

Coleman Supportive Oncology Initiative

Palliative Training Module

Topic: Primary vs. Specialized Palliative Care

Presenters: Catherine Deamant, MD and Christine Weldon, MBA

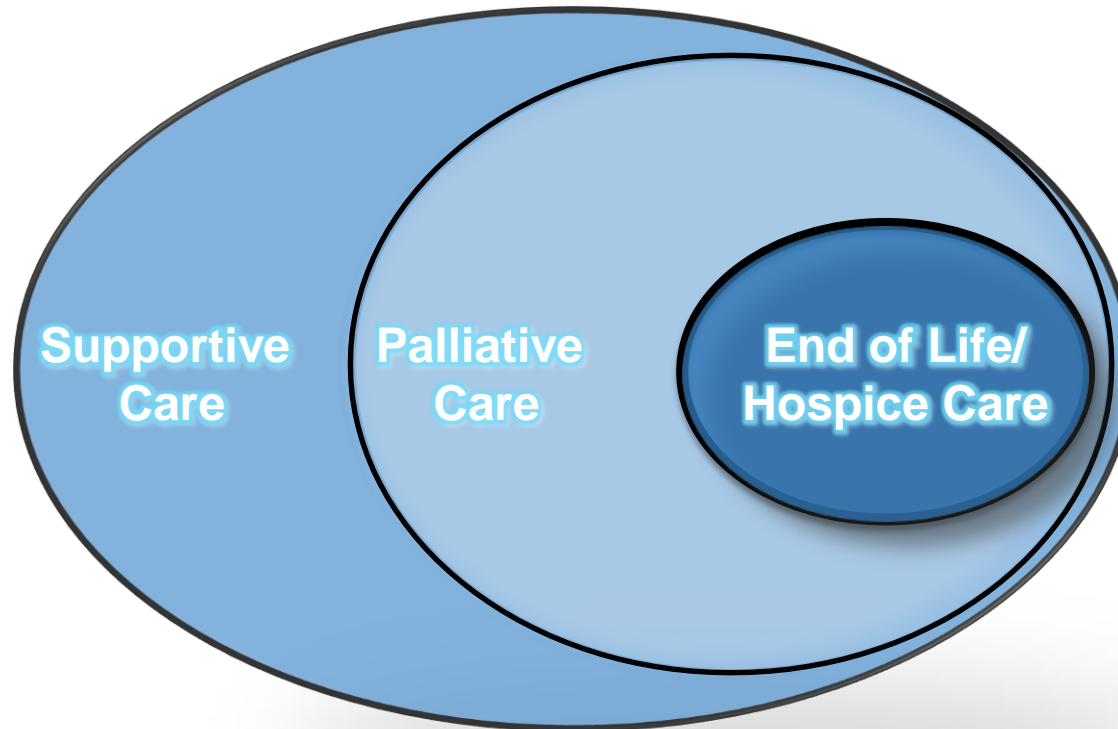
Version: 08072017

Learning Objectives

By the end of this module you should be able to:

- 1. Differentiate between supportive care, palliative care and hospice care**
- 2. Identify primary oncology team practices that are considered “primary palliative care”**
- 3. Compare palliative care provided by a primary oncology team to care provided by a palliative medicine specialist**

