




Advanced Illness Management Strategies

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A report from the AHA Committee on Performance Improvement:

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The APPENDIX identifies a number of valuable resources, including the AHA's Circle of Life information that can be found at www.aha.org/circleoflife.

Executive Summary

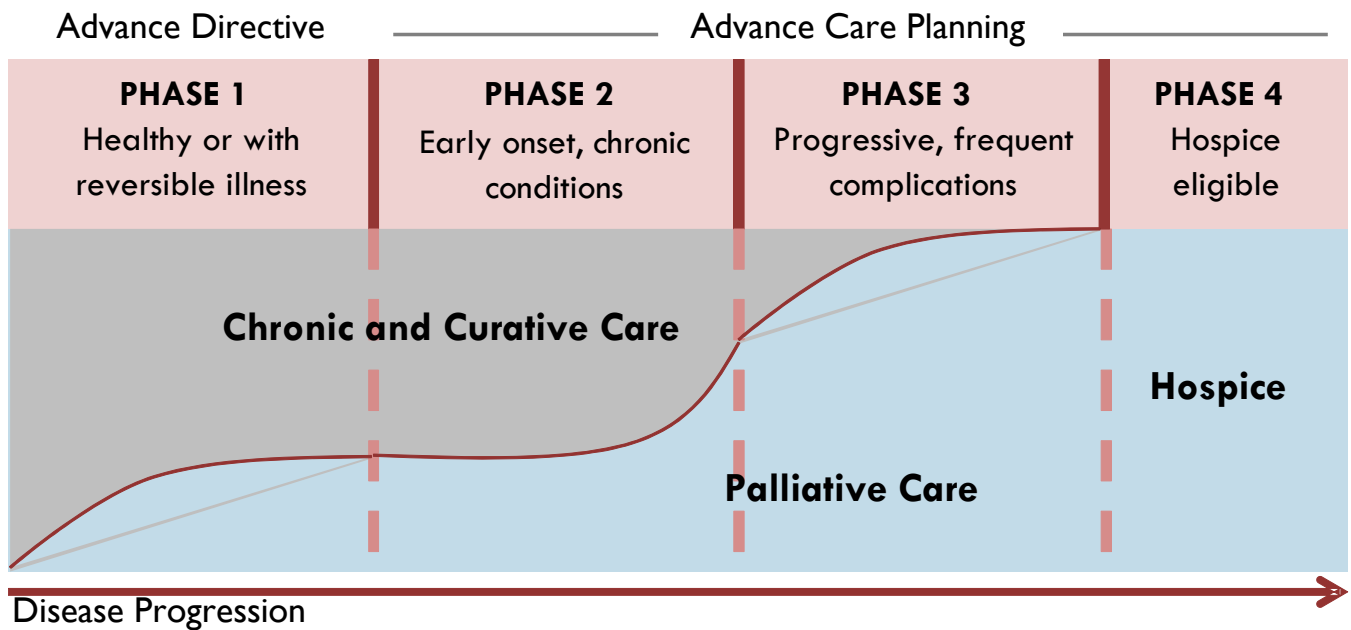
The American Hospital Association (AHA) Board Committee on Performance Improvement (CPI) was created in 2010 to support performance improvement across the AHA membership to align with the AHA's strategic platform—Hospitals in Pursuit of Excellence. The inaugural 2011 CPI report *Hospitals and Care Systems of the Future* is based upon economic futurist J. Ian Morrison's "first-curve-to-second-curve" framework. It describes the shift of payment incentives impacting health care providers' core business models in terms of care and service delivery and demonstrates why progressing from the first curve to the second curve is a vital transition for hospitals.

In 2012, CPI focused on approaches to managing *life in the gap*—the transition period between the first-curve and second-curve economic markets, specifically in **advanced illness management (AIM)**. Hospitals are uniquely positioned to implement best practice strategies to 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 care team throughout disease progression. Effectively integrating AIM into the continuum of care will position the hospital and health system to manage the gap between the first and second curve and support the transition to the second-curve business, care and service delivery model.

Defining AIM

While many people can and do recover from serious potentially life-threatening illnesses, such as cancer, the trajectory of "advancing illness" leads to death. That decline in health and physical and/or mental capacities needs to be matched by the nature, scope and goals of care. "End of life care", "serious illness" or "advanced illness" are some of the terms used to categorize the set of services for patients and families during the course of illness. The Coalition to Transform Advanced Care (CTAC) defines 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." For the purpose of this report, AIM is being used as the overarching term.

As depicted in the figure on the following page, AIM evolves through four phases as the patient's health declines. During the first phase, people are basically healthy and can recover from reversible illnesses. Their major AIM actions are to have conversations with trusted family, friends and providers, and sign an advance directive. A person in phase two typically has manageable, early or stable chronic condition(s) for which palliative care may supplement disease treatment as part of maximizing quality of life. Phase three begins when the condition(s) continue to progress, placing increasing limits on the person's activities, independence and quality of life. The final phase begins when the person is deemed hospice-eligible. Although there are four main segments to AIM (advance directives, palliative care, advanced care planning and hospice care), successful programs integrate these four segments into one overarching AIM initiative. The treatment plan will increasingly be driven by the personal goals and decisions of the patient and his or her family.



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

Why AIM?

