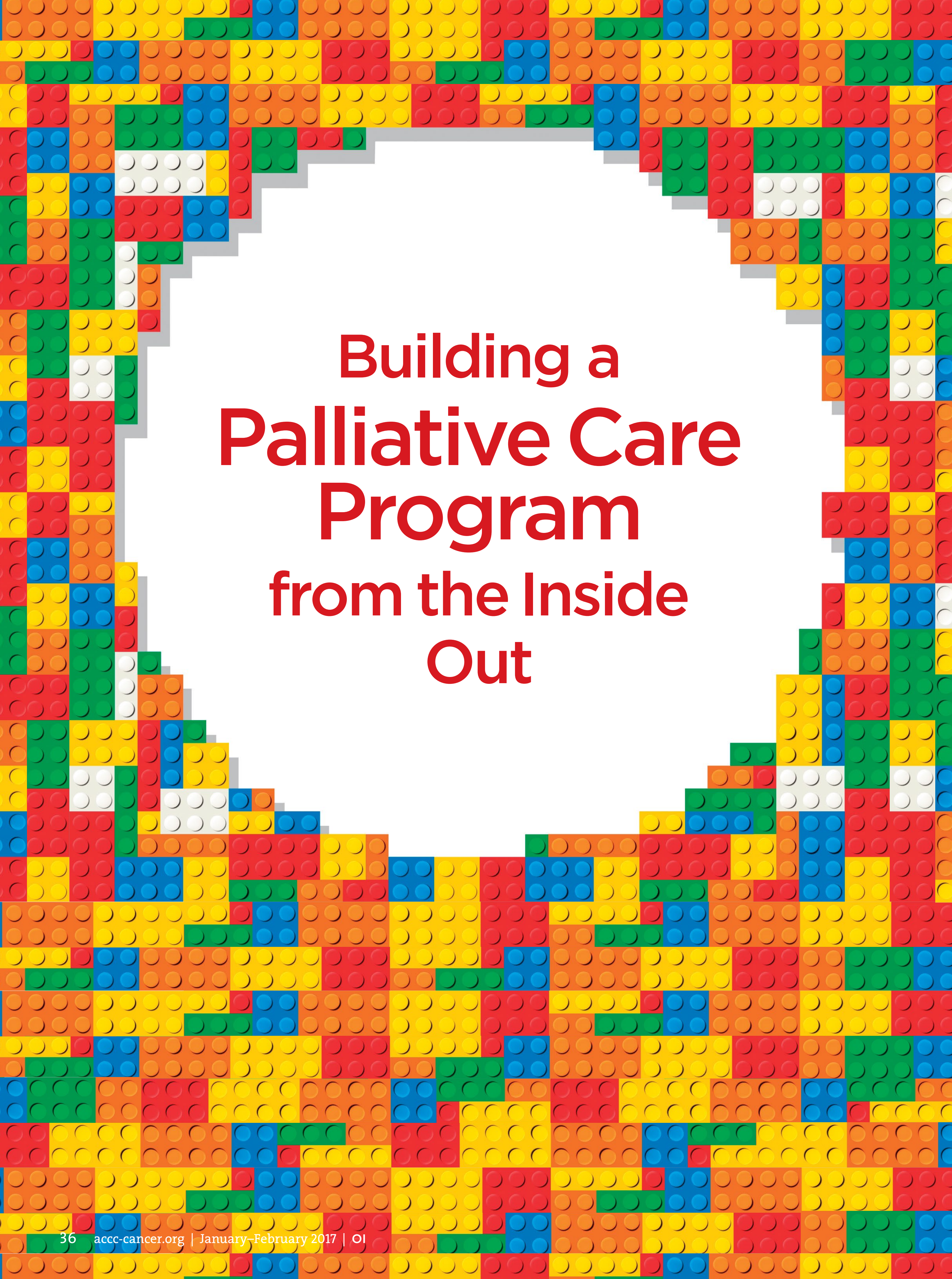

Building a Palliative Care Program from the Inside Out

BY MICHELLE ABRAMOWSKI, CRNP, AND
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2016 ACCC INNOVATOR AWARD
ASSOCIATION OF COMMUNITY CANCER CENTERS

In the summer of 2014 an important and complex question was asked at the Kaufman Cancer Center: "*How can the palliative care services provided in our center be expanded and enhanced, make a difference for the patients we serve, align with value-based care, and be accomplished utilizing our existing team?*" A tall order indeed. The answer became, "Building a Palliative Care Program from the Inside Out."