Conceptual Framework

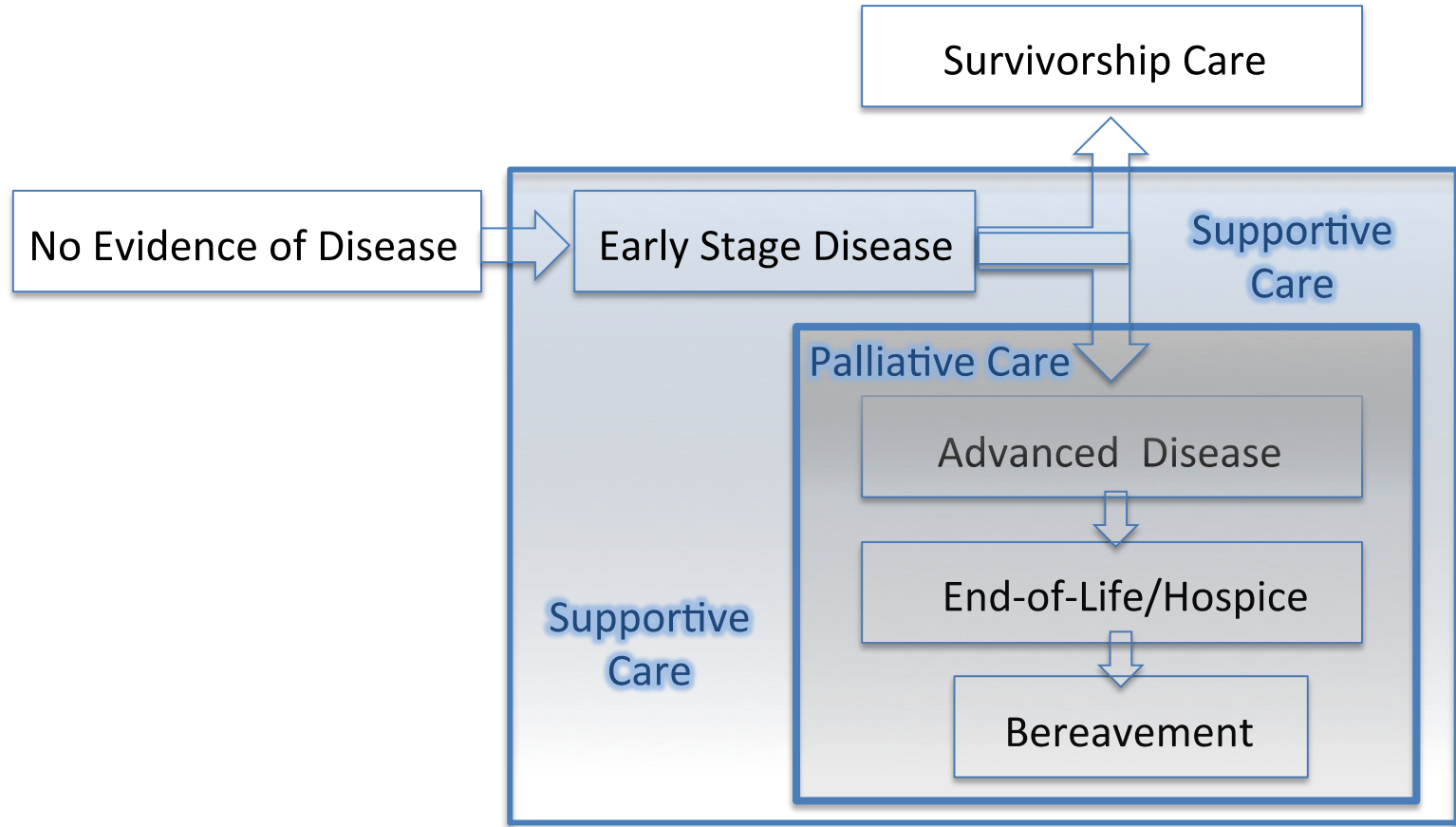


Supportive care: throughout various stages of disease (diagnosis; active treatment; end of life; survivorship)

Palliative care: addresses progressively greater care needs as disease advances

End-of-Life / Hospice care: is a subset of palliative care delivered near the end of life

Conceptual Framework



Definition of Palliative Care



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DEFINITION OF PALLIATIVE CARE^{a,c}

Palliative care is a special kind of patient- and family-centered health care that focuses on effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs, and cultures. The goal of palliative care is to anticipate, prevent, and reduce suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care begins at diagnosis and should be delivered concurrently with disease-directed, life-prolonging therapies and should facilitate patient autonomy, access to information, and choice. Palliative care becomes the main focus of care when disease-directed, life-prolonging therapies are no longer effective, appropriate, or desired. Palliative care should be initiated by the primary oncology team and then augmented by collaboration with an interdisciplinary team of palliative care experts.