Studies evaluating clinical, satisfaction and process measures explore the ability of AIM to reduce pain, increase quality, improve patient and family satisfaction and remove some of the inefficiencies within the health care system. Studies show that:

- Patients receiving palliative care have improved quality of life and fewer major depressive symptoms based on Functional Assessment of Cancer Therapy Scale (FACT-L)ⁱ
- Family and caregivers are five times more likely to have post-traumatic stress disorder and 8.8 times more likely to have prolonged grief disorder if the patient dies in the ICU compared to at home with hospice.^{ii iii}
- Medicare patients with AIM use 13.5 days of hospital care in the last two years of life compared to 23.5 as the national average^{iv}
- On average, patients who received palliative care incurred \$6,900 less in hospital costs during a given admission than a matched group of patients who received the usual care.^v

Goals of AIM and Strategies to Meet Them

The goals of AIM are to improve patient and family satisfaction, increase quality of care, reduce inefficiencies and increase care coordination. This will exist in an environment where:

1. All hospitals and care systems are able to support and deliver high quality AIM;
2. All health care professionals have the knowledge and skills to provide AIM care; and
3. Every patient and his or her family have the knowledge and skills to understand the benefits of advanced illness planning.

The literature points to three key strategies that hospitals should implement to pursue the goals of well-developed AIM initiatives:

1. **Access:** Patient access to AIM services can be greatly increased when all hospitals and care systems are able to support and deliver high quality AIM.
2. **Workforce:** Excellence in AIM depends upon educating and training all health care professionals to provide care over the continuum of health and decline.
3. **Awareness:** Patient and family AIM awareness and understanding of the benefits of advanced illness planning and management can be significantly raised through community-wide strategies.

The current report frames the AIM issues and examines in further depth the first strategy on access to AIM services. A second report will examine workforce and awareness strategies.

Strategy: Increasing Access to AIM Services

Hospitals should examine how they can increase access to AIM services, both across their patient population and across the care continuum. Which treatments patients will want as illness progresses varies based on their age, specific condition, availability of medicine to sustain life and family and caregivers.

Larger organizations have the opportunity to develop full-scale initiatives, while smaller and rural hospitals and care systems may partner with other community entities to achieve the same goals. Successful organizations integrate specific characteristics of each service into one program that would best care for their surrounding populations. Other keys to success include:

1. Developing a multidisciplinary care team with leadership buy-in;
2. Identifying qualifying patients through evidence-based protocols;
3. Thinking beyond the traditional four walls of the hospital to promote AIM collaboration throughout the surrounding community; and
4. Using a performance improvement framework to measure, monitor, evaluate and adapt program between disease states and throughout time.

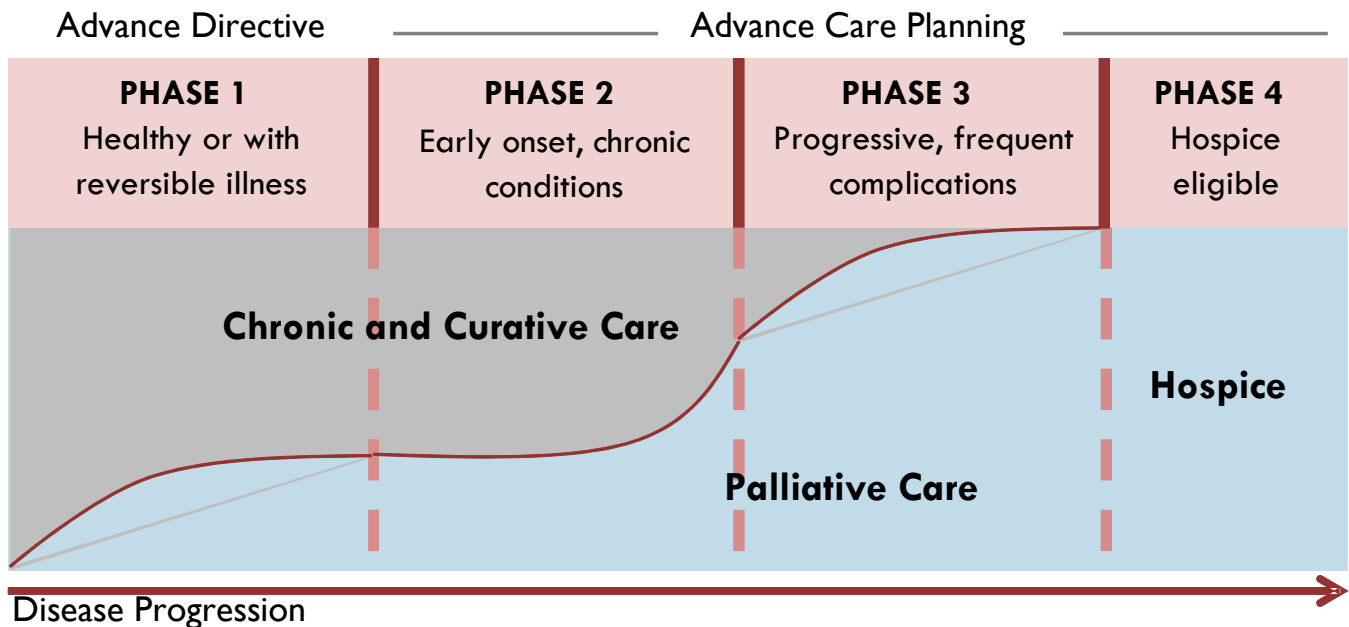
Defining AIM

The trajectory of “advancing illness” leads to death. While many people can and do recover from a serious illness, “advancing illness” can be managed and held in check for only so long (it can be decades, years or months) before it does not respond to existing chronic and curative treatments. Depending on the nature of the illness, it begins to limit what the person can do, produces complications that reduce quality of life, compromises their ability to live independently, and/or interacts with other chronic or emergent conditions to weaken the entire body. Managing its care requires proactive disease management, and balancing changing, expanding needs with the patient’s goals. Ideally, advancing illness is managed as a coordinated continuum of care where quality of life becomes the primary goal of care in its later phases.

