approach to disseminate its curriculum.¹⁵⁸ This model involves educating a cadre of physician or EPEC trainers who will teach what they have learned to a second tier of practicing physicians.^{159, 160} This strategy was adopted under the premises that the educational materials will be useful to those who want to teach others and trainers will utilize them when teaching.¹⁶¹ For example, EPEC distributes to participants slides, videos, and teaching tips and encourages their liberal use with appropriate acknowledgment.^{162, 163}

Results

Studies show that 90 percent of EPEC trainers were actively using its curriculum to teach others.¹⁶⁴ It is estimated that from a sample of 184 initial trainers, they taught 120,000 other professionals.¹⁶⁵ As of 2012, EPEC reports there are more than 2,000 trainers in the United States and 16 other countries.¹⁶⁶ Based on this information, reports estimate that the EPEC curriculum has reached more than 1 million end-learners.¹⁶⁷

Because of its successes, EPEC extended its model and collaborated with various partners to adapt the curriculum to the needs of various and specific populations. This expansion led to programs such as A Progressive Palliative Care Education Curriculum for the Care of African Americans at Life's End (APPEAL), EPEC-Roman Catholic, EPEC-Caregiver and EPEC-India.¹⁶⁸ In addition, to expand the scope and range of palliative care, EPEC and its partners introduced adaptations of the original curriculum into new settings and broadened the definitions to include the entire spectrum of illness.¹⁶⁹ Examples of medical specialty partners include EPEC-Oncology, EPEC-Emergency Medicine and EPEC-Geriatrics/Long-term Care.¹⁷⁰

Lessons Learned

Since its inception, EPEC has solicited feedback from participants to augment its program.¹⁷¹ For example, following development of the curriculum, four regional conferences were held in Phoenix, Atlanta, Boston and Chicago in 1999.¹⁷² In 1999, EPEC educational materials were presented as a working draft to 271 participants who were offered an opportunity to constructively criticize and provide feedback on the program.¹⁷³ A process evaluation was also conducted in the last three field testing sites involving 195 participants.¹⁷⁴ At the end of each workshop module, participants were asked to evaluate the relevance of the topic, effectiveness of the teaching tools and learning objectives of the module.¹⁷⁵ Results show that an overwhelming majority agreed or strongly agreed that (1) the module topics were clinically relevant to the care of patients facing the end of life, (2) EPEC highlighted important concepts, a clear indication of excellent coverage of the topic, and (3) educational materials such as slides and trigger tapes were clear and useful in learning the curriculum.¹⁷⁶

With thousands attending its programs each year, EPEC is continuously finding ways to improve and update its curriculum to meet the needs and goals of future participants and address the growing and evolving educational demands of physicians.

Education on Palliative and End-of-Life Care (EPEC)

(312) 503-3087

<http://www.epec.net/>

Appendix

Resources to improve AIM programs and services:

1. AHA's Committee on Performance Improvement report: *Advanced Illness Management Strategies* (August 2012)
<http://www.aha.org/aim-strategies>
2. Health Research & Educational Trust/Center to Advance Palliative Care guide: *Palliative Care Services: Solutions for Better Patient Care and Today's Health Care Delivery Changes* (November 2012)
<http://www.hpoe.org/resources/hpoehta-guides/1148>
3. AHA's Hospitals in Pursuit of Excellence
<http://www.hpoe.org>
4. AHA's Circle of Life Award
<http://www.aha.org/circleoflife>
5. Center to Advance Palliative Care
<http://www.capc.org>
6. Coalition to Transform Advanced Care
<http://thectac.org/>
7. Institute for Healthcare Improvement's Conversation Project
<http://theconversationproject.org/>
8. Joint Commission's Palliative Care Certificate Program
http://www.jointcommission.org/certification/palliative_care.aspx
9. National Comprehensive Cancer Network
http://www.nccn.org/professionals/physician_gls/f_guidelines.asp#supportive
10. National Consensus Project for Quality Palliative Care
<http://www.nationalconsensusproject.org>
11. National Hospice and Palliative Care Organization
<http://www.nhpco.org/templates/1/homepage.cfm>
12. National Quality Forum's Palliative Care Guidelines
http://www.qualityforum.org/Topics/Palliative_and_End-of-Life_Care.aspx
13. Respecting Choices
<http://respectingchoices.org>

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