Palliative care focuses on:

- Patient- and family-centered care
- Effective management of pain and other distressing symptoms
- Psychosocial and spiritual care based on patient/family needs, values, beliefs and culture

[NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) Palliative Care](#)

^aHui D, Mori M, Parsons HA, et al. The lack of standard definitions in supportive and palliative oncology literature. J Pain Symptom Manage 2012;43:582-592.

^cIOM (Institute of Medicine). 2014 Dying in America: Improving quality and honoring individual preferences near the end of life. Washington, DC: The National Academics Press. (iom.edu/endoflife)

Definition of Palliative Care



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The goal of palliative care is to:

- Anticipate, prevent and reduce suffering
- Support the best possible quality of life for patients and their families

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Palliative care begins at diagnosis

- Is delivered concurrently with disease-directed, life-prolonging therapies
- Facilitates patient autonomy, access to information and choice
- Becomes the main focus when disease-directed, life-prolonging therapies are no longer effective, appropriate or desired by patients

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Palliative care should be initiated by the primary oncology team and then augmented through the collaboration of interdisciplinary palliative care experts:

- Board-certified palliative medicine physicians
- Advanced practice nurses and physician assistants
- Counselors, social workers or psychologists
- Chaplains
- Pharmacists

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^aHui D, Mori M, Parsons HA, et al. The lack of standard definitions in supportive and palliative oncology literature. J Pain Symptom Manage 2012;43:582-592.

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“Primary Palliative Care” Provided by Primary Oncology Team

The primary oncology team provides palliative care as a standard skill and competency expected of all physicians and health care professionals.

- Guidance with complex decision-making and goals of care discussions
- Pain assessment and management
- Side effect and symptom management
- Screening for distress and palliative needs at initial visit and at appropriate intervals and connecting patients with indicated services

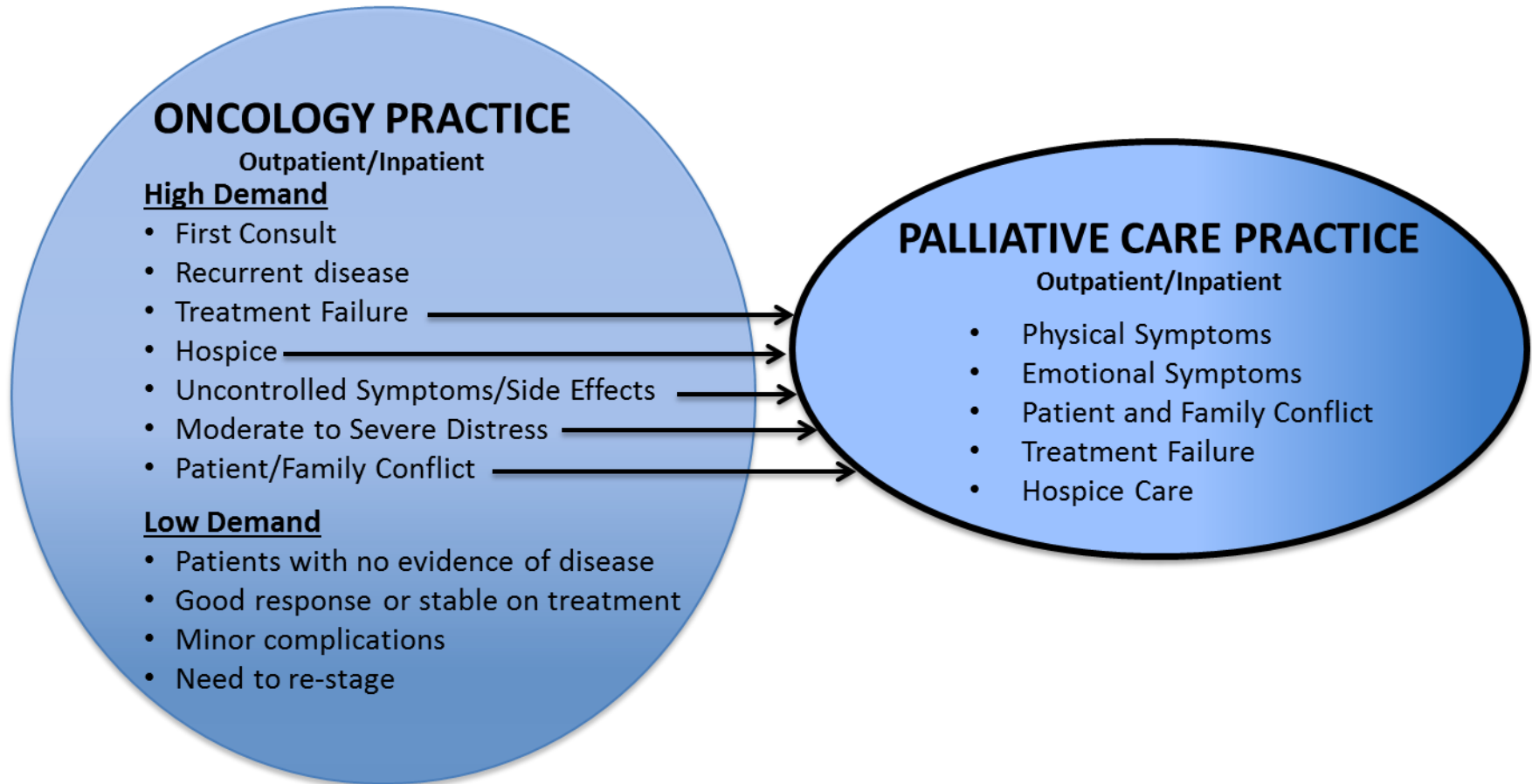
Comparison of “Primary Palliative Care” provided by Primary Oncology Team to Palliative Specialist Care

