

Greetings & Welcome

Rosa Berardi Program Officer Coleman Palliative Medicine Lead

September 16-17, 2016



Private foundation established by Dorothy and J.D. Stetson Coleman





Main Program Areas

- Entrepreneurship education
- Cancer treatment and care
- Services for individuals with developmental disabilities

Coleman Cancer Program Area

Palliative Care falls within the cancer program area.

Cancer Impact Vision

Cancer patients in the Chicago Metro area are fully engaged in their cancer treatment, and achieve the best possible outcome, and quality of life.

Coleman Supportive Oncology Initiative

Cancer patients are:

- regularly screened for distress, psychosocial support and palliative care needs; and
- receive services identified by screenings from a collaboration of multiple, high quality, community service providers that have core competencies in delivering cancer care.

Supportive Oncology – from diagnosis through survivorship and end-of-life.

Supportive Oncology Initiative Program Approach

Design Process Teams

- Northwestern
- NorthShore

Process Improvement Sites

- Rush University Medical Center
- University of Chicago Medical
- University of Illinois Hospital
- Mercy Hospital
- Sinai Hospital
- John H. Stroger Hospital of Cook County

Patient Safety Organization (PSO)

Metropolitan Chicago Breast Cancer Task Force

Core Program Support & Reimbursement Facilitation

Center for Business Models in Healthcare

Coleman Supportive Oncology Initiative

Supportive Oncology Improvement Sites:

measures, tools, training; identify gaps; implement

Conduct current state assessment of processes, resources,

Process Design Teams:

Define processes, stratification factors, measures, tools, education

S	measures,	tools, education	improvements				
points	North- western <u>Distress</u> and Survivorship	Define optimal care process / pathways to improve delivery of distress services		(Rush	Implement improved supportive oncology care process / pathways	
ŭ		Feedback from providers, patients,					
project		Identify validated tools for pilots			University of Illinois	Implement improved supportive oncology care process / pathways	
		Develop process training for Pilots		N			
priat	NorthShore <u>Palliative</u> <u>and</u> <u>Hospice</u> <u>Referral</u>	Define optimal care process / pathways	\rightarrow		University of Chicago Mercy	Implement improved supportive oncology care process / pathways	
oro		for delivery of palliative distress services				oncology care process / pathways	
api		Feedback from providers, patients				Implement improved supportive	
at		Identify validated tools for pilots Develop process training for Pilots				oncology care process / pathways	
Interact and align at appropriate					Sinai	Implement improved supportive oncology care process / pathways	
teract a		Adjust Project 1-4 design of profess Frocess Team Feedback from provider	ic care	Processes and tools	Stroger	Implement improved supportive oncology care process / pathways	
Ē		Pediatric Supportive Identify validated tools		Team – <u>Pediatric</u>			
		Oncology Develop process trainin	g for Pilots	<u>Supportive</u> Oncology			

Program Critical supporting capabilities / infrastructure	Program facilitation, alignment, common methodology, consortium facilitation	Reimbursement Reporting and performance metrics standards Business Process Improvement standards and methods Program / Project Facilitation
"CORE"	Data collection infrastructure	Database of Metrics – Patient Safety Organization (PSO)

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Supportive Care

Distress Screening Tool

Addresses 35 Care Concerns

Please answer these questions to help us address what you need. - continued Page 2 of 2

Patient Screening Questions for Supportive Care

Page 1 of 2

All patients are asked to complete this questionnaire as part of their standard of care. Please take a few minutes to answer the following questions to help us better address your needs.

Over the last 14 days, how often have you	been bothered by the following problems? ²
-------------------------------------------	-------------------------------------------------------

Please mark one box per row	Not at all	Several Days	More than half the days	Nearly every day
Feeling nervous, anxious or on edge				
Not being able to stop or control worrying				
Little interest or pleasure in doing things				
Feeling down, depressed, or hopeless				

Indicate if any of the following has been a concern for you in the past 7 days, please check Yes or No for each.