> Key leaders and team members came together to assess the strengths and challenges of our cancer center.

In the Beginning

When emerging studies concluded that early palliative intervention with cancer patients leads to better quality of life and reduces cost of care, palliative care became a focus for Kaufman Cancer Center leadership.[1-3] Given the move to value-based healthcare, the rising cost of emerging cancer therapies, and new *Choosing Wisely* recommendations endorsed by the American Society of Clinical Oncology (ASCO) and the American Society for Radiation Oncology (ASTRO), the timing for developing innovative ways to incorporate early palliative care into our center was perfect.

In making the decision to move forward with this initiative, key leaders and team members came together to assess the strengths and challenges of our cancer center. We identified the following strengths, which laid the foundation of our model:

- An existing, strong, mature, inpatient palliative care team that could support this initiative
- An enhanced supportive care services model through the Cancer LifeNet Program
- Increased staff awareness and documentation of the status of advance directives
- Existing leaders and clinicians with a passion for and experience with palliative care, including:
  - An oncologist board certified in oncology and palliative care
  - A medical director of the cancer center and newly appointed director of population health for our hospital
  - An executive director of the cancer center with a background in palliative care and hospice
  - A nurse practitioner (NP) with hospice experience
- A healthcare system transitioning from fee-for-service to a value-based payment model.

The team recognized that there were challenges to overcome as well. The challenges described below guided us toward the solutions that became the building blocks of our model:

- No budget
- An existing navigation model focused on newly-diagnosed patients, not on palliative or end-of-life care
- Inadequate communication between departments and treatment team members regarding patients' status
- Lack of in-house educational resources for team members related to palliative care and end-of-life care
- An existing inpatient palliative care team with a central focus on inpatient care and ICU patients
- An existing outpatient palliative care clinic within the Kaufman Cancer Center with limited hours and resources.

Getting Started

After some thoughtful review, a workgroup was established to begin the process of developing and formalizing our palliative care program. We began by identifying key members of our team who were passionate about providing palliative care to our patients, as well as key leaders who supported our efforts. The early planning phase included the hospital's inpatient palliative care physician, one of our medical oncologists who was also board certified in palliative care, and our medical director who was fully committed to growing this initiative. This phase also included:

- Extensive research of various existing models
- A thorough literature review
- Development and finalization of our model
- A review of the national metrics to determine the outcomes we would use to measure our program.

The Advisory Board Company (advisory.com) has identified five palliative care models:

1. Embedded specialists, including a nurse and physician
2. An inpatient consult service
3. A dedicated palliative care inpatient unit
4. An outpatient clinic
5. A home-based palliative care program.

Already existing within our healthcare system were embedded specialists, including a physician, NPs, and a social worker, which comprised our inpatient palliative consult service. This program also included a limited outpatient palliative care clinic run by our inpatient palliative physician. One of the limitations of the clinic was that our inpatient physician and team were asked to focus mainly on inpatient needs and had limited availability for outpatient services.

Our focus moved to an extensive literature review—determining how we would implement the program to meet the palliative care needs of our patients across the entire disease trajectory. We were able to determine the most effective way to screen our patients, the potential cost-savings, and, finally the impact a palliative care program would have on patient care. After review of a 2011 study from Glare et al., we selected a five-item questionnaire to determine which patients were appropriate for a palliative care referral (see Table 1, below). The tool includes a scoring system of 0-13, with scores greater than or equal to 5 considered high risk and appropriate for a palliative care referral. The questionnaire was formatted for our EHR to allow for ease of documentation.

With an increasing focus on population health and value-based care, our team also considered the economic impact of the palliative care program. A 2015 prospective study by May et al. examined cost savings among inpatients with advanced cancer.

