Moving Beyond Goals of Care

Melanie Cama MSN, RN, CHPCA, NEA-BC
Susan Daniels MSN, RN, CHPN

Objectives

By the end of this presentation, learners will be able to:

- Define goals of care from a palliative care perspective
- Identify Patients Goals of Care using an Evidence Based Tool
- Develop a Plan to Align Resources to Patients Goals of Care
- Review of Case Studies

The Smarter Choice for Care

Middlesex Health

WHY???

Factors contributing to complexity of patient care

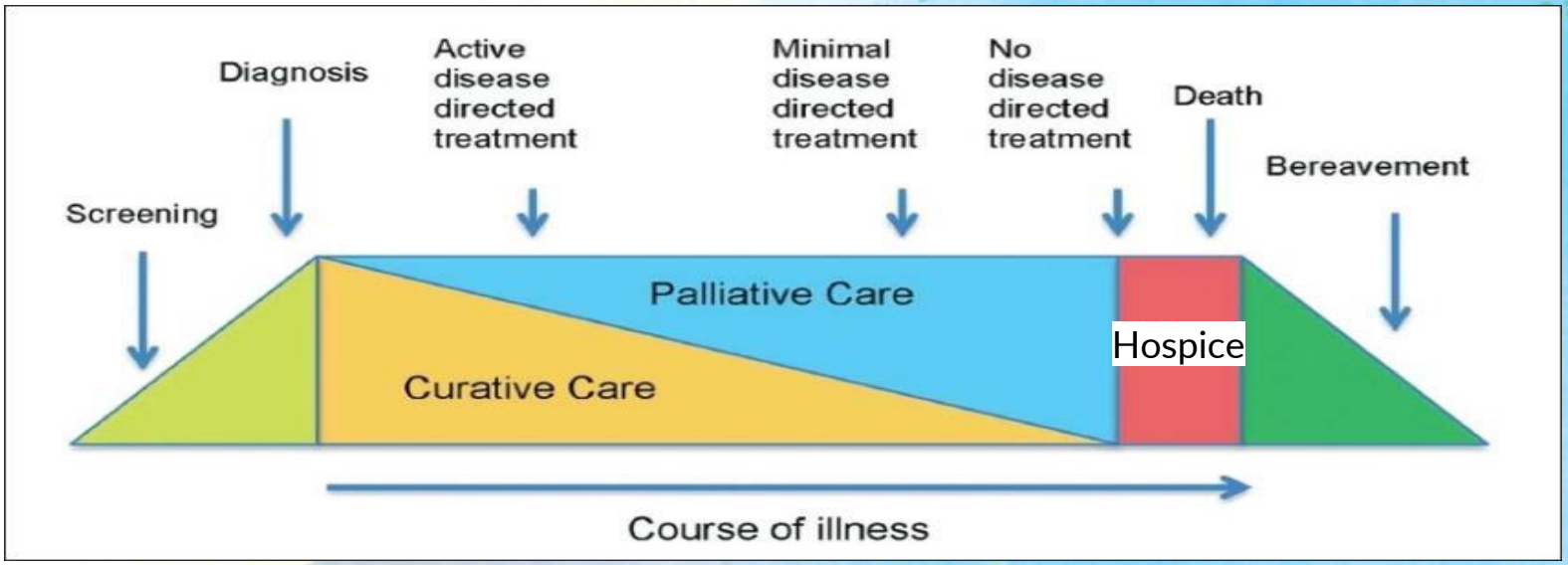
- Aging population
- Patients have serious, life-limiting illnesses or multiple comorbidities
- Overall deterioration of functional status
- Patient/family social determinants
- Patient/family desire for life-extending treatment
- General public's lack of understanding of options for care

WHAT???

"Palliative care means patient and family centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care through the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs to facilitate patient autonomy, access to information, and choice"

-US Department of Health and Human Services, 2017

WHEN?



https://youtu.be/lDHhg76tMHc

The Smarter Choice for Care

Middlesex Health

Primary Palliative Care	Secondary Palliative Care
“Manage first, refer second”	“An extra layer of support”
Provided by generalist	Provided by specialist
Basic prevention and treatment of sx	Complex symptom management
Identify treatment options	Assist with difficult decisions
Advance Care Planning	Assess goals of care
	Counseling and support

What if we made it easier for people to opt *in* to informed choices based on their goals of care?

The Smarter Choice for Care

Middlesex Health

What are Goals of Care?

- Patient engagement in healthcare
- Identification of values- What brings meaning to life?
- What do you understand about your condition?
- How will the treatment impact quality of life?
- Who do you want involved in your care planning?

The Smarter Choice for Care

Middlesex Health

Barriers to Goals of Care Conversations

No training for providers or nurses

- Education is focused on curative care
  - Most schools do not offer course in palliative, emotional or spiritual care
    - 68% report not having training
    - Provider-centric culture disempowers patients
    - End of life care seen as medical “failure”
- Society is focused on curative care
  - Expect to live forever
  - Technology
  - Die more slowly and older
  - No longer live with extended family

Reimbursement

- Advance Care Planning reimbursement- Jan 2016
  - 99497 First 30 minutes (minimum of 16 minutes) 99498 Add-on for additional 30
  - There are no limits to the length and number of times you can report ACP CPT codes.
- Healthcare traditional pays for curative care not preventative care
  - CMS penalties
    - 30 day all cause inpt readmission
    - Acute care hospitalization during the first 60 days of home health