Figure 1 depicts four continuous phases of AIM. As the patient progresses through each phase, the nature of care evolves, but the quality remains the same—person-centered, integrated care by a multidisciplinary team of health care professionals adhering to evidence-based, best practice guidelines. The treatment plan is driven by the personal goals and decisions of the patient and his or her family. During the first phase, people are basically healthy and can recover from reversible illnesses. Their major AIM actions are to have conversations with trusted family, friends, and providers and sign an advance directive. A person in phase two typically has manageable, early or stable chronic condition(s). Palliative care may supplement disease treatment as part of maximizing quality of life. Phase three begins when the condition(s) continue to progress, placing increasing limits on the patient’s activities, independence and quality of life. The final phase begins when the person is deemed eligible for hospice.

Although each phase can be denoted by a key marker, successful programs integrate these four segments into one AIM initiative, combining important aspects of each.

Figure 1: Phases of AIM



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

Advance Directives

Advance directives should be started during phase one. An advance directive is made by a mentally capable person regarding goals of care or treatments for a possible or probable health event. It can be expressed orally or in writing. While having a legal document is important, informing trusted family members, friends and care providers about one's intentions, values and preferences allows care providers and family to accurately interpret the patient's will while minimizing guilt.

Advance Care Planning

Anticipatorily planning is an ongoing process and should be based on potential or likely disease scenarios and future medical decisions. The patient and his or her family caregiver need to understand the disease course and make medical decisions based on that information. They need to reason and reflect about their preferences, discuss them and share their legal documents with those who need to carry out their intentions. With the objective of knowing, understanding and documenting a patient's preferences and intentions, an effective plan should include four main parts: 1) the selection of a well-prepared health care agent or proxy; 2) the creation of specific instructions that reflect informed decisions geared to the person's health state; 3) the availability of these plans to treating physicians; and 4) the incorporation of these plans into medical decisions.^{vi}

Palliative Care

Palliative care encompasses a broad spectrum of care services aimed at alleviating uncomfortable, debilitating, painful or embarrassing symptoms of a disease or side effects of treatment—such as hair loss and nausea from chemotherapy, or shortness of breath from chronic obstructive pulmonary disease. It can be provided concurrently with curative care (care to cure the patient of the disease) or by itself. It aims for achieving the best quality of life possible at any phase of a disease. Palliative care can be delivered in homes, hospitals, intensive-care units, clinics, nursing homes, assisted living or hospice. It can include emotional, social and spiritual care, as well as medical care.

Palliative care is employed to relieve the symptoms causing discomfort, anxiety and suffering as the body deteriorates. It can greatly improve the quality of life for persons with advancing illnesses and the quality of their time with friends and families. It can be provided in conjunction with other appropriate medical treatments, including curative and life-prolonging therapies (Figure 1). As the illness advances, the range of palliative care services utilized in treatment expands. Palliative care is provided by a multidisciplinary team of doctors, nurses, chaplains, social workers and other specialists who assess and treat symptoms, explore care goals, coordinate care, provide support for complex decision making and provide practical, spiritual and psychosocial support.^{vii}

Palliative care specialists recognize and know how to treat symptoms and their interrelationships. For example, a person suffering from end-stage heart failure may want cold water even though their extremities are cold and blue. This is because the heart is working to protect core organs, not extremities and the person may be too warm. Perhaps she suffers from a urinary tract infection (UTI) and becomes agitated, restless and confused. The UTI or medication could be contributing to the restlessness or present as delirium and confusion. The expertise of palliative care specialists can be illustrated by the kinds of symptoms and their interrelationships that they recognize and know how to treat while other health professionals might not recognize the interrelationship.

Hospice

Hospice is a philosophy and a comprehensive yet flexible set of services designed to meet the fluctuating, changing and expanding medical, social, emotional and spiritual needs of those approaching the last stages of life. In order to qualify for the hospice benefit, Medicare requires that two physicians certify a patient's prognosis of six months of life or less and the patient foregoing life-extending treatments. Rather than "fighting" the disease and attempting to cure it, hospice allows the advancing illness to take its course while making the patient as physically and mentally comfortable as possible. Its goal is to improve symptom management and quality of life for patients with a terminal illness. Intriguingly, patients often live longer under hospice care than patients who don't enter hospice.

Hospice care includes a broad array of palliative care and support services provided by a multidisciplinary team. Usually headed by a registered nurse, the team includes licensed practical nurses and social workers who meet regularly with the hospice medical director. The team is supplemented by on-call nurses, night nurses, chaplains, schedulers, volunteers and others. Although some hospices offer residential services, most care is delivered in the home or nursing home. Caregivers can receive instructions and guidance on how to care for their dying loved one. For example, they are trained on repositioning the person so they don't get bedsores, and transferring the person from chair to wheelchair to toilet and lifting them up again without injuring their own backs.

One of the most startling changes that family caregivers notice when working with hospice is how easily and quickly palliative medications are available to address new symptoms. At the outset of the relationship, the family caregiver has a long meeting with the registered nurse, during which they identify drugs that can be dispensed immediately and later checked with the patient's physician or the medical director. During this meeting, varying dosages and medication forms are discussed (liquids when swallowing pills become problematic; suppositories when swallowing anything is an issue). Therefore, when an uncomfortable symptom appears, the caregiver does not have to call the doctor, wait for a callback, wait for the pharmacy, and figure out how to get it delivered. Instead, the item has been anticipatorily preordered on the protocol, the nurse lets the pharmacy know what's needed, and within a short timeframe, the pharmacy delivers it to the home. The pharmacy also delivers listed pharmaceuticals (such as lorazepam and morphine) for which a log is kept and monitored to the drop.

Why AIM?

