ICSI’s Palliative Care Strategic Initiative

The Need for Palliative Care
Chronic, debilitating, life-limiting and life-threatening illnesses affect nearly 90 million people in the United States, according to the Centers for Disease Control and Prevention (CDC). Experts have found that patients whose pain and symptoms are well managed through palliative care can tolerate more aggressive or longer treatments, and their quality of life is improved. Unlike hospice care, palliative care is not dependent on a patient’s prognosis. Instead, it can help patients move forward with treatments that either cure or prolong life.

Palliative care for patients with a serious* illness has been a growing specialty within the health care community. It is administered with an interdisciplinary team approach. And as we see an increase in our aging population, many of who are afflicted with serious illnesses, integrating a model for the care of these patients into the mainstream of our health care system becomes increasingly important.

There is certainly a need for this type of care, as, without it, the episodic manner that patients with life-limiting illnesses receive care can lead to long and sometimes repeated hospital stays, exacerbation of symptoms and unnecessary financial charges. However, the present perception of palliative care as an end of life, hospice type of service creates a need for a redefinition and recreation of this aspect of health care.

ICSI Action
In 2009, the Institute for Clinical Systems Improvement (ICSI) began a strategic initiative to integrate palliative care into routine care delivery, recognizing that a palliative care specialty may not be available in all health care settings. This initiative was designed to create a more efficient model for the delivery of pain and symptom management, care coordination and shared decision-making for the patient newly diagnosed with a serious illness.

* Chronic, debilitating, life-limiting, and/or life-threatening illness
It focused on involving primary and non-palliative specialty care clinicians in introducing the components or domains of palliative care, and collaborating with the patient and their family in creating a plan of care. The objective was to create a partnership between patients, families and clinicians as well as the community to address the patient’s physical, cultural, psychological, social, spiritual and financial needs.

Introducing palliative care earlier in the care continuum improves a patient’s quality of life, can improve outcomes, and reduces health care costs over the long term. It addresses all three areas of the Institute for Healthcare Improvement’s Triple Aim, which seeks to:

- Improve the health of the population
- Enhance the patient experience of care (including quality, access and reliability)
- Reduce, or at least control, the per capita cost of care

As a first step, ICSI conducted a survey to identify palliative care services and programs available to Minnesota patients and their families. This survey asked questions of integrated health care systems, hospitals, clinics, home care, long-term care, hospice, public health facilities and multispecialty health networks that offered palliative care services. It provided a baseline of palliative care information and explored the role of decision-making between providers, patients and families. Existing services identified included in-patient consultation, hospice, in-patient and ambulatory palliative care, palliative home care, palliative care consultation in long-term care, and structured palliative care services in long-term care.

Program successes were noted, including increased referrals, increased patient satisfaction and quality of life, decreased overall costs, reduced patient symptoms, excellent patient and family outcomes, and increased receptiveness to palliative care among physicians and other health care providers. At the same time, the survey identified three significant obstacles to moving elements of palliative care earlier in the care continuum:

- Cost
- Staffing
- Program design

ICSI convened a steering committee to lead the effort. Its charter said: “The ICSI Palliative Care Initiative will focus on identifying the elements of palliative care delivery which create value and quality health care. It will address the care delivery redesign, payment model and elements of patient/family-centered care necessary to implement and sustain the concept. The scope will address the time frame from the diagnosis of a serious illness through the end of life.”
Lack of reimbursement was seen as a challenge by more than two-thirds of respondents. Almost 58 percent cited inadequate funding and the need for training and education; 47 percent noted a lack of physician buy-in and 26 percent a lack of administrative support.

To bring further clarity to its strategy, ICSI drafted a “Case for Providing Palliative Care Services in Primary Care and Secondary Care.” This white paper outlined patient benefits, cost reductions, operational benefits and some of the challenges of moving forward with a broader palliative care program. In 2010, to show the need for continuity of care the ICSI palliative care steering committee mapped out the current state of a patient with a progressive heart disease condition entering the current care delivery system (Figure 1). It then created the ideal state of care for this patient (Figure 2), which would be created by delivering the components of palliative care at the time of diagnosis of the heart disease.

**Figure 1. Current state for a patient with a progressive heart disease condition.**

During this period of uncoordinated episodic care, the steering committee indicated the patient and their family experienced panic, anxiety, discord, frustration, confusion, anger, isolation and hopelessness. Conversely, care providers were thought to experience feelings of inadequacy, frustration, and disappointment in providing appropriate care.
Under coordinated, palliative care, this same patient would experience the following:

- Prognosis, goals of plan of care, and advanced care planning are discussed
- Patient/family knows the plan of care
- Patient is provided optimal medical management
- Care plan has prepared for changes
- Patient/family knows point person(s)
- Patient/family discuss options
- Patient prepared for final days
- Hospice, other options discussed

**Challenges**

The steering committee faced several challenges in trying to introduce the elements of palliative care to achieve the ideal state. A key one was that the term “palliative care” was engrained in clinicians’ minds as a specialty, and that it referred primarily to end of life or hospice care. To change this embedded perception, the group renamed the care it wished to deliver as LiLLIE—Living with a Life-Limiting Illness Every Day. The name LiLLIE represents a more realistic description of what patients and families face when dealing with serious illnesses.
The LiLLIE model acknowledges the care preferences of a patient when diagnosed with a serious illness so they can receive the highest quality, patient-centered care that relieves their suffering, and improves their quality of life and that of their family. It is offered through primary care and non-palliative specialty care clinics in conjunction with all other appropriate forms of medical treatment, including curative care. When the primary or non-palliative specialty clinic can no longer meet the patient’s needs, the model recommends transitioning the patient into an interdisciplinary palliative care specialty.

