Clinical and Behavioral Management of the Complex and Critically Ill – When to Consult for Palliative Care

Lori Hess, MD, Brian Masterson, MD and Dianna Candelaria, PharmD, BCACP
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Disclosures

Lori Hess, MD has no relevant financial relationships to disclose.

Brian Masterson, M.D. has no relevant financial relationships to disclose.

Dianna Candelaria, PharmD, BCACP has no relevant financial relationships to disclose.

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Agenda

- Palliative Care Definition
- Why palliative care?
- Who needs palliative care and what is the criteria for assessment?
- The Palliative Care Team
- The Palliative Care Assessment
- Psychological and Behavioral Considerations
- Coordination of Care
- Case Studies

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Objectives

At the end of this activity, participants should be able to:

- Identify who should be considered for palliative care or palliative care assessment
- Identify members of the palliative care team
- Outline the basic components of a palliative care assessment
- State the relationship between physical and behavioral health and its impact on complex medical conditions and serious illness

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Definition

Palliative Care

- An interdisciplinary specialty focused on preventing and relieving symptoms, and supporting the best possible quality of life for patients (and their families) facing a serious and/or life-threatening illness
- Services may be provided concurrent with or independent of curative or life-prolonging care
- Encompasses physical, intellectual, emotional, social and spiritual needs to facilitate independence, knowledge and choice

2013 Healthcare Spending

The National Institute for Health Care Management (NIHCM) Foundation is a nonprofit, nonpartisan organization dedicated to improving the health of all Americans

Reality:

Top Spenders	% of Healthcare dollars
10%	65%
5%	50%
1%	20%

Source: National Institute for Health Care Management Foundation analysis of data from the 2013 Medical Expenditure Panel Survey

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Question # 1

True or False?

The majority of medical spend is for patients during their last 12 months of life.

Source: NCBI Book Dying in American

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Question # 1

True or False?

The majority of medical spend is for patients during their last 12 months of life.

FALSE

Source: NCBI Book Dying in American

Facts

Top Spenders	% of Healthcare dollars
5%	50%

- Only 11% of the costliest 5% are dying or in their last 12 months
- 50% of the costliest 5% have short term/limited conditions
- Approximately, 40% of the costliest 5% have persistent costs
- Palliative care improves quality and reduces costs of care
- Palliative care also improves survival: 11.6 mo. vs 8.9 mo. ($p<.02$)

Sources: IOM Dying in America Appendix E, https://www.ncbi.nlm.nih.gov/books/NBK285684/
NEJM2010, Temel et al. Early palliative care for patients with non-small-cell lung cancer ; pp 363:733-42

Who are the 40% and what might they have in common?

- Frailty
- Functional limitations
- Dementia
- Exhausted family members
- Social/Behavioral health challenges
- +/- Serious medical illness

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Center to Advance Palliative Care™ - Checklist

Center to Advance Palliative Care™ (CAPC), is a professional national organization to improve access to palliative care for patients and their families by providing training, tools and technical assistance. CAPC consensus panel developed a checklist for palliative care screening at the time of *hospital admission*:

Primary Criteria

- Surprise question
  - Would you be surprised if patient died within an year time-frame?
- Frequent in-patient readmitter
- Poorly controlled symptoms
- Requires complex care
- Decreasing function or failure to thrive

Secondary Criteria

- Acute admit from long term care
- Cognitively impaired elder with hip fracture
- Metastatic or incurable cancer
- Requires home oxygen
- History of cardiac arrest
- History of prior hospice care
- Lack of family support
- No advanced directives

Source: Journal of Palliative Medicine, Identifying Patients in Need of a Palliative Care Assessment in the Hospital Setting

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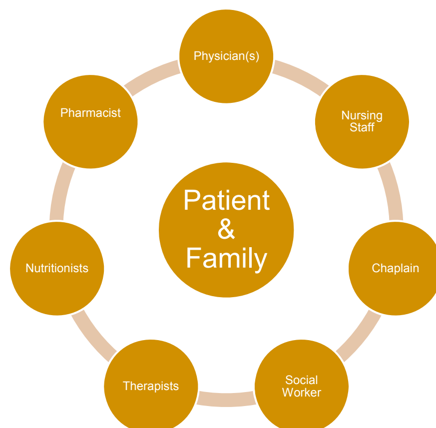
The Palliative Care Team

The patient-centered communication and shared decision-making framework puts the patient and family in the center of the care model