YES	NO	Practical Concerns	YES	NO	Physical Concerns
		Child care issues			Breathing
		Issues paying for food or housing			Constipation
		Issues with transportation to/from treatment			Diarrhea Fevers
		Work / school issues			Nausea or vomiting
		Insurance coverage issues or no health insurance			Sleep Changes in urination
		Paying for medication or medical care			Difficulty chewing or swallowing Mouth sores
YES	NO	Family/Caregiver Concerns		_	
		Concerns about my children			Dry mouth Swollen arms or legs
	ū	Concerns about my partner	ā	ū	Feeling full quickly or swollen
ā	ā	Concerns about caregivers	_	_	abdomen
		Ability to have children			Sexual intimacy or function
		Concerns about other family members			Skin dry/itchy, blister/pain
					Tingling in hands/feet
YES	NO	Nutrition Concerns			Appearance
		Weight loss or lack of appetite			Use of alcohol/drugs
		Weight gain			
		Issues with taste	YES	NO	Spiritual / Faith / Religious Concerns
		Concerns about nutrition and food			I have a sense of purpose or meaning
YES	NO	Treatment or Care Concerns	ū		I feel peaceful
TES	NO	Treatment or Care Concerns			I find strength in my faith and beliefs
		I want to better understand my cancer diagnosis or stage	-	-	Third Sectification of the section o
		I want to better understand my prognosis or long term outcome			
		I have questions about my treatment options, medication, or my plan of care			
		I want help communicating my wishes for treatment			

	YES	NO	
- 1			In the past 7 days, have you been in Pain? ^{1,4,5}

If YES, you have been in Pain, <i>please mark one box per row below</i>						
	No pain	Mild	Moderate	Severe	Very Severe	
In the past 7 days how intense was your pain at its worst?						
In the past 7 days how intense was your average pain?						

Fatigue/Low Energy

What is your level of pain right now?

Please mark one box per row ⁶	Not at all	A little bit	Somewhat	Quite a bit	Very much
During the past 7 days I feel fatigued (low energy)					
During the past 7 days I have trouble <u>starting</u> things becau I am tired	use 🗖				
In the past 7 days how run-down did you feel on average?	2 🗆				
In the past 7 days how fatigued were you on average?					
<u>Physical Activity</u> Please mark one box per row ⁷	Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
Are you able to do chores such as vacuuming or yard work?					
Are you able to go up and down stairs at a normal pace?					
Are you able to run errands and shop?					
Are you able to be out of bed most of the day?					
Are you able to be out of bed most of the day:	_				
Are you able to be out of bed most of the day? Are you able to take care of your personal needs (dress, comb hair, toilet, eat, bathe)?					

*This tool is adapted from: (1) The National Comprehensive Cancer Network, NCCN Guidelines version 2.2014 Distress Management; (2) the PHQ-4 developed by Drs. Robert L. Spitzer, Janet B.W., Williams, Kurt Kroenke and colleagues; (3) (Asiaer, MJL, et al., Validation of the Mini Nutritional Assessment short-form (MNA-SF): a practical tool for identification of nutritional status. J Nutr Health Aging, 2009. 13(9): p. 782-8; (5) PROMIS Item Bank v1.0 Pain Intensity Short Form 32; (6) PROMIS Item Bank v1.0 Fatgue Short Form 42; (7) PROMIS Item Bank v1.0 Physical Function Short Form 42; and PROMIS Item Bank v1.0 Physical Ford.

The development of this tool was supported by The Coleman Foundation



Sample **Follow Up Reference Document**

52 distress 47 survivorship

- > American Cancer Society, Information on Taste and Smell Changes
- > Cancer.Net. Information on Taste Changes
- > AICR, Heal Well, A Cancer Nutrition Guide

Journey Connections

Any clinician seeking to apply or consult the Coleman Supportive Oncology Initiative Follow up Guidance is expected to use independent medical judgement in the context of individual clinical clinical mustances to determine any patient's care or treatment. The Coleman Foundation makes no representations or warranties of any kind regarding their content, use or application and disclaims any responsibility for their application or use in any way.