As a patient has items on the right, consultation with palliative care specialists is indicated:

Primary Oncology team	Palliative Care team
Patient’s pain is well controlled	Pain is interfering with patient’s life and/or pain intensity is not controlled
Controlled symptoms and side effects	Uncontrolled symptoms/side effects
Mild to moderate distress	Moderate to severe distress
Patient/family goals, decision making and care planning are aligned	Patient/family concerns about decision-making and/or course of disease
	Patient or family requests palliative care

Criteria for Palliative Care Referral

High demand with physical or emotional distress,
refractory disease or the need for transition of care



Summary of Points Covered

In this training module we addressed:

- **The distinction between supportive care, palliative care and hospice care**
- **The importance of the oncology team in providing primary palliative care**
- **Identified criteria for patients with high levels of distress (physical, emotional or spiritual) that may benefit from referral to palliative care experts**

Next Steps

For more detailed training on this topic, you can go to the following resources:

National Comprehensive Cancer Network®

- [NCCN Guidelines® for Palliative Care, Version 2.2017](http://www.nccn.org/professionals/physician_gls/pdf/palliative.pdf)

http://www.nccn.org/professionals/physician_gls/pdf/palliative.pdf

NIH National Cancer Institute

- [EPEC™ O-Self-Study](http://www.cancer.gov/resources-for/hp/education/epeco)

<http://www.cancer.gov/resources-for/hp/education/epeco>

Faculty Bio for Catherine Deamant, MD

Catherine Deamant , MD, graduated from Rush Medical College and completed her internal medicine residency at Michael Reese Hospital in Chicago, IL.

From 1990-2014, she worked as a general internist in the Division of General Internal Medicine at Cook County Health and Hospitals System (CCHHS), with a focus on HIV care and homeless healthcare. In 2001, she established the Palliative Care Program for CCHHS.

From 2012-2014, she served as the Program Director for the Hospice and Palliative Medicine Fellowship, in collaboration with Rush University Medical Center and Horizon Hospice. She was an assistant professor at Rush Medical College.

She is board certified in hospice and palliative medicine. Currently, she is an associate hospice medical director for JourneyCare.

Faculty Bio for Christine B. Weldon

Christine Weldon is director and co-founder of the Center for Business Models in Healthcare (CBM-HC), an independent health services research organization focused on personalized care and precision medicine in oncology. Ms. Weldon's work involves quality improvement collaborations with academic institutions, including Northwestern University and University of California San Francisco, medical centers, health care payers, product development companies and patient advocacies.

Christine has over twenty years of experience in business advisory, research and consulting services. Her expertise includes business model design, business visioning and planning, strategic decision-making support, facilitation of complex initiatives, business process optimization, organizational design and information management.