Table 1. Five-Item Palliative Care Screening Tool[2]

SCREENING ITEMS	POINTS
1. Presence of metastatic or locally advanced cancer	2
2. Functional status score, according to ECOG performance status score	0–4
3. Presence of one or more serious complications of advanced cancer usually associated with a prognosis of < 12 months (e.g., brain metastases, hypercalcemia, delirium, spinal cord compression, cachexia)	1
4. Presence or one or more serious comorbid diseases also associated with poor prognosis (e.g., moderate-severe COPD or CHF, dementia, AIDS, end stage renal failure, end stage liver cirrhosis)	1
5. Presence of palliative care problems:	
• Symptoms uncontrolled by standard approaches	1
• Moderate to severe distress in patient or family, related to cancer diagnosis or therapy	1
• Patient and/or family concerns about course of disease and decision-making	1
• Patient and/or family requests palliative care consult	1
• Team needs assistance with complex decision-making or determining goals of care	1
Total Score	0–13

* Abbreviations: CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; ECOG, Eastern Cooperative Oncology Group

Kaufman Cancer Center's Palliative Care Case Conference.

We learned that early palliative care interventions were associated with larger cost savings. In addition, timely palliative care intervention after hospitalization was also associated with cost savings, suggesting that early palliative care should be more widely implemented.

In determining the framework of our model, we looked at the Advisory Board's hallmarks of an integrated program, which include:

- Oncologists who trust the palliative care team
- Scrupulous care coordination
- A process to ensure that advance care planning is routine for all cancer patients
- A care team who is highly visible in the cancer center
- Clinicians that share responsibility for initiating palliative care
- Oncology clinicians who are trained to provide it.

One of the benefits of utilizing our existing resources was an already established, trusting partnership between the physicians and the cancer center team, as well as existing trust from our patients and families. Our palliative care specialists were not arriving on the scene at the end of life as outsiders. Rather, these providers already had an established relationship with patients and families. We focused our attention on being visible within the cancer center and reaching out to all cancer center team members to refer patients when appropriate. Also, we developed an additional subgroup of multidisciplinary team members that specifically focused on developing palliative care skills and training within the cancer center.

The clinical impact of the palliative care program and the potential benefits for patient care were given careful consideration as well. A 2010 study from the *New England Journal of Medicine* examined the effect of early palliative care for patients with metastatic non-small cell lung cancer (NSCLC).[1] The study found early integration of palliative care in patients with metastatic NSCLC resulted in significant improvement in a patient's mood, mindset, and quality of life (QOL). In fact, this intervention resulted in an approximate two-month longer survival when compared to patients receiving aggressive treatment at the end of life. Earlier data also suggested that a lower QOL and a depressed mood were often associated with shorter survival. We learned that when individuals had early outpatient palliative care, it resulted in earlier documentation of preferences regarding resuscitation in the EHR and less aggressive care at the end of life, including chemotherapy, as well as earlier and longer enrollment in hospice care.

Finally, we looked to national metrics to determine which outcomes we would use to measure the success of our palliative care program. We specifically looked at benchmarks from the Advisory Board's Palliative Care Dashboard (Table 2, page 40), which utilized data from the National Quality Forum, the National Hospice and Palliative Care Organization, and ASCO. We chose

(continued on page 41)

Table 2. Advisory Board's Palliative Care Dashboard

MEASURE	DEFINITION	BENCHMARK	ENDORSED BY
PROCESS—APPROPRIATE UTILIZATION			
New chemotherapy at end-of-life	Percent of patients who died from cancer that started new chemotherapy regimen in the last 30 days of life	Best observed: <2%	
Chemotherapy utilization at end-of-life	Percent of patients who died from cancer that received chemotherapy in the last 14 days of life	National Average: 6% 10th percentile: 4% 50th percentile: 5.9% 90th percentile: 7%	NQF #0210, ASCO
Hospitalizations at end-of-life	Percent of patients who died from cancer with one or more hospitalizations in the last 30 days of life	Best observed: <4%	NQF #0212
ED utilization at end-of-life	Percent of patients who died from cancer with one or more ED visits in last 30 days of life	Estimated typical performance: 8–10% Best observed: 2%	NQF #0211
ICU utilization at end-of-life	Percent of patients who died from cancer admitted to ICU in last 30 days of life	Estimated typical performance: 8–12% Best observed: <4%	NQF #0213
Acute care utilization at end-of-life	Percent of patients who died from cancer within an acute care setting	Best observed: <17%	NQF #0214
Hospice utilization at end-of-life	Percent of patients who died from cancer who were not admitted to hospice	Estimated typical performance: 65–85% Best observed: <55%	NQF #0215
Hospice referral timeliness	Percent of patients who died from cancer, were admitted to hospice, and spent less than 3 days there	Estimated typical performance: 27–35% Best observed: 8%	NQF #0216
Hospice median length of stay	Median length of stay for patients who were admitted to hospice	National median length of stay: 19.7 days	NHPCO

Source: Advisory Board Company, 2013.