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The Palliative Assessment

- Pain/Symptom Assessment
- Social/Spiritual Assessment
- Assessment of Understanding
  - Diagnosis
  - Prognosis
  - Disease trajectory
  - Treatment options
- Patient Goals – What matters most?
  - Independence – most common response
  - Family goals may be different
  - Do goals match treatment options?
  - Advanced Directives and Advanced Care Planning
- Transition of Care Assessment

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Advance Care Planning vs. Advanced Directives

- **Advanced Care Planning:**
  - ***Logistic*** preparation for current and future healthcare needs
  - Encourages the patient to formulate and to communicate their own healthcare preferences
  - Takes into account medical health goals, values and belief systems
  - Provider should be made aware of patient wishes regarding prognostic information and communication preferences
- **Advanced Directives:**
  - ***Legal*** tool
  - Appoints surrogate decision maker
  - May include “Code” status/Do-not-resuscitate (DNR) order

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The Symptom Assessment

Mnemonic- PAIN RULES and MOPQRST

Pain
Anorexia
Incontinence
Nausea
Respiratory Symptoms
Ulcerations (pressure sores)
Level of Function
Energy
Sedation

Meaning of symptom
Onset of symptom
Palliating and provoking
Quality of the symptom
Related factors, radiation
Severity
Temporality

Source: UpToDate Overview of comprehensive patient assessment in palliative care, Text used for educational purpose

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Question # 2

What percentage of the top 5% who use 50% of health resources have mental health conditions?

A. < 20%
B. 20-40%
C. 40-60%
D. 60-80%
E. >80%

Source: Kathol RG, Perez R, Cohen JS. *The Integrated Case Management Manual*, Springer Publishing Co, NY, 2010, pp 16.

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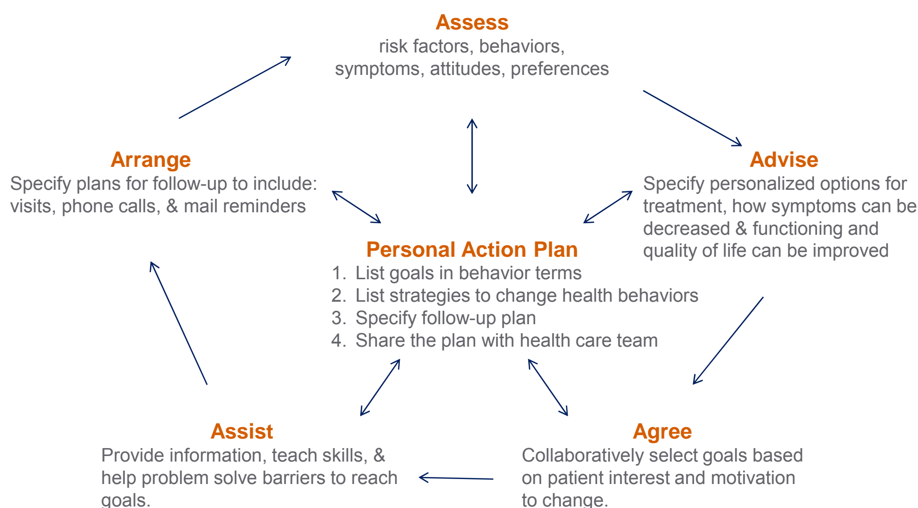
Behavioral Health Paradigm for Evaluation

- Biological
  - Genetic predisposition and Exposures
  - Medical Causes of Brain Dysfunction
    - Rule out the WHIMP (**W**ernicke's: **H**ypo's & **H**yper's (K+, Ca++, Thyroid, etc.) & **H**IV; **I**nfections & **I**ntracranial events; **M**etabolic & **M**etastases; **P**oisonings & drugs
- Psychological
  - What are the rules we learned along the way
- Social
  - What are the interactions
  - What are the social determinants
- Community and Health Systems
  - What are the complexities to getting care and assistance

The 5 A's for Evaluation and Management of Behavior



Source: R.E. Glasgow, et.al., 2002, Annals of Behavioral Medicine, *24*, pp. 80-87, Copyright 2002 by Erlbaum, Text reprinted with permission

Common Psychiatric Disorders

- Delirium: A symptom of acute mental status change manifested by attention deficits, disorientation, lability, distorted perceptions
- Depression: Symptoms should be at least two weeks in duration, hallmark symptoms are low mood and anhedonia, followed by the SIGECAPS (**S**leep, **I**nterest in pleasurable activities, **G**uilt/remorse, **E**nergy/ fatigue, **C**oncentration/Focus, **A**ppetite, **P**sychomotor retardation/agitation, **S**uicidal)
- Anxiety: "Sense of impending doom," may be existential in nature
- Insomnia: Multiple causes – sleep hygiene needs evaluation
- Suicidal Ideation: A psychiatric emergency – don't be afraid to ask about thoughts of self-harm – you won't give the person ideas
- Assaultive Behavior: Intentional or unintentional – always make sure you have an unobstructed exit
- Treatment Refusal and Capacity: Medical ethics – must respect individuals autonomy to make decisions – capacity is the ability to understand and articulate the ramification of one's decisions