Ms. Weldon is an Adjunct Faculty member of the Northwestern University Feinberg School of Medicine and possesses an MBA from the Kellogg School of Management, Northwestern University and a BSBA from Drake University.

List of Ms. Weldon's publications available at:

<http://www.ncbi.nlm.nih.gov/sites/myncbi/1Bc7czwoYfu/bibliography/43309719/public/?sort=date&direction=ascending>

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Coleman Supportive Oncology Initiative

Palliative Training Module

Topic: Reasons to Refer to Hospice and Palliative Care

Presenters: Joanna Martin, MD, Amy Scheu, MSH CHPCA
and Jen Obel, MD

Version: 08072017

Learning Objectives:

By the end of this module you should be able to:

- **Describe the basics of what a palliative care program provides**
- **Differentiate how an outpatient palliative care program differs from hospice**
- **Identify when to make an inpatient or outpatient palliative care or hospice referral**
- **Explain the basics of what hospice provides and when a patient is eligible for hospice care**

Continuum of Care



Never 'Nothing' More To Do: Care and Hope when Cancer Treatment is Limited, Eytan Szmulowicz, MD Director, Section of Palliative Medicine Northwestern Medicine. Used with permission.

Palliative Care Programs

- **Provide co-management with the oncologist to assist with management of advanced symptoms**
- **Discuss goals of care and difficult advance care planning**
- **Provide services to patients who will recover from their cancer, as well as patients that will not**
- **Can help with patients' decision-making aligning with their goals at important junctures in care:**
 - During the creation of a goals of care plan
 - In the event of disease progression
 - When determining whether or not hospice is appropriate
 - When transferring to home-based palliative care

Palliative Care Programs by Type

■ Palliative Care Inpatient Programs

- Usually involve a team with a physician(MD) and an advanced nurse practitioner(APN)
- Sometimes includes a psychosocial team member
- In-patient palliative care programs can be certified by The Joint Commission

■ Palliative Care Outpatient Clinics

- MD or APN may staff outpatient appointments

■ Palliative Care Outpatient Home-Based Programs

- Many are moving towards a nurse practitioner case management model; may or may not have physician coverage
- Unlike hospice, these are not paid for with a daily rate
 - visits are usually billed similar to an outpatient visit

Palliative Care Outpatient Home Based Programs Compared to Hospice

Home-Based Palliative programs provide:	Home-Based Hospice programs provide:
<ul style="list-style-type: none"> • May or may not have 24/7 call coverage • May have appointments with advanced nurse practitioner 1-2 times per MONTH • May have physician oversight and ability for a physician consult visit 	<ul style="list-style-type: none"> • 24/7 emergency call coverage • RN case management (usually visits 1 to 2 times per WEEK) • MD oversight and ability of MD and/or ANP to see patients at home
DOES NOT COVER MEDICATIONS, medical equipment or oxygen. Patient is still being cared for by primary physician and care team.	Medicare pays all charges related to hospice. Most private insurers also have benefits. In most states, Medicaid pays all charges related to hospice. Primary physician may remain involved in care or care can be delegated to hospice physician.
May or may not have some interdisciplinary team support (physician, nurse, social worker, chaplain, but no home health aid)	Interdisciplinary team support (physician, nurse, social worker, chaplain and home health aid)
May or may not have other ancillary service	Volunteer services, alternative therapies and bereavement support

Palliative Care Reasons for Referral Inpatient or Outpatient

- 1. Needs someone to support or lead a challenging advance care planning or goals of care discussion**
- 2. Has progressive disease where uncontrolled symptoms interfere with quality of life or performance status**
- 3. Has a cancer diagnosis and has failure to thrive or frailty**
- 4. Patient or family requests a palliative care consult**
- 5. Has a life limiting cancer and poor functional status (ECOG of 3) and the patient or health care agent has declined a hospice referral**
- 6. Has chemotherapy-refractory advanced cancer with a good functional status and is not yet being referred for hospice**
- 7. Has any stage cancer diagnosis, but quality of life and/or survival is limited by debility, has frequent hospitalizations and/or other concurrent chronic medical issues such that prognosis is less than 1 year**