(continued from page 39)

to focus our measures on:

1. Chemotherapy utilization at the end of life
2. ED (emergency department) utilization at the end of life
3. ICU (intensive care unit) utilization at the end of life
4. Hospice utilization
5. Hospice referral timeliness.

Developing Our Model

Specific structural and functional components of our model became apparent as our team undertook the development process. The three foundational building blocks for this program were: 1) weekly palliative care case conferences, 2) ongoing proactive goals of care meetings, and 3) the development of in-house palliative care specialists. The key element of this structure is a multidisciplinary team bringing existing and newly acquired skills and knowledge of palliative care to the program (see Figure 1, right). The four primary functions of the model help meet the needs of patients and their families by providing comprehensive support, enhanced communication, meticulous coordination of care, and thorough symptom management (Figure 2, page 42).

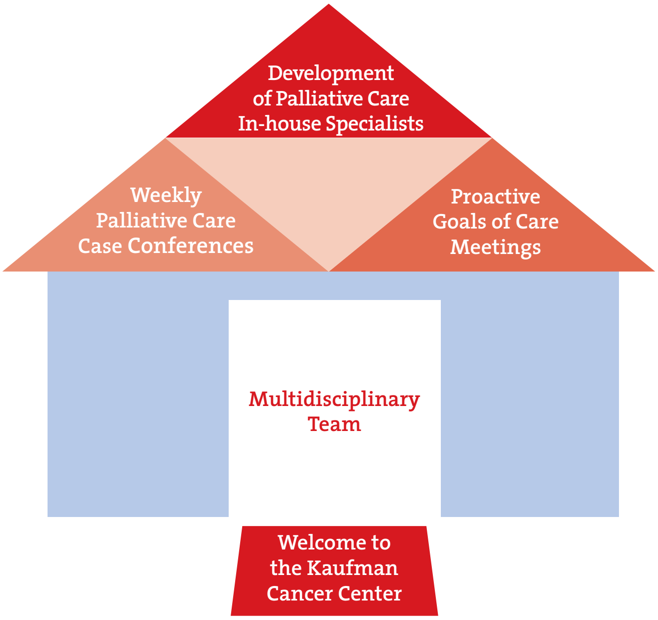
Palliative Care Case Conference

An integral component of the program is the palliative care case conference. These conferences began in October 2014 and continue on a weekly basis. The interdisciplinary conference is open to all members of the cancer center. Prior to conference, a summary sheet is prepared for each patient by one of the palliative care specialists and shared with the team.

Referral to the palliative care conference is open to all team members and follows a specific case, including evidence of noncurative disease, and/or a performance status of 2 or greater (ECOG scale) and advanced disease with or without significant co-morbidities. These criteria trigger the completion of the palliative care five-item questionnaire in the EHR before a referral is made to the palliative care team leaders and the patient is added to the conference agenda.

The palliative care case conference follows a specific format beginning with a review of the patient's status, including understanding of the disease process, response to treatment and overall prognosis, presented by the referring team member. The patient's current functional status, patient and family dynamics, the patient's code status, and completion or lack of advance directives are also reviewed. After the initial presentation, reports from each of the disciplines, including physician/NP, nurse navigator, infusion center nurse, social worker, and dietitian are presented. After the reports are completed, discussion is open to all and the patient's status is summarized and recommendations are formulated. The recommendations are documented in the EHR and communicated back to the treating oncologist. If recommended, a goals of care

Figure 1. The Structural Model of Palliative Care in the Kaufman Cancer Center



Members of Kaufman Cancer Center's Palliative Care In-House Specialists Group.