NIH, PDQ[®], Nutrition in Cancer Care, Nutrition Therapy,

Alterations of taste and smell



Coleman Supportive Oncology Initiative Inpatient Oncology or ICU Reasons to Refer

Inpatient Reasons for Referral to Palliative Specialist

- Needs someone to support or lead a challenging advance care planning or goals of care discussion¹
- Has progressive disease where uncontrolled symptoms interfere with quality of life or performance status¹
- 3. Has a cancer diagnosis and has failure to thrive or frailty1
- 4. Patient or family requests a palliative care consult¹
- Patient with life limiting cancer and poor functional status (ECOG of 3) and patient or health care agent has declined a hospice referral
- Patient with chemotherapy-refractory advanced cancer with a good functional status who is not yet being referred for hospice¹
- Patient with any stage cancer diagnosis whose 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 one year¹
- Patient has a life limiting oncologic illness and prolonged hospital stay (greater than seven days) without evidence of clinical improvement¹
- Stage IV malignancy or refractory hematologic malignancy in the setting of poor functional status¹
- 10. Current or past enrollee of hospice program¹

ICU - Reasons for Referral to Palliative Specialist

- 1. ICU stay longer than seven days without evidence of improvement¹
- 2. Cardiac arrest (either in or out of hospital)¹
- 3. Multi-system organ failure (three or more) *
- 4. Stage IV malignancy or refractory hematologic malignancy¹
- 5. Poor neurologic prognosis with low chance of meaningful recovery¹
- 6. Inability to wean a patient from the ventilator¹
- 7. Team/family discussing tracheostomy, feeding tube or long term care placement
- 8. Current of past enrollee of hospice program¹
- Family disagreement with the medical team, with the patient's advance directive, or with each other¹
- 10. Patient or family request'



Outpatient Reasons for Referral to Palliative Specialist

- Needs someone to support or lead a challenging advance care planning or goals of care discussion¹
- Has progressive disease where uncontrolled symptoms interfere with quality of life or performance status¹
- 3. Has a cancer diagnosis and has failure to thrive or frailty¹
- 4. Requests a palliative care consult¹
- Patient with life limiting cancer and poor functional status (ECOG of 3) and patient or health care agent has declined a hospice referral
- Patient with chemotherapy-refractory advanced cancer with a good functional status who is not yet being referred for hospice¹
- Patient with any stage cancer diagnosis whose 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 one year¹

Reasons for Referral to Hospice Care

- 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 less than six months and goals of care focused on comfort⁴
- Poor performance status (ECOG 2 or more) inhibits use of chemotherapy
- Patient with a cancer diagnosis, other serious chronic comorbidities, debility and/or frequent hospitalizations and a life expectancy less than six months^{2,4}

¹Weissman DF, Meier DE. Identifying patients in need of a paliative care assessment in the hospital setting: A consensus report from the Center to Advance Paliative Care. J Paliat Med. 2013;14:17–23.

¹National Hospice and Paliative Care Organization. <u>http://www.nhpco.org/sites/default/files/public/HRHP_Paliative_Care_Pocket-</u> Card.pdf. Accessed January 22, 2016.

⁹Prigerson, H., Bao, Y., Shah, M. et al, Chemotherapy use, performance status, and quality of life at the end of life. JAMA Oncol. 2015.

⁴Medicare Guidelines for Hospice eligibility

<u>CFI 2014 Supportive Oncology Initiative Goal:</u> Cancer patients are 1) regularly screened for psychosocial support and pallative care needs; and 2) receive all services as identified by these screenings (from diagnosis through survivorship and end-of-life) from a collaboration of multiple high quality service providers that have core competencies in delivering cancer care.

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Connecting to Community Service Providers JourneyConnections (Compliments of Lilly Oncology)

	Christine Weldon	11/16/2015	1 of 4
PATIENT NAME	AUTHOR	DATE	PAGE
JOURNEY CONNECTIONS	ACCESSORIES SOLUTIONS CREATIVE	WIG DESIGN	\$ (773) 283-4674
The Coleman Foundation (773) 368-7279	Comments for Patients: Talk to Jennifer, she is really g and will help you get a free wi		AVE, 4
NOTES:			
	ACCESSORIES Wig Salon Program Comments for Patients: If Jennifer is not able to help y this number will help you find wig, it may not be as close.		(800) ACS-2345
Created for you by Christine Weldon on 11/16/2015 Page 1 of 4		Added 50)0 service p