In working to develop a new care model, two very important concepts embedded in LiLLIE were identified—collaborative conversations and shared decision-making. Collaborative conversations take place between patients, their families and the care team and are based on a trusting relationship between a clinician and a patient. Under the LiLLIE model, these conversations are initiated at the time of diagnosis of the patient’s serious illness and continue through the patient’s illness.

Collaborative conversations lead to shared decision-making between the clinician and the patient and their family in formulating a realistic plan of care that takes into account the patient’s physical, psychological, cultural, social, spiritual and financial needs. This care plan can include such things as advance care planning and advance health directives to ensure that the wishes of the patient and their family are met when the patient is no longer capable of making those decisions.

Another challenge was that many within the health care community as a whole had difficulty in agreeing upon what elements made up palliative care. While similar terms were often used, there was a lack of a common definition for those elements.

To address this issue, ICSI engaged CJ Peek, PhD, from the University of Minnesota, to work with the steering committee to create a parametric analysis of palliative care in action. This process focuses on the use of a paradigm case (an idealized description of palliative care) as a
framework for moving a group to identify a common set of underlying principles and functions which would characterize the “new” palliative care (or LiLLIE). Through this analysis, the steering committee agreed that palliative care must include the following elements in delivering appropriate care for the patient diagnosed with a life-limiting illness:

1. The population must know there is care system help for living with life-limiting illnesses.
2. There are multiple ways to identify quickly those who may benefit from assessment.
3. An ongoing assessment dialogue should be initiated, with patient and family readiness and needs at the center.
4. A plan of care should be produced from this assessment.
5. The plan of care is handled through interdisciplinary teamwork across all seven domains of palliative care.
6. Coordination of care across episodes of care and venues for care must take place.
7. Practice-based data is collected for use in decision making and improving outcomes.
8. Consistent and reliable operations systems and business models support the system.

With this common lexicon in place, and taking into consideration parallel processes involving community and provider education, identification of patients, advance care planning, shared decision-making and care management, the elements of palliative care became the basis for the coordinated LiLLIE care model.

ICSI then created sub-committees to develop a LiLLIE model and a communication plan for introducing elements of palliative care at the time a patient was identified with a serious illness. Goals included identifying metrics to evaluate the model and creating a plan to ensure the model’s financial sustainability. The design team identified what palliative care might look like in primary care, long-term care, home care and specialty care settings. Process and outcomes measures were created for use by sites piloting the care model, and a Care Practice Group Assessment Survey and Financial Models Grid comparing payment methods were developed.
ICSI understands that the discussion of palliative care is as important as other medical interventions and should be given the same amount of time. It has found that introducing the components of palliative care at the time of diagnosis, whether by a physician or some other member of the care team, can be completed with proper training and tools.

**LiLLIE implementation**

As the LiLLIE model work evolved, and the universal importance of collaborative conversations and shared decision-making in all facets of patient care became more evident, it became apparent to those involved that it was extremely important that this framework become an integrated part of practice redesign. This redesign is presently heavily focused on the health care home, patient-centered care, reducing avoidable hospital admissions/readmissions, and accountable care organization efforts developing around the state and the country.

In the face of this holistic approach, there was a feeling that the continuation of a separate parallel effort focused on palliative care as an individual topic might preclude its consideration as
a critical element of the care model redesign. Instead, the elements agreed upon through the parametric analysis plus other principles identified through the effort should be incorporated into other health care redesign efforts.

For example, Dr. Peek had similarly used parametric analysis to create a common lexicon on what constitutes a Medical/Health Care Home. A crosswalk between the LiLLIE and Health Care Home parametric analyses showed that the elements of LiLLIE care are core to the whole-person care promised through the concept of Health Care Homes.

The body of conceptual and application work created through the LiLLIE initiative holds promise for integration into other health care redesign initiatives. As we move forward in our efforts within the health care system to create a whole-person approach centered on the needs of our patients, it behooves us to consider how we can actively promote the incorporation of the elements identified thus far in LiLLIE into that evolving body of work. As the elements of LiLLIE care become part of the routine care for patients with life-limiting illnesses, ways to improve their effectiveness in primary and specialty care settings should be enhanced and spread.

The ICSI strategic initiative on palliative care was successful in bringing together a community of those with varying degrees of interest, experience, and expertise to further our understanding of this important area of care. As LiLLIE moves from being a free-standing initiative to a source of information and support for our efforts in total care redesign, we have an obligation to ensure that the lessons learned are visible and present in whatever new models for care become the framework for the co-creation needed in transforming our health care system.