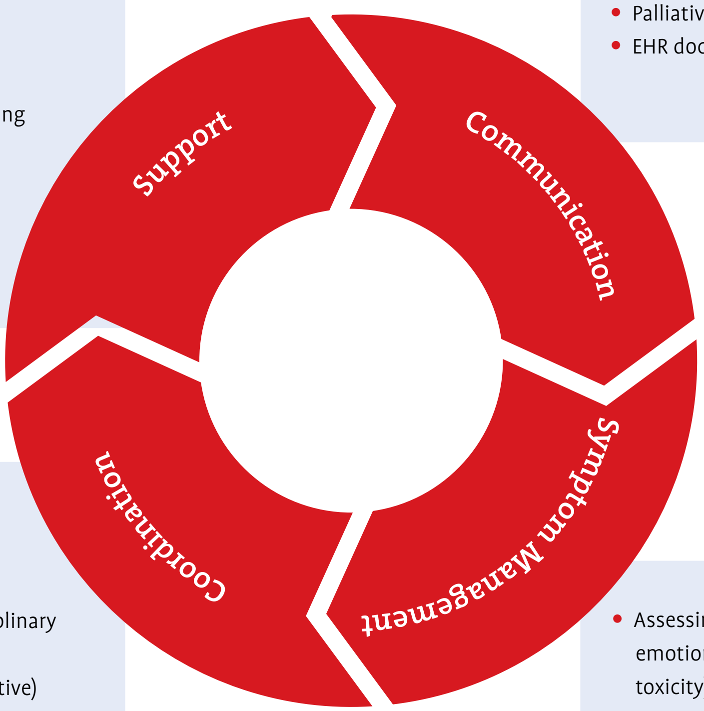
meeting is arranged. This meeting is a billable visit led by the NP and social worker, ensuring a multidisciplinary approach. The results of the goals of care meeting are also documented in the EHR (Figure 3, right).

Proactive Goals of Care Meetings

In the best interest of patient care, we moved to a proactive approach, addressing goals of care with our patients in advance of a crisis. Our strategy involves ongoing monitoring and increased awareness of the status of our patients by our providers and the treatment team to determine the optimal time to discuss a plan of care with both patients and their loved ones. Goals of care meetings are patient and family conferences that facilitate shared decision-making to establish how patients wish to move forward with their care. The meeting—or series of meetings—provide(s) an opportunity to help patients and families understand the patient's current medical status and to summarize the "big picture" issues. They also allow the palliative care team to provide emotional support and to learn about the patient's values, beliefs, and wishes so that the team is best able to support the patient moving forward.

To prepare for goals of care meetings, we utilize the SPIKES protocol, which is a clear and validated protocol for delivering

Figure 2. The Four Primary Functions of the Palliative Care Program in the Kaufman Cancer Center



- Patient-centered care
- Advance care planning
- Advance directive & medical orders for life-sustaining treatment
- Body, Mind & Spirit Integrative Health (meditation, yoga, massage, mindfulness-based stress management, exercise)
- Support groups
- Individual & family counseling (patients and caregivers)
- Community resources (hospice, Hooper House, palliative home care)
- Short-term bereavement

- Patient & family
- Kaufman Cancer Center providers & team members
- Community-based healthcare providers
- Goal of care meetings
- Palliative care case conference
- EHR documentation

- Kaufman Cancer Center treatment teams: infusion center, radiation oncology, supportive care, multidisciplinary providers
- Inpatient care teams (palliative)
- Outpatient palliative care clinic
- Community-based providers (home care, hospice, other MDs)
- Choosing Wisely Campaign
- Palliative care case conference

- Assessing symptoms (physical, emotional, psychological, financial toxicity)
- Recommendations from palliative care case conference
- Medication management
- Specialist referral
- Behavioral health & supportive care