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Management

- Treat underlying medical condition
- Psychotropic medication use as appropriate for psychiatric symptoms
  - Attempt to limit drug-drug interactions
  - If multiple drugs are used for symptomatology – limit the number of drugs from any given class
- Listen to the individual
  - Meet the patient where they are
- This is a team sport – communication is critical!

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Question # 3

What percentage of the top 5% who use 50% of health resources receive no mental health treatment?

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C. 55-70%
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Coordination of Care

- Assess Understanding
- Reassessment
- Confirm Communication Chain
  - Who to call for what
  - Follow-Up plan

Case Study

Mr. G is an 85yo who lives with his 83yo spouse in a second floor walk-up apartment. They have 2 adult children who live out of state. Mr. G has PMH of obesity, diabetes, COPD, BPH, stable CLL, OA of the knee, and mild dementia.

- Admitted x3 in last 2mo for constipation, acute mental status and falls
- Current admit fall at home, spouse could not get him up
- BS found to be >1000 d/t not taking meds
- Further investigation revealed member has missed several appointments with PCP

QUESTION:

Should this member have a Palliative Care Assessment?

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QUESTION:

Should this member have a Palliative Care Assessment?

YES!!!

Case Study – Continued

Primary Criteria

- Surprise question
  - Would you be surprised if patient died within an year time-frame?
- Frequent in-patient readmitter
- Poorly controlled symptoms
- Requires complex care
- Decreasing function or failure to thrive

Question:

Which primary criteria suggests need for palliative care assessment for Mr. G?

Case Study – Continued

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Which primary criteria suggests need for palliative care assessment for Mr. G?

✓ Frequent admitter
✓ Requires complex care
✓ Decreasing function
✓ Poorly controlled symptoms

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Case Study – Continued

Secondary Criteria

- Acute admit from long term care
- Cognitively impaired elder with hip fracture
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- History of prior hospice care
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- No advanced directives

Question:

What secondary criteria also supports need for palliative care assessment?

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Case Study – Continued

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- History of prior hospice care
- Lack of family support
- No advanced directives

Question:

What secondary criteria also supports need for palliative care assessment?

✓ Lack of family support

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Case Study – Continued

For this case, what part of the palliative care assessment is imperative to perform *before* discharge?

A. Living will
B. Transition of care assessment
C. Advanced directive
D. Spiritual assessment

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Case Study – Continued

For this case, what part of the palliative care assessment is imperative to perform *before* discharge?

A. Living will
B. Transition of care assessment
C. Advanced directive
D. Spiritual assessment

Appendix

Other Tools and Useful Links

UptoDate: PEACE tool for symptom management in palliative care
(requires a user id and password)

- Assesses the Physical, Emotive, Autonomy, Communication, Economic, and Transcendent domains

Distress Thermometer

- Tool for assessing psychological distress in people affected by cancer

UpToDate: Serious Illness Conversation Guide, (requires a user id and password)

- Checklist is to improve care for patients with serious illnesses and their families by facilitating and documenting discussion

CAPC website: getpalliativecare.com

- Is a resource to help locate palliative care provider by zip code/city & state

OptumHealth Education Activity

- Meier, Diane E, M.D, FACP, *Community-based Palliative Care; Meeting the Needs of the Seriously Ill.* 2016

Appendix: Tool – PEACE, (continued)

PEACE* tool for symptom management in palliative care

The answers to the questions are intended to be quantified (scale 0 - 10) with the PEACE Tool Distress Thermometer.						
In the past week, how much have you been bothered by or suffered from:	**Date/Initials**					
1. Pain						
2. Appetite loss						
3. Incontinence of bladder or bowel						
4. Nausea, vomiting, constipation or other bowel problems						
5. Breathing problems or cough						
6. Ulcers, dryness or mouth sores						
7. Lesser (diminishing) ability to carry out daily activities and functions (cleaning, showering, lifting, walking, etc.)						