Palliative Care Reasons for Referral Inpatient, Non-ICU

- 1. Needs someone to support or lead a challenging advance care planning or goals of care discussion**
- 2. Has progressive disease where uncontrolled symptoms interfere with quality of life or performance status**
- 3. Has a cancer diagnosis and has failure to thrive or frailty**
- 4. Patient or family requests a palliative care consult**
- 5. Has a life limiting cancer and poor functional status (ECOG of 3) and the patient or health care agent has declined a hospice referral**
- 6. Has chemotherapy-refractory advanced cancer with a good functional status and is not yet being referred for hospice**
- 7. Has any stage cancer diagnosis, but quality of life and/or survival is limited by debility, has frequent hospitalizations and/or other concurrent chronic medical issues such that prognosis is less than 1 year**
- 8. Has a life-limiting oncologic illness and prolonged hospital stay (greater than 7 days) without evidence of clinical improvement**
- 9. Stage IV malignancy or refractory hematologic malignancy in addition to poor functional status**
- 10. Current or past enrollee of hospice program**

Palliative Care Reasons for Referral, Inpatient ICU

- 1. ICU stay longer than 7 days without evidence of improvement**
- 2. Cardiac arrest (either in or out of hospital)**
- 3. Multi-system organ failure (3 or more)**
- 4. Stage IV malignancy or refractory hematologic malignancy**
- 5. Poor neurologic prognosis with low chance of meaningful recovery**
- 6. Inability to wean a patient from the ventilator**
- 7. Team/family discussing tracheostomy, feeding tube or long term care placement**
- 8. Current or past enrollee of hospice program**
- 9. There is a family disagreement with the medical team, with the patient's advance directive, or with each other**
- 10. Patient or family requests a palliative care consult**

Hospice Care Programs

- Is not a place, but a program of care
- Is a comprehensive program that provides care for the patient at their place of residence (home or nursing home)
- Does not provide a caregiver, but it does support the caregiving system
- Is for patients with a prognosis of less than 6 months
- Paid for by Medicare, Medicaid, other insurers or charity

Hospice Programs Provide

- **RN case management**
- **Social worker**
- **Chaplain**
- **Medications related to primary diagnosis**
- **Medical equipment (e.g., hospital bed, bedside commode, walker)**
- **Certified nursing assistants**
- **Volunteers**
- **Bereavement resources**
- **MD oversight and visits**
- **24/7 crisis call coverage**
- **May provide complementary and alternative medicine services**

2013/14 Hospice Statistics

■ In 2013:

- Approximately 43% of all deaths in the U.S. were under the care of a hospice program

• In 2014:

- Less than 25% of all U.S. deaths were caused by cancer, with the majority of deaths due to other terminal diseases
- 36.6% of all hospice admissions had a cancer diagnosis
- 35.5% of hospice patients died or were discharged in less than 7 days of admission
- Median length of service was 17.4 days
- Average length of service was 71.3 days
- Majority (66.6%) of hospice patients' location of death was at their personal place of residence

Hospice Care Reasons for Referral

- 1. The patient is no longer able to come into the oncology clinic for visits due to debility, symptoms etc.**
- 2. Patient with chemotherapy-refractory metastatic solid tumor malignancy or refractory hematologic malignancy**
- 3. Life expectancy is less than 6 months and the patient's goals of care are focused on comfort**
- 4. Poor performance status (ECOG 2 or more) which inhibits the use of chemotherapy**
- 5. Patient with a cancer diagnosis, other serious chronic comorbidities, debility and/or frequent hospitalizations, as well as a life expectancy of less than 6 months**

- **Palliative care and hospice are part of a continuum of care**
- **Hospice and palliative care programs differ and referrals should be matched to the patient's prognosis and goals of care**

Next Steps

For more detailed training on this topic, you can go to the following resources:

National Comprehensive Cancer Network® (NCCN®)

- [NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) Palliative Care, Version 2.2017](#)

http://www.nccn.org/professionals/physician_gls/PDF/palliative.pdf

Faculty Bio for Joanna Martin, MD

Joanna Martin MD is board certified in Internal Medicine, Geriatrics, and Hospice, and Palliative Medicine. She is a palliative care physician at the Jesse Brown VA and a Health Systems Clinician at Northwestern Memorial Hospital. Dr. Martin was previously employed by Horizon Hospice and Palliative Care and Presence St. Joseph Hospital in Lincoln Park from 2006 through 2015. She was medical director of Horizon Hospice and Palliative Care and the Director of Palliative Care at Presence St. Joseph Hospital from 2007 through 2015.