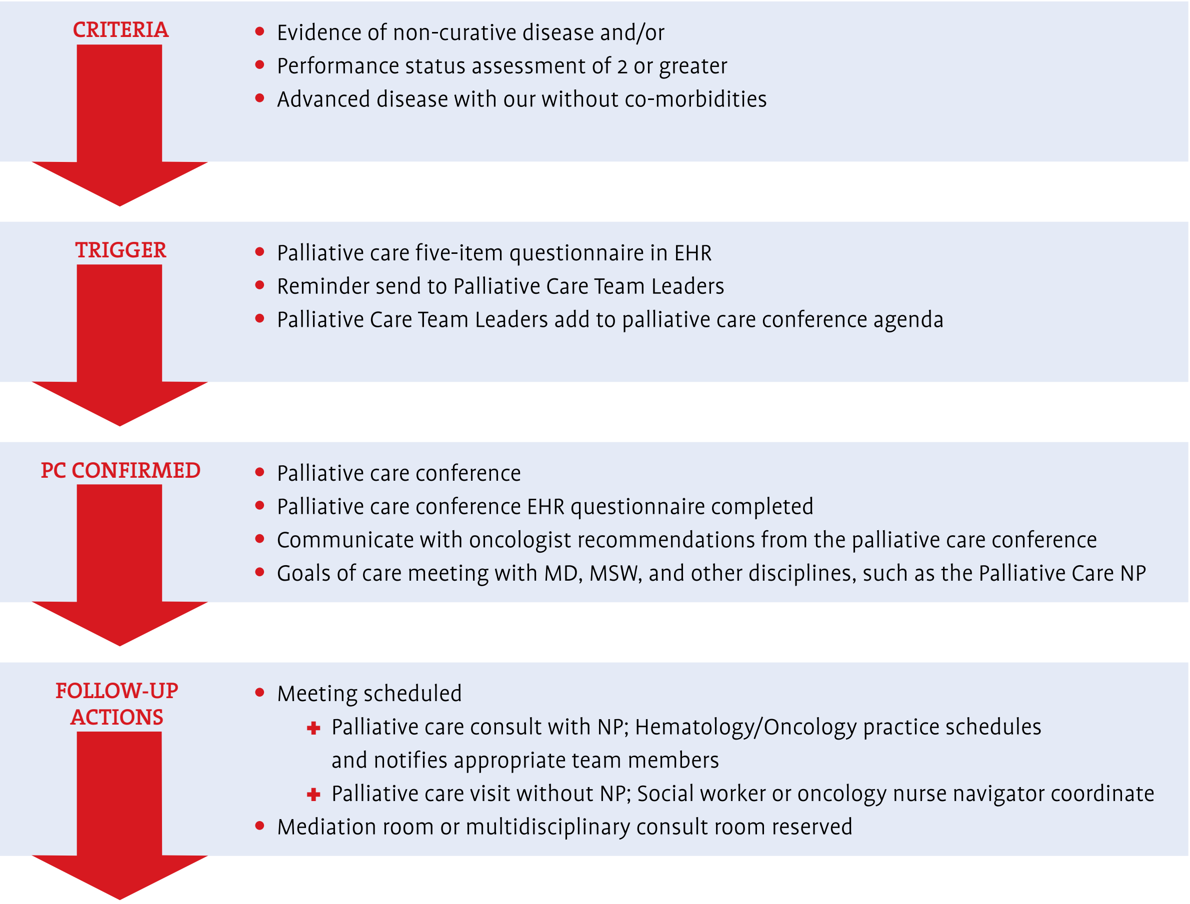


Figure 3. Palliative Care Referral Decision Process

CRITERIA

- Evidence of non-curative disease and/or
- Performance status assessment of 2 or greater
- Advanced disease with our without co-morbidities

TRIGGER

- Palliative care five-item questionnaire in EHR
- Reminder send to Palliative Care Team Leaders
- Palliative Care Team Leaders add to palliative care conference agenda

PC CONFIRMED

- Palliative care conference
- Palliative care conference EHR questionnaire completed
- Communicate with oncologist recommendations from the palliative care conference
- Goals of care meeting with MD, MSW, and other disciplines, such as the Palliative Care NP

FOLLOW-UP ACTIONS

- Meeting scheduled
  - Palliative care consult with NP; Hematology/Oncology practice schedules and notifies appropriate team members
  - Palliative care visit without NP; Social worker or oncology nurse navigator coordinate
- Mediation room or multidisciplinary consult room reserved

"bad news."[4] This protocol includes:

- Setting up the interview
- Assessing the patient's perception of his or her disease and current medical situation
- Obtaining the invitation from the patient
- Giving knowledge and information to the patient
- Addressing the patient's emotions with empathic responses
- Strategizing and summarizing the discussion and plan.

It is important to arrange for privacy and to involve significant family members and loved ones of the patient's choosing. It is also important that "before you tell, ask." Use open-ended questions to create an accurate picture of how the patient perceives his or her medical situation. From there, determine how much information the patient would like to have. While some patients may want specific details, others may prefer a more general discussion. Before conferring on a treatment plan, ask the patient if he or she is ready for this discussion. Finally, summarize all the decisions that were made and allow time for debriefing with the team.