U.S. health care spending has increased dramatically for the past two decades, with care during the last six months of life driving a large part of that spending. According to the Agency of Healthcare Research and Quality (AHRQ), 5 percent of the population accounts for 49 percent of total health care expenses. Currently, 90 million people in the United States live with at least one chronic illness, and seven out of 10 die from chronic disease^{viii} and by 2050, the U.S. Census Bureau projects the population 85 years and older will reach nearly 21 million. As the population grows older, it is more likely to suffer from multiple, chronic diseases. Multiple chronic conditions typically require more clinical treatments, are costlier to treat, experience lower quality outcomes and demand higher care coordination to manage effectively.

American hospitals are rapidly filling with seriously ill and frail adults. Most people facing advancing illness will end up in the hospital at some point in their illness, typically at the end of life. However, more than 80 percent of patients say that they wish to avoid hospitalization and intensive care during the terminal phase of illness, according to the Dartmouth Atlas of Health Care. AIM success reduces hospital admissions and unnecessary utilization, improves clinical outcomes, patient and family satisfaction and length of stay and honors the wishes of the person being treated. Table 1 aggregates study results that have investigated the benefits of well-developed AIM programs.

Table I. Proven Results of AIM

Quality	Hospitals using AIM provide patients with improved quality of life, reduced major depression and increased length of survival.
	<ul style="list-style-type: none"> Improved quality of life when referred to earlier palliative care based on Functional Assessment of Cancer Therapy Scale (FACT-L).^{ix} Fewer patients in a palliative care group versus a standard group had major depressive symptoms (16% versus 38%).^x Median survival among early palliative care patients is longer (11.6 months versus 8.9 months).^{xi} Patients with cancer who died in an intensive care unit or hospital experience more physical and emotional distress and worse quality of life at the end of life compared with patient who died at home with hospice.^{xii} Patients referred to hospice care over non-hospice care saw an increased mean survival of 29 days (varying by disease from 81 days for congestive heart failure to 4 days for prostate cancer).^{xiii}
Utilization	Overall, patients enrolled in AIM experience a lower utilization of clinical treatments and hospital admissions at the end of life, due to improved coordination and honoring the patient and family’s wishes.
	<ul style="list-style-type: none"> Medicare patients with AIM use 13.5 days of hospital care in the last 2 years of life compared to 23.5 as the national average.^{xiv} Fewer ICU admissions^{xv} and as much as an 85% reduction in ICU days.^{xvi} Reduced number of ED visits (2002 CAPC survey) with one system experiencing a 25% reduction in ED visits for its AIM patients.^{xvii} Reduced hospital admissions, with one system seeing a 58% reduction in AIM patients.^{xviii} Lowered number of laboratory tests and reduced pharmacy utilization (2002 CAPC survey). Patients receiving earlier palliative care received less aggressive end-of-life care (33% vs. 54%). For example, this means the patient receives less chemotherapy 14 days or less before death, and more hospice care and less hospitalization in the last month.^{xix} Palliative care recipients in four New York state hospitals spent less time in intensive care and were more likely to receive hospice referrals.^{xx}
Satisfaction	AIM programs lead to improved satisfaction scores for patients, family, caregivers and from the multidisciplinary AIM-trained staff.
	<ul style="list-style-type: none"> Knowledge and respect of patient’s preferences.^{xxi} Increased time devoted to family meetings and counseling.^{xxii} Reduced family and caregiver depression, distress, and documented anxiety.^{xxiii} Compare to hospice care at home, care in the hospital intensive care unit is associated with 5 times the family risk of post-traumatic stress disorder.^{xxiv} Compared to hospice care at home, care in the hospital associated with 8.8 times risk of prolonged grief disorder.^{xxv}
Spending	Due to improved care coordination and associated prevention of crises, a secondary impact of AIM programs is the reduction in aggregate spending.
	<ul style="list-style-type: none"> Palliative care patients discharged alive had adjusted net savings of \$1,696 in direct spending per admission and \$279 in direct spending per day, including significant reductions in laboratory and intensive care unit charges.^{xxvi} Palliative patients who passed away while in admission to the hospital had an adjusted net savings of \$4,908 in direct spending per admission and \$374 in direct spending per day.^{xxvii} On average, patients who received palliative care incurred \$6,900 less in hospital costs during a given admission than a matched group of patients who received usual care.^{xxviii} Preliminary data indicates fewer hospitalizations amounting in an average savings per patient of about \$2,000 per month.^{xxix} Hospitals experienced a positive net contribution margin of \$1,333 per AIM enrollment.^{xxx}

Source: AHA CPI analysis, 2012.

Where Are We Now?

Hospitals have been growing AIM program components and improving the care for serious illness. According to a recent study done by the Center to Advance Palliative Care (CAPC), palliative care programs are now available at more than 80 percent of hospitals with more than 300 beds, with more than 85 percent of hospitals having dedicated, trained AIM staff. From 2003 to 2007, the percentage of chronically ill Medicare patients dying in hospitals and the average number of days they spent in the hospital before their deaths both declined. The percentage of deaths associated with a stay in intensive care also decreased in most regions of the US.^{xxxi}