As a clinician educator, Dr. Martin has experience educating all levels of learners in geriatrics and palliative care in the home and hospital setting. She is currently serving as a Design Team Leader for the Coleman Supportive Oncology Initiative, a multi-hospital initiative to improve access to supportive oncology services. Dr. Martin attended medical school at the University of Minnesota Medical School in Minneapolis and completed an Internal Medicine residency and two year Geriatrics Fellowship at the University of Chicago.

Faculty Bio for Amy Scheu, MSH, CHPCA

Joined Advocate at Home, the home care division of Advocate Health Care, in 2007 and currently serves as Administrator of Advocate Hospice and System Palliative Care. In this role, she has led implementation and operations of hospice programs across the Chicago area and central Illinois that serve more than 2,200 patients annually. In 2010, Amy was asked to lead efforts to further assure care across the continuum by designing and implementing a system wide palliative care program for Advocate Health Care. Through her efforts, Advocate has launched successful home- and skilled nursing facility-based programs; established four outpatient clinics serving patients in the south, west and north areas of the city and suburbs; and expanded inpatient palliative care services at several hospitals. Amy has also been instrumental in initiating physician palliative medicine education efforts through Advocate Physician Partners, Advocate Health Care's PHO. She has also worked with Advocate Medical Group to secure funding and implement a palliative care pilot serving Medicare Advantage patients on Chicago's south side.

Amy has been certified as a hospice and palliative care administrator by the National Hospice and Palliative Care Organization. She received her bachelor of arts degree from Marquette University and a master's degree in health services administration from Cardinal Stritch University, Milwaukee. She also has a certificate from Harvard School of Public Health in Healthcare Project Management.

Faculty Bio for Jen Obel, MD

Dr. Jennifer Obel is a board-certified medical oncologist who specializes in gastro-intestinal malignancies and palliative care. She earned her medical degree from Northwestern University's Feinberg School of Medicine, where she also completed an internship and residency in Internal Medicine and completed her hematology and oncology fellowship at the University of Chicago. Dr. Obel is an Assistant Clinical Professor, University of Chicago, prior to that she was an Assistant Clinical Professor of Medicine at Northwestern University.

Dr. Obel is the PI for the Palliative and Hospice design team of the Coleman Supportive Oncology Initiative, as well as community PI for a national study evaluating the role of early integrated palliative care. Prior to this role Dr. Obel led an oncology and outpatient quality improvement team, as part of the advance care planning initiative at NorthShore. As lead, Dr. Obel created and implemented goals-of-care workflow for newly diagnosed, stage IV cancer patients. She also developed the NorthShore advance care planning effort for end-stage congestive heart failure (CHF) patients. CHF patients also are confronted with decisions regarding resuscitative measures near end-of-life, typically during hospitalization. Data demonstrate only 12 percent of cardiologists engage their morbidly-ill, CHF patients in yearly discussions regarding EOL preferences and have difficulty identifying prospectively which of their CHF patients are at significant risk for death and who should be referred to early, integrated palliative care and hospice. Dr. Obel has developed internal medicine residency training programs for second and third year residents to enhance their ability to conduct in-depth advance care planning discussions. These curriculums are multi-modality, involving directly observed, video-taped encounters with patients actors as well as real-life encounters with patients. Lecturers, feedback sessions from trained experts, and online interactive course work are also involved.

Dr. Obel has worked successfully with numerous administrative leaders and department and division heads, along with informatics, quality improvement, spiritual care and nursing division members (over 50 different providers). She has successfully listened to multiple viewpoints, integrated those views into the project design, and navigated multiple challenges in order to implement new care processes for these significantly ill patients.

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