Palliative Care In-House Specialists

As we began the weekly palliative care case conferences and the proactive goals of care meetings with our patients, providers and team members came together to become part of a professional development group we called our "Palliative Care In-House Specialists." This voluntary group was self-selected and included representation from nursing, social work, administration, pharmacy, and spiritual care. The group met bi-monthly with the purpose of learning new information and palliative care skills, which could then be shared with other members of the multidisciplinary team. As part of this process, group members engaged in a self-assessment exercise—both individually and collectively as a group—using the *Interdisciplinary Team Competency Grid* from the National Hospice and Palliative Care Organization.[5] Group members shared these self-assessments and set personal goals for development. This exercise served as a guide for identifying topics for enhanced learning and external subject experts who were then invited to provide additional palliative care education to the group. The group also discussed their own attitudes

Members of Kaufman Cancer Center's Palliative Care Case Conference.

and beliefs surrounding death and dying. Some of the educational areas explored included:

- Communicating with patients and families
- Learning and sharing the SPIKES protocol
- Implementing language sensitivity and cultivating a culture of such in our center
- Developing religious and cultural sensitivity
- Understanding physician-assisted death
- Managing symptoms, such as terminal restlessness syndrome, respiratory secretions, pain, nausea, anorexia, dyspnea, nutrition, and others.

Presenting subject experts included:

- Palliative care physicians
- Medical director of hospice
- Chaplain
- Hospice and oncology nurses
- Certified pain management nurse
- Certified oncology social workers
- Certified oncology pharmacist
- Administrators with expertise in palliative care.

Two members of the Palliative Care In-House Specialists group became certified in palliative care in their respective professions—nursing and social work. This group has also addressed self-care for themselves and other team members by providing debriefings at the end of palliative care case conferences. In addition, the group was instrumental in instituting an annual remembrance ceremony where Kaufman Cancer Center providers, team members, and volunteers are invited to pay respects to those who have died and to acknowledge the difficult work they do daily.

Programmatic Impact

The palliative care program resulted in a significant culture shift within our cancer center. We became proactive regarding palliative care and end-of-life discussions and moved away from a reactive culture, which often resulted in crisis. Early palliative care has become the mainstay. In addition, we have expanded awareness about language sensitivity and how to deliver bad news to our patients. We avoid phrases such as, "the patient failed chemotherapy" or "we are stopping treatment." The patient did not fail; chemotherapy failed the patient. And we will be continuing to provide treatment to our patients through end-of-life—palliative care and hospice are treatment too. We have worked diligently to move away from the perception that palliative care is hospice care. Rather, hospice is under the umbrella of palliative care. Any patient can receive palliative care throughout the trajectory of his or her disease, whether receiving curative treatment or not. There is also greater emphasis on completing advance directives, medical orders for life-sustaining treatment (MOLST), and ongoing discussions of advance care planning. Finally, we continue to streamline our palliative care program to meet the growing demands of our population-health initiatives and value-based care.

The palliative care program has also included other community providers and the inpatient palliative care team, resulting in greater partnerships. We have reached out to local hospice and palliative care agencies for input and collaboration concerning mutual patients. We hosted Meet & Greets in December 2014 and March 2016 to increase exposure for our palliative care team members and the community agencies. A local hospice representative joined the weekly palliative case conference in March 2015 and continues to attend, providing valuable information and continuity of care for many of our patients. We also have continuous collaboration with our inpatient palliative care team. This has resulted in a smoother transition for patients in the palliative care program if they are hospitalized and seen by the inpatient palliative care team.

The implementation of this program has had significant effects on patient care, utilization of hospice, goals of care discussions, and implementation of advance care planning (Table 3, below). When compared to national benchmarks, we have seen:

- Fewer ED visits
- Reduced ICU admissions
- Earlier admission to hospice
- Reduction in end-of-life chemotherapy
- Earlier and more frequent "goals of care" meetings
- Improved communication between patients, families, and the treatment team.