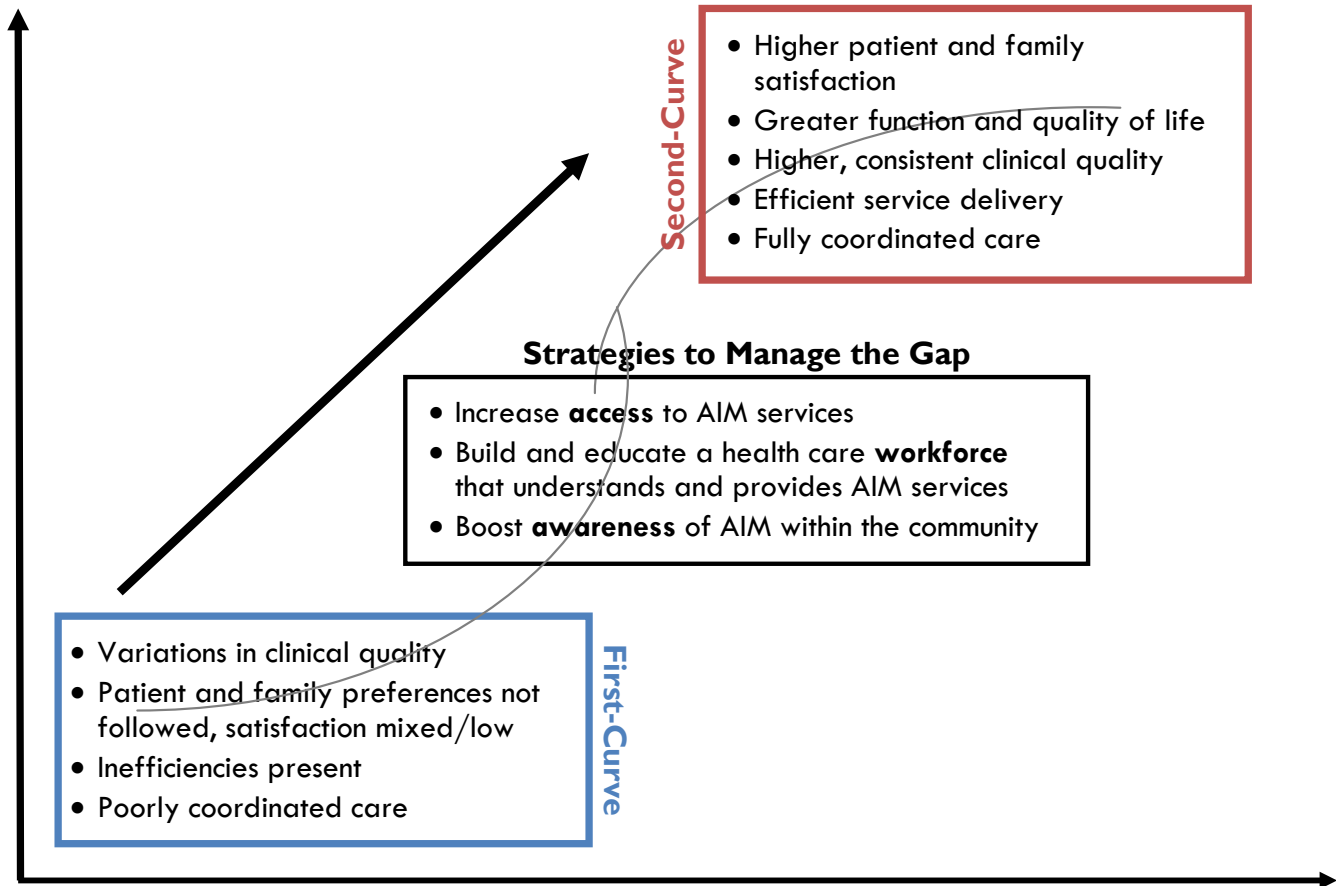
External policy and quality-focused organizations have started to push hospitals toward developing programs on their own or through external partnerships. The National Quality Forum, the Centers for Medicare & Medicaid and the Joint Commission have all either published quality metrics or created guidelines to advance AIM. Please see the **Appendix** for links to some of the external organizations.

Although hospitals have made significant gains, there is still room for improvement in both the number and coordination of AIM programs. For instance, while the percentage of Medicare beneficiaries dying in hospitals declined overall between 2003 and 2007, the Dartmouth Atlas found that during that same period there were sharp increases in the amount of physician labor per patient during the last two years of life, indicating that care can be further optimized to benefit the patient's wishes.

AIM Goals

The goals of AIM are to improve patient and family satisfaction and quality of life, increase clinical quality, reduce inefficiencies and increase care coordination. In a second-curve, value-based environment where incentives are aligned, a success AIM program includes: 1) all hospitals and care systems supporting and delivering high quality AIM; 2) all health care professionals possessing the knowledge, understanding and skills to provide AIM care; and 3) every patient and his or her family having the knowledge and skills to understand the benefits of AIM. Successful programs also address cultural sensitivities related to managing advanced illness.

Figure 2. Navigating AIM



Source: AHA CPI analysis, 2012.

While great strides have been made in AIM, the current volume-driven market has produced large variances in quality, unnecessary costs and utilization, low-patient satisfaction, and the inability to honor and follow the preferences of patients and their families.

Hospitals face several obstacles in the push toward AIM's second-curve goals. Current reimbursement schedules foster more inpatient care rather than proactively managing care in the outpatient setting. Some providers have mixed feelings about the use of AIM services. Many physicians and other clinicians still view AIM as an alternative to chronic and curative treatments, rather than as a simultaneously delivered adjunct to disease-focused, superior quality treatment. Low-community awareness of the availability, utility and benefits of these services also decrease use. Thus, despite the increasing availability of AIM services in U.S. hospitals and the evidence displaying the benefits, the use of AIM still remains low.

Strategies to Manage the Gap

As portrayed in Figure 2, the literature has pointed to three key strategies—**access, workforce and awareness**—that hospitals should implement to pursue the goals of AIM initiatives to increase clinical quality, reduce inefficiencies, coordinate care, improve patient and family satisfaction and quality of life. This report focuses on strategy one—**access**. A second report will focus on strategies two and three.