Added 500 service providers Access 180 social workers

Distress Training Modules

Live on NCCN Website

Module	Objectives	Faculty
1. The Importance of Distress Screening in Patient Care.	 Understand the importance of screening for distress and practical and physical concerns in patient care, outcomes and adjustment to cancer. Explain the standards and guidelines on distress screening (Commission on Cancer) and understand the importance of distress screening and the role distress screening has on meeting ACOS, COC, QOPI, NAPBC Accreditation Standards. Describe three components of distress and supportive oncology screening (psychosocial, practical, physical). 	Frank J. Penedo, PhD James Gerhart, PhD
2. How to conduct a Supportive Oncology Screening.	 Explain which guidelines and instruments inform various sections of the supportive oncology screening tool. Describe the appropriate timing and frequency of / to utilize / of administration of the supportive oncology screening tool. Discuss examples of how different healthcare organizations have used the supportive oncology screening tool. 	Jen Obel, MD Christine Weldon, MBA
3. How to handle distress (mild, moderate and severe PHQ-4 results).	 Explain how to score and interpret the PHQ-4 in real time. Understand the follow up process for patients scoring with mild, moderate or severe depression and/or anxiety. Understand the need for immediate follow up for patients indicating immediate risk of harming self or others. 	James Gerhart, PhD Suzanne Armato, MA
4. How to talk to a patient about their practical and family concerns.	 Identify the most common practical and family concerns patients face. Understand what interventions and resources are available to share with patients reporting mild, moderate and severe levels of distress with practical and family concerns. Documentation needed to communicate your follow up efforts. 	Melissa Minkley, MSW, CSW, OSW-C Anne Bowman, CHES Megan McMahon, PhD
5. What is Supportive Oncology?	 Describe the supportive oncology components. Explain the appropriate timing of supportive oncology service initiation. Differentiate components that may be more needed on early vs. late stage cancer (young adult vs. elderly). 	Frank J. Penedo, PhD Nancy Vance, BS Craig A. Pressley, MSW, LCSW, OSW-C Shelly S. Lo, MD
6. What and how to document supportive oncology needs and care/referrals in patient's medical records.	 Explain the key components of supportive oncology that should be tracked in medical records in order to: Support the patient through their care continuum, Communicate across the care team, Demonstrate compliance with the Commission on Cancer standard. Contrast how care sites have implemented supportive oncology screening, results and care in EPIC. Describe how care sites have implemented supportive oncology screening, results and care in Cerner. 	James Gerhart, PhD Cathy Deamant, MD Julia Trosman, MBA

Survivorship Training Modules

Live on NCCN Website

Module	Objectives	Faculty
1. What is survivorship?	 Define who is a cancer survivor. Understand what is survivorship care. Discuss trends of the survivorship population. 	Frank J. Penedo, PhD Stephanie Merce Boecher, RN, OCN, MSN, BSN,BA Sara M. Goetzman, BA
2. Comprehensive Care for Cancer Survivors.	 Understand what is comprehensive follow-up care for cancer survivors. Common models of survivorship care. Major challenges of survivorship care. 	Sheetal Kircher, MD Javier Macias, BA Frank J. Penedo, PhD
3. Commission on Cancer Requirements for Survivorship Care.	 Identify the minimal data elements required by CoC Program Standard 3.3 to be included in cancer survivorship care plans. Identify to which patients CoC-accredited institutions need to provide comprehensive care summaries and follow-up plans under Standard 3.3. Summarize the timeline by which CoC-accredited institutions need to provide comprehensive care summaries and follow-up plans to increasing numbers of eligible patients. 	Sofia F. Garcia, PhD Sara M. Goetzman, BA
4. Common Late and Long Term Effects.	 Understand the late effects of cancer treatment. Understand long term complications of cancer treatment. 	Patricia Robinson, MD Sara M. Goetzman, BA
5. Lifestyle and Behavioral Factors.	 Understand why it is important for cancer survivors to achieve and maintain a healthy lifestyle following active treatment for cancer. Describe the lifestyle/behavioral domains associated with the NCCN standards for survivorship. Describe the benefits/risks of engaging in healthy lifestyle behaviors as part of cancer survivorship. 	Teresa A. Lillis, PhD Carol A. Rosenberg, MD
6. Common Psychosocial Challenges of Survivors/Psychosocial Sequela of Cancer.	 Identify common psychosocial experiences and concerns of cancer patients and survivors. Understand experiences of depression, emotional distress and fear of cancer recurrence. Understand financial concerns and return to work and/or other other roles. 	Teresa A. Lillis, PhD Frank J. Penedo, PhD
7. Prevention and Cancer Screening.	 Discuss appropriate cancer screening. Identify cancer prevention strategies. 	Patricia Robinson, MD Frank J. Penedo, PhD
8. Genetic Testing for Patients, Families and Survivors.	 Identify the reasons to perform genetic testing on a cancer survivor. Describe the impact of a BRCA mutation on medical management of a cancer survivor. Describe the impact of Lynch Syndrome on medical management of a cancer survivor. 	Carol A. Rosenberg, MD Shelly S. Lo, MD