Appendix: Tool – PEACE, (continued)

In the past week, how much have you been bothered by or suffered from:	Date/Initials					
8. Feeling weak or tired or having low energy						
9. Feeling sleepy during day and/or not sleeping at night						
10. Feeling anxious, nervous, uneasy, tense or frightened						
11. Feeling sad, depressed, helpless or unable to enjoy things						
12. Feeling confused, restless or agitated						
13. Feeling **not** in control of your care and/or **not** being understood what you want						
14. Feeling **not** prepared for, and/or fearing what is still ahead of you						
15. Feeling more need for support than your family, friends or insurance can provide						
16. Feeling abandoned or punished by God or **not** supported by your						

Appendix: Tool – PEACE, Ending Questions

In the past week, how much have you been bothered by or suffered from:	Date/Initials					
From the list above, which problem are you suffering the most						
From the list above, which problem are you suffering the second most						
Notes (are there any **other** problems that have bothered you recently?)						

Appendix: Tool – NCCN Distress Thermometer

NCCN National Comprehensive Cancer Network®

NCCN Distress Thermometer and Problem List for Patients

NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress 10 – 9 – 8 – 7 – 6 – 5 – 4 – 3 – 2 – 1 – 0 No distress

PROBLEM LIST
Please indicate if any of the following has been a problem for you in the past week including today.
Be sure to check YES or NO for each.

YES	NO	Practical Problems	YES	NO	Physical Problems
❑	❑	Child care	❑	❑	Appearance
❑	❑	Housing	❑	❑	Bathing/dressing
❑	❑	Insurance/financial	❑	❑	Breathing
❑	❑	Transportation	❑	❑	Changes in urination
❑	❑	Work/school	❑	❑	Constipation
❑	❑	Treatment decisions	❑	❑	Diarrhea
			❑	❑	Eating
		Family Problems	❑	❑	Fatigue
❑	❑	Dealing with children	❑	❑	Feeling swollen
❑	❑	Dealing with partner	❑	❑	Fevers
❑	❑	Ability to have children	❑	❑	Getting around
❑	❑	Family health issues	❑	❑	Indigestion
			❑	❑	Memory/concentration
		Emotional Problems	❑	❑	Mouth sores
❑	❑	Depression	❑	❑	Nausea
❑	❑	Fears	❑	❑	Nose dry/congested
❑	❑	Nervousness	❑	❑	Pain
❑	❑	Sadness	❑	❑	Sexual
❑	❑	Worry	❑	❑	Skin dry/itchy
❑	❑	Loss of interest in usual activities	❑	❑	Sleep
			❑	❑	Substance abuse
			❑	❑	Tingling in hands/feet
❑	❑	**Spiritual/religious concerns**			

Other Problems: ______________________

Version 2.2016, 07/25/16. The NCCN Clinical Practice Guidelines (NCCN Guidelines®) are a statement of evidence and consensus of the authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult the NCCN Guidelines is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network® (NCCN®) 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. The NCCN Guidelines are copyrighted by National Comprehensive Cancer Network®. All rights reserved. The NCCN Guidelines and the illustrations herein may not be reproduced in any form without the express written permission of NCCN. ©2016.

Source: nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf, text used for educational purpose

Appendix: Tool – Conversation Guide

Serious Illness Conversation Guide

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. ***Set up the conversation*** · Introduce purpose · Prepare for future decisions · Ask permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"
2. ***Assess understanding and preferences***	"What is your **understanding** now of where you are with your illness?" "How much **information** about what is likely to be ahead with your illness would you like from me?"
3. ***Share prognosis*** · Share prognosis · Frame as a "wish...worry", "hope...worry" statement · Allow silence, explore emotion	"I want to share with you **my understanding** of where things are with your illness..." *Uncertain:* "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility." OR *Time:* "I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ *(express as a range, e.g. days to weeks, weeks to months, months to a year).*" OR *Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."
4. ***Explore key topics*** · Goals · Fears and worries · Sources of strength · Critical abilities · Tradeoffs · Family	"What are your most important **goals** if your health situation worsens?" "What are your biggest **fears and worries** about the future with your health?" "What gives you **strength** as you think about the future with your illness?" "What **abilities** are so critical to your life that you can't imagine living without them?" "If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"
5. ***Close the conversation*** · Summarize · Make a recommendation · Check in with patient · Affirm commitment	"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
6. ***Document your conversation***	
7. ***Communicate with key clinicians***	

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Source: talkaboutwhatmatters.org/documents/Providers/PSJH-Serious-Illness-Conversation-Guide.pdf, text used for educational purpose

Questions and Answers

Questions? Contact OptumHealth Education at moreinfo@optumhealtheducation.com

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