1. Increase access to AIM Services

Hospitals should provide patients and their families and caregivers support and services for each phase of the AIM process (defined in Figure 1). For larger organizations, this may mean the development of stand-alone palliative care services and hospices, while smaller and geographically challenged hospitals can turn to partnerships throughout the community to help provide these services. AIM services should not be seen as four unique segments but include elements integrated within the care continuum for all patients. Standards should be promoted and implemented as these programs develop further and quality of service is improved.

2. Build and educate a workforce that understands and can provide AIM services

Awareness among the clinical workforce is spreading, but most practitioners still require significant training both to provide and to communicate these services. The workforce must receive rigorous training to identify patients that would qualify and benefit from AIM services, communicate about these services, and coordinate and provide these services with a multidisciplinary team.

3. Boost AIM awareness within the community

Working with clinicians to reach patients about AIM services is an effective means to incorporate these programs within the care continuum. However, public awareness of AIM benefits needs to be increased. Patients currently equate hospice services with death. Patients will only recognize AIM benefits on improved quality of life and survival through increased community awareness and education. Communicating directly with patient populations about the availability of advance care planning services, as well as the patient and family role within the continuum, improves the results.

To effectively improve the prevalence of AIM programs and its integration into the care continuum, hospitals should expand AIM services, educate clinical and administrative staff, collaborate with other organizations, and spread awareness of AIM benefits throughout the community. Although the literature treats these strategies as separate, they are better understood as working together in an integral way. Access to services begins with availability, the supply side of the equation. Awareness of these services is essential to increasing demand for them. Having a workforce that can and will provide a continuum of care for advancing illness works both the supply and the demand sides. For AIM services to be available and beneficial, and for people to have access to skilled services, a well-trained workforce is necessary. That workforce needs to be an integral part of people utilizing AIM services.

Thus, these three strategies should be viewed as forming an interactive triangle whose three points need to be equal and connected, instead of separate pieces. If demand ramps up too quickly, would the hospital and hospice infrastructure of services be able to manage it? If people aren't educated about the benefits of AIM, will they utilize the programs when they become available? If the workforce isn't trained properly, will the programs be effectively carried out?

Increasing Access to AIM Programs

As the health of those with serious illness declines, chronic and curative treatment plans lead to significant increases in medical service utilization—ranging from specialist appointments and lab tests to procedures and hospital admissions. The average Medicare beneficiary with one or more chronic conditions consults with eight different physicians annually.^{xxxii} Research confirms that providing more care does not necessarily lead to better outcomes or truly represent the wishes of patients and their families.

Hospitals are in a unique position to increase patient access to AIM services by incorporating each of the specific phases (as defined in Figure 1) into the traditional patient-care continuum. Hospitals could change the ways medical services are utilized to improve outcomes and honor the wishes of patients and families.

Larger organizations may develop stand-alone initiatives, while smaller and rural hospitals and care systems may partner with other community entities to achieve the same goals. However, one strategy is consistent; hospitals and care systems need to integrate specific characteristics of each of the four phases into a single program. As with other implementation strategies, standards should be established as the programs continue to develop, and organizations must continually analyze the quality of their AIM services for improvement.

The remainder of this report provides:

- A programmatic framework for AIM;
- Metrics that can be used to measure progress; and
- Four case examples that illustrate the ability to provide and increase access to AIM services. Additional case studies may be found at AHA's Circle of Life website at www.aha.org/circleoflife and other resources identified in the **Appendix**.

AIM Program Framework

Hospitals understand the benefits of AIM but struggle with implementation. Complete program design varies among organizations. AIM decisions are some of the most difficult decisions made by clinical providers, patient and their families; therefore programs need to take into account the complexity and interdependence of issues. In addition to patient and family preferences, religious beliefs, cultural sensitivity and local practice patterns, workforce capabilities and financial incentives also shape the organization’s capacity for AIM development.

The chart below provides a basic framework that hospitals and health systems can use as a guide to coordinating AIM services and increasing access. There are no designations between AIM segments in the framework (advance directives, palliative care, advanced care planning and hospice care) because organizations should consider all four segments across the continuum, combine these into one program and decide which services would be best for the surrounding population. Program design will require adjustment once implementation begins to ensure continuous quality and to meet the changing needs of physicians, patients and families.

Develop planning team	<p>Since AIM impacts many clinical areas, it is important to form a multidisciplinary planning team. This will help ensure that the program meets the needs of patient and hospital.</p> <ul style="list-style-type: none"> • Physician leadership • Physicians (employed and community-based) • Nursing leadership • Nursing staff • Pain management specialist • Palliative/hospice leadership • Hospital senior administrator • Medical social worker • Clinical pharmacist • Nutritionist • Chaplain • Front-line administrators • Resource/case managers
Align with organization mission	<p>AIM involves clinical, psychosocial and spiritual elements. Therefore it is important to create a program that complements the specific organization’s mission and vision.</p>
Analyze current situation	<p>Organizations must perform quantitative and qualitative analysis on current capabilities based on current programs. This should be an internal and external capability assessment, identifying existing external resources and gaps in AIM services. Additionally, hospitals should calculate current metrics for a baseline and compare it to state and national trends to recognize strengths and areas for improvement.</p>
Set goals	<p>Hospitals and care systems must set a goal for the program breadth that they can support and identify external organizations to partner with to fill in gaps in the care continuum.</p>