Moving Forward

This innovative program is evolving and growing. There is continuous refinement of the weekly palliative care case conference, optimizing the process and the number of patient care issues that can be addressed efficiently. A systematic and expanded identification process of patients who should be presented at weekly case conferences continues to be a focus. Incorporating palliative care consults into multidisciplinary clinics within the cancer center is in the forefront of leadership's attention as well. Continuous data tracking

Table 3. Kaufman Cancer Center Palliative Care Outcome Measures

2014–2016	NATIONAL BENCHMARKS	OCT NOV DEC 2014	JAN FEB MAR 2015	APR MAY JUN 2015	JUL AUG SEPT 2015	OCT NOV DEC 2015	JAN FEB MAR 2016	APR MAY JUN 2016
Proportion receiving chemotherapy in the last 14 days of life	Average: 5.6–6.4%	13%	3%	4%	1%	6%	8%	8%
Proportion with more than one emergency room visit in the last days of life	Average: 8–10% Best observed: 2%	7%	14%	0%	3%	2%	2%	4%
Proportion admitted to the ICU in the last 30 days of life	Average: 8–12% Best observed: <4%	4%	11%	2%	6%	4%	6%	8%
Proportion admitted to hospice for less than 3 days	Average: 27–35% Best observed: <4%	12%	12%	35%	6%	0%	8%	4%
Proportion not admitted to hospice	Estimated typical performance: 65–85% Best observed: <55%	55%	38%	45%	53%	41%	51%	46%
Advance Care Plan	Observed average: 41%	38%	46%	87%	70%	73%	82%	90%

and review is an essential task, along with diving deeper into the data to identify outlying trends and areas for improvement.

The palliative care in-house specialists continue to meet bi-monthly to re-assess their competencies and identify areas for growth. Some recent ongoing initiatives include:

- Exploring how we can record actual goals-of-care meetings (audio or video) to critique and develop professional skills
- Creating a Kaufman Cancer Center pocket resource card to be distributed to all team members
- Implementing a more formally structured resiliency program intended to promote ongoing self-care for all team members.

Additional certifications in palliative care are under pursuit for members of the group and membership remains open to other Kaufman Cancer Center team members. Overall, these initiatives will increase awareness and visibility of our palliative care resources for providers, caregivers, and patients.

Reaching out to our community partners is another area we continue to explore. Keeping our hospice and in-home palliative care providers informed of our model and practices is crucial. Recently some members of the in-house specialist team have joined a newly-formed community group whose members are involved with providing various services to people at end-of-life in our community. Engaging in these relationships and conversations is essential to create an environment where people can receive appropriate and sensitive care at a critical time.

Lessons Learned

What have we learned from this process? To begin with, we have learned that you must start somewhere. Use the valuable resources you already have and tap into people's passions and talent. Be inclusive. Invite everyone on the care team to participate. Multidisciplinary expertise is vital to the success of the program. Each team member has something unique to offer. Secure support from leadership early in the process. This support will provide the strong foundation needed to move processes forward. Early palliative care is vital. It improves patient care and outcomes. Finally, keep at it. It is a fluid, on-going process. Be open to change and be flexible. Ultimately the goal is to improve outcomes for our patients and families. OI

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CANCER CENTER

Our Program At-a-Glance

The Kaufman Cancer Center is in north central Maryland, in Harford County, which is home to approximately 250,000 people who live in a combination of rural and suburban communities. Thanks in part to strong philanthropic support from the community, the Center provides enhanced supportive care services through its Cancer LifeNet program in a state-of-the art community cancer center that is part of the University of Maryland Cancer Network. This community support has been driven largely by the higher than average rates of cancer incidences: 480.6 per 100,000 as compared to 440.7 and 450.6 for Maryland and the entire United States respectively. Learn more at umuch.org/cancer.

References

1. Temel JS, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Eng J Med*. 2010;363(8):733-742.

2. Glare PA, et al. Palliative care in the outpatient oncology setting: evaluation of a practical set of referral criteria. *J Oncol Practice*. 2011;7(6):366-370.

3. May P, et al. Prospective cohort study of hospital palliative care teams for inpatients with advanced cancer: earlier consultation is associated with larger cost-saving effect. *J Clin Oncol*. 2015;33(25): 2745-2752.

4. Baile WF, et al. SPIKES-a six-step protocol for delivering bad news: application to the patient with cancer. *The Oncologist*. 2000;5(4):302-311.

5. The National Hospice and Palliative Care Organization (2011). Interdisciplinary Team Competency Grid. Available online at: www.nhpco.org/sites/default/files/public/education/Competency_level_grid_final.pdf . Last accessed Dec. 13, 2016.