Palliative Training Modules

Live on NCCN Website

Module	Objectives	Faculty
1. Pain Assessment: The Basics	 Understand different types of cancer pain. Understand how to thoroughly assess pain. Understand and treat opioid side effects. 	Shelly S. Lo, MD Joanna Martin, MD
2. Pain – Beyond the Basics	 Understand treatment options for pain management including opioids and adjuvant medications. Understand opioid pharmacology. Understand optimal dosing of opioids. Convert from one opioid to another. 	Shelly S. Lo, MD Joanna Martin, MD
3. How to Communicate Prognosis	 Understand how we communicate is as important as what we communicate. Identify barriers common pitfalls to empathic communication of serious news to patients and families. How to communicate a prognosis, responding to patient emotions in an empathic and respectful manner, eliciting a patient's understanding of their illness and what is most important to their future. 	Lauren Wiebe, MD Megan McMahon, PhD Betty Roggenkamp, BA
4. Goals of Care	 Understand how we communicate is as important as what we communicate. Identify barriers common pitfalls to empathic communication of serious news to patients and families. Tailor conversations and recommendations for a plan of care to a patient's individual goals and preferences. 	Lauren Wiebe, MD Megan McMahon, PhD Betty Roggenkamp, BA
5. POLST – Physician Orders for Life Sustaining Treatment, Using Illinois POLST as Example	 Distinguish the relationship between an advance directive and the POLST (Practitioner Orders for Life- Sustaining Treatment) Form. Identify patients who are appropriate to initiate a discussion about POLST. Utilize the IL POLST form to create actionable medical orders for ensuring seriously ill patient's decisions about life- sustaining treatments are respected across settings of care. 	Catherine Deamant, MD Amy Scheu, MSH
6. Advance Care Planning Over Time	 Review the components of advance care planning discussion tailored to stages of health. Describe the elements of an advance care plan based on a model of behavior change. 	Catherine Deamant, MD Amy Scheu, MSH
7. Reasons to refer to Hospice and Palliative Care	 Know basics of what an outpatient palliative care program provides and when a patient would be eligible. Know basics of what hospice provides and when a patient is eligible for hospice care. Understand how an outpatient palliative care program differs from hospice. Know when to make an inpatient or outpatient palliative care or hospice referral. 	Joanna Martin, MD Amy Scheu, MSH Jen Obel, MD
8. Nausea	 Identify common etiologies of nausea in oncology patients. Access and evaluate etiology of nausea/vomiting. Use pharmacologic and non-pharmacologic methods for managing nausea and vomiting. 	Kathleen Derov, RN Lauren Wiebe, MD
9. Constipation	 Assess for cause and severity of constipation. Treat constipation in cancer patients. 	Kathleen Derov, RN Lauren Wiebe, MD
10. Primary Palliative Care verses Specialty Palliative Care	 Define palliative care. Identify primary oncology team practices that are considered "primary palliative care". Compare palliative care provided by a primary oncology team to palliative specialist care. 	Catherine Deamant, MD Christine Weldon, MBA
11. Dyspnea & Shortness of Breath	 Describe the causes of dyspnea. Understand how to assess for dyspnea. Review pharmacologic and nonphamacologic ways to manage dyspnea. Understand how to educate the patient and/or family about dyspnea. 	Joanna Martin, MD

Coleman Supportive Oncology Initiative

Cycle 2 - begins January 1, 2017

- Invited proposals 6 process improvement sites
- 4 new sites

Coleman Supportive Oncology Initiative for Children with Cancer

Project lead: Lurie Children's Hospital

Process sites:

- Rush Children's Hospital
- UOC Comer Children's Hospital
- Lurie Children's Hospital

Thank you for participating in the Primary Palliative Medicine Training Program