<p>Develop individualized program based on capabilities</p>	<p>AIM initiatives must be hospital and community specific. Program design will vary based on several factors such as:</p> <ul style="list-style-type: none"> • Clinical staff interest • Current case management and discharge planning capabilities • Leadership priorities • Surrounding population demographics • Available workforce—physicians, nurses, social workers, etc. • Existing relationships with external AIM organizations • Hospital chaplaincy program status • Pain program status • Community interest in AIM • Multicultural environments • Available physical location
<p>Implement an integrated program</p>	<p>While implementation plans will vary, there are essential features of any initiative:</p> <ul style="list-style-type: none"> • Clinical and administrative leadership should have a strong consensus on the goals of the AIM program. • Metrics measuring access should be continually analyzed for progress • Guidelines should be written for evidence-based evaluation.
<p>Collaborate and educate</p>	<p>Hospitals should develop educational materials for all staff within the facility and throughout the community, in addition to materials for the larger population. This process of education and spreading awareness will be discussed in a separate publication.</p>
<p>Track progress</p>	<p>Hospitals must continually measure outcome, progress and various balance metrics to gauge improvement and recognize challenges to improving AIM access and availability. For true growth, metrics should be distributed to all staff involved in AIM for feedback.</p>

Source: AHA CPI analysis, 2012.

AIM Metrics

Metrics are useful to evaluate the current state of the organization, monitor progress, identify challenges and recognize unforeseen results of a coordinated AIM program implementation. There are many options that can be analyzed, and organizations may see statistical quantitative differences at different phases in program development and implementation. Gaining an understanding of the metrics in the beginning will aid teams in appropriate program development. Organizations will not be able to measure all of the metrics below, but should choose the ones that make the most sense for their situation. Metrics will vary by disease state.^{xxxiii}

Outcome Metrics

How is the system performing? What are the patient-centered results?

<ul style="list-style-type: none"> • Meeting patient preference on longevity and quality of life • Rate of major depression • Pain control scores • Symptom management control scores 	<ul style="list-style-type: none"> • Family and caregiver depression, distress, anxiety (post traumatic stress disorder/prolonged grief disorder) • Patient satisfaction • Family and caregiver satisfaction
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Process Metrics

Is the hospital performing as expected?

<ul style="list-style-type: none"> • Hospice referrals/consults • Palliative care referrals/consults • Advanced care planning discussions • Frequency of goal documentation 	<ul style="list-style-type: none"> • Percent of patients with advance directives • Treatment decisions consistent with instructions • Days with at-home hospice care • Inpatient hospice length of stay
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Balancing Metrics

What happened to the hospital after improvement in outcome and process metrics? What are the unanticipated consequences?

<ul style="list-style-type: none"> • Clinical staff retention and satisfaction • Independent physician satisfaction • Emergency department utilization • Hospital stay cost • 30-day readmissions rates • Spending per admission • Medical specialist visits • Surgery in last month of life 	<ul style="list-style-type: none"> • Days of hospital care in last 2 years of life • Admissions in last 6 months of life • ICU admissions and length of stay • ICU days in last 2 years of life • Laboratory utilization • Pharmacy utilization and spending • Treatment aggressiveness (chemotherapy 14 days or less before death, imaging studies in the last week of life, etc.)
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Source: AHA CPI analysis, 2012.

Successful AIM Examples

Reducing readmissions through streamlined AIM

Mercy Medical Center, Cedar Rapids, Iowa, has a well-developed AIM program that spans the entire continuum. This program has made a large impact on readmission rates. The hospital is ranked in the top 3 percent for readmission rates for heart attack, heart failure and pneumonia.^{xxxiv}

What they did

Mercy participates in the Iowa Physician Order for Sustaining Treatment (IPOST) program that is modeled on the Physician Orders for Life-Sustaining Treatment Paradigm program (www.polst.org). IPOST is a collaborative tool recognized by emergency medical technicians and organizations that promote communication of the patient's wishes. Specific medical orders, signed by a physician, travel with the patient across the care continuum and care venues—nursing facility, hospital, home—and can be revocable or altered by the patient at any time.

Before a form is signed, a palliative care team leads a discussion about advanced care planning, the date of which is posted on the wall within the facility. This multidisciplinary team—typically the patient's physician, a palliative-care consulting physician, an advanced-practice nurse, a social worker, the patient and his or her family—develop a care plan centered on the patient's preferences. This discussion is guided by a facilitator specifically trained to have these conversations, a program called Respecting Choices. This palliative-care consult is provided to patients that meet a specific level of complex illness or serious health conditions. They are identified by frequent visits to the emergency department, unnecessary inpatient admissions or prolonged lengths of stay.

Hospice of Mercy is also part of the Mercy Medical Center system. Run by the same leadership as the palliative-care program, the hospice program develops care plans both for the home and for the 12-bed inpatient facility. Analysis revealed that readmission rates were highest when patients were discharged to the nursing home, so Mercy deployed hospice nurses to provide care in these nursing homes, making it more likely that a patient transfer to the hospital only when clinically necessary.

Keys to success

- Multidisciplinary effort from the beginning
- Identifying qualified patients upon emergency department usage, unnecessary inpatient admissions or prolonged lengths of stay
- Leadership crosses the AIM continuum
- Well-designed advance care planning discussions using a team approach and documented with IPOST forms that can be honored across settings of care.
- Promoting AIM throughout the surrounding community.^{xxxv}

Providing palliative consults for rural providers through the Rural Palliative Care Network

Fletcher Allen Health Care, a university-based health system in Burlington, Vermont, serves rural areas in Vermont and northern New York. While the organization has an AIM program through a large donation, it created the Rural Palliative Care Network to provide palliative and hospice care education to physicians and patients throughout the region.

What they did

There are four main components to the Rural Palliative Care Network:

1) Telephone hotline available 24 hours a day, seven days a week

This assists both referring physicians and patients.

2) Telemedicine consults for patients

The Fletcher Allen team provides palliative-care consults for patients before transferring them to the facility's medical intensive care unit. During these consults, the palliative team answers questions from the patient, his or her family, the MICU-attending physician, or the referring physician. This begins relationship and team building.

3) Mentorship program for community providers

Community physicians can receive one day of training from the Fletcher Allen palliative care team.

4) Visits to hospitals to observe palliative care services

Fletcher Allen palliative care team members visit other community hospitals and physician practices to educate different audiences about the benefits of AIM services.

Keys to success

- Knowledge of the specific communities
- Establishing a care team, consisting of the patient, physician and family
- Educating physicians and others in the community on available services^{xxxxvi}

Structuring disease-based AIM transitions program for better outcomes

Sharp Hospice, part of Sharp Healthcare, San Diego, established their AIM program called Transitions. It focuses on keeping patients at home rather than in the hospital while managing advanced illness according to their wishes during their last two years of life.

What they did

As opposed to other general programs, Sharp's Transitions program is disease-specific, allowing for more evidence-based approaches. Currently managing the advanced illness progression for patients with heart failure, chronic obstructive pulmonary disorder and dementia, it is expanding capacity to stage IV cancer, cirrhosis and geriatric frailty syndrome in 2012.

Based on education, early symptom recognition and the creation of a road map to reach care goals, each patient in the program is designated a multidisciplinary care team consisting of a nurse, social worker, spiritual care counselor and the patient's physician. There are four pillars to Sharp's Transitions program:

- 1) Comprehensive home-based patient and family education;
- 2) Disease specific, evidence-based prognosis;
- 3) Proactive management of the caregiver to set realistic expectations on survival; and
- 4) Advance care planning with accurate descriptions of what treatments can provide.

These pillars are accomplished through both active management strategies (with each patient receiving an average of 10 home-based visits from mostly nurses and social workers annually) and maintenance approaches using telephone contact and nurse visits.

From June 2007 through December 2008, patients enrolled in the Transitions program experienced a 94 percent reduction in emergency department visits and hospitalizations as compared to pre-enrollment in the program. There was a 71 percent reduction in spending among this patient population. Transition patients are transferred to hospice 80 percent of the time. Nationally, 63 percent of congestive heart failure patients die in the hospital. Only three of the 109 program members died while admitted.

Keys to success

- Retain physician champions and other key stakeholders to engage support in development process
- Select one diagnosis and work through issues as each condition must be treated differently
- Think outside the four walls of the hospital
- Use a performance improvement framework to measure, monitor, evaluate and adapt program between disease states and over time.^{xxxvii}

Providing ambulatory palliative care to patients gives them options

Sutter Health serves patients in more than 100 Northern California cities. Sutter Health implemented the AIM program on a limited basis in 2009 to a group of patients who were already enrolled in home health care services through Sutter Health. In 2010, the program was expanded to patients with advanced illness in the Sacramento, Roseville and Davis metropolitan areas. More than 1,600 patients have participated in the program in the two-year period.

What they did

Sutter's AIM program is targeted at individuals in the last 12 months of their lives. Generally, these patients have at least 2 chronic conditions. The program is considered "ambulatory palliative care," and provides patients with an alternative to receiving care at the emergency department or hospital.

When the patient enters the program, at the hospital or from the community, they are assigned a care manager to serve as their main contact. Patients are also given a number they can call 24 hours a day, seven days a week. The AIM patient and care manager have a support network of a multidisciplinary team that consists of many health providers—physicians, nurses and home health professionals. Physicians are viewed as partners in providing care and are trained on what to look for in eligible patients. Nurses are specifically trained for the program to ensure care is given according to the patients' goals. Palliative care physicians oversee the clinical care of the AIM team and serve as an important liaison to the primary physicians. The first step is to have "the conversation" with patients regarding their care goals and preferences. These are then incorporated into Sutter's electronic health record. All providers have access to the health record and a patient may change his/her goals at any time. Patients are typically seen in the hospital, at home for 30 to 60 days and through office-based care with telemanagement.

Moving forward, the program wants to incorporate biomonitors to remotely track patient health status through key biometrics such as weight and blood pressure. The program works because it has a systems approach. Patients are referred from all areas of the system—40 percent from physician practices, 34 percent from the hospital, 20 percent from home health and hospice, and the remainder from other sources. Physician engagement is essential for the program's success. With a multidisciplinary team, the physician isn't the patient's only contact. Physicians are assisted by other experts skilled in tackling social, family and medical issues. AIM also helps provide better care to the patient in terms of symptom relief and quality of care.

Keys to success

- Physician engagement
- Team-based care that is protocol driven
- A board and system that supports a patient-centered care approach
- An integrated, system approach to care delivery.

Endnotes

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APPENDIX

Resources to improve AIM programs and services

1. AHA's Hospitals in Pursuit of Excellence
<http://www.hpoe.org>
2. AHA's Circle of Life
<http://www.aha.org/circleoflife>
3. Center to Advance Palliative Care
<http://www.capc.org>
4. Coalition to Transform Advanced Care
<http://www.advancedcarecoalition.org>
5. Institute for Healthcare Improvement's Conversation Project
<http://app.ihp.org/ittemp/ConversationProject/>
6. Joint Commission's Palliative Care Certificate Program
http://www.jointcommission.org/certification/palliative_care.aspx
7. National Comprehensive Cancer Network
http://www.nccn.org/professionals/physician_gls/f_guidelines.asp#supportive
8. National Consensus Project for Quality Palliative Care
<http://www.nationalconsensusproject.org>
9. National Hospice and Palliative Care Organization
<http://www.nhpco.org/templates/1/homepage.cfm>
10. National Quality Forum's Palliative Care Guidelines
http://www.qualityforum.org/Topics/Palliative_and_End-of-Life_Care.aspx
11. Respecting Choices
<http://respectingchoices.org>