The Smarter Choice for Care

Middlesex Health

STUCK AND UNCOMFORTABLE

The Smarter Choice for Care

Middlesex Health

Starting the Conversation

- A life well lived is a life well planned
  - Communication is key
  - Does your provider/family know your most important decisions?
  - Never too early to start
  - Never “One and done”
- Get comfortable with being uncomfortable

The Smarter Choice for Care

Middlesex Health

Goals of Care Assessment

- Aligns medical care with patients goals
- Chart review first
- Use tool to guide conversation and ensure consistency
  - Telephonic provides less distraction
  - Multiple family members can participate
- Use Palliative Performance Scale to assist with physical assessment and functional status
- Helps to identify which level of care is most appropriate

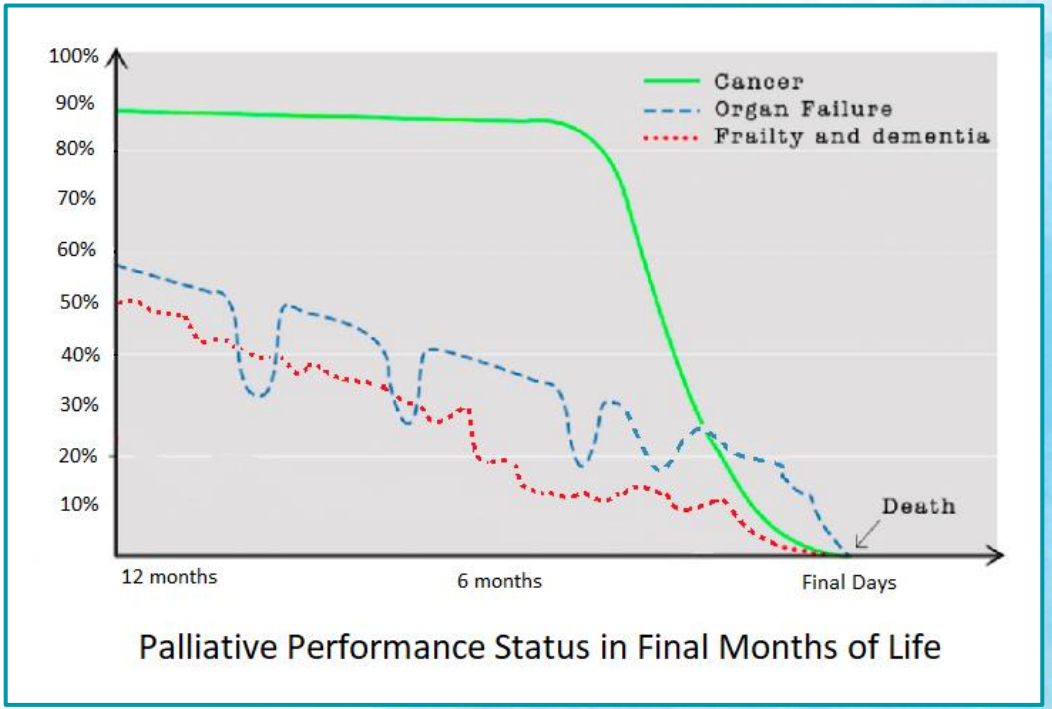
The Smarter Choice for Care

Middlesex Health

The Script

- Physical symptoms-frequency/impact
- Emotional symptoms-frequency/impact
- Functional status-using the PPS
- The “Imagine if” question
- Advance Directive
- Recommendations

Functional Decline in the Final Year of Life



Palliative Performance Status in Final Months of Life

- Blue line: typical trajectory for COPD, Heart Failure
- Red line: typical trajectory for frailty and dementia (pneumonia)
- Generally, people </= 40% will turn out to be hospice appropriate
- We always hope to have our patients “know us before they need us”!

The Smarter Choice for Care

Middlesex Health

Palliative Performance Scale

PPS	Ambulation	Activity/Evidence of Disease	Self Care	Oral Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Only 10% of patients with PPS score <= 50%
would be expected to survive > six months

The Smarter Choice for Care

Middlesex Health

"Imagine you had to make a decision right now about how your doctors should take care of you. Would you prefer a course of treatment that focuses on extending life as much as possible even if it means more pain/discomfort? Or would you want a plan of care that focuses on symptoms, even if you might not live as long?"

Classification of Goals

- Restorative
  - Full code, desires all medical treatments available/offered, promote improvement in function and minimize deterioration.
- Conservative- “Best Supportive Care”
  - an approach to treating disease utilizing non-invasive treatment options, such as IV antibiotics, fluids, medications as well as PT/OT to maintain function. Modified code status may be in place.
- Comfort- Hospice Care
  - Treatments no longer available or wanted, prognosis <6mo, aggressive symptom management

Recommendations may include…

- Non-pharmaceutical advice from a homecare nurse!
  - Not all solutions require a prescription
- Chronic Care Management
  - Education on disease process COPD, Diabetes, Heart Failure Outpatient Programs/Services
- Outpatient Palliative Clinic
  - Patients with serious, life-limiting disease who are not homebound or don't have a skilled need
  - Progression of illness or new diagnosis at an advanced stage with difficult to control symptoms
  - Challenging, complex patients and family with difficult decisions to make about treatment plan.
- Care at Home for skilled care
  - Connect calls, telemonitoring
- Hospice Services

The Smarter Choice for Care

Middlesex Health

Process

- Referral is received from care at home team, IDT, cold calls, inpt team
- Calls are made by Hospice Clinical Resource Nurse, LCSW using the tool for consistency of assessment
- Document a flag in Epic and send a collaboration note to the referral source and/or attending physician
- Identify a plan/recommendations based on the assessment and pt/family goals

Case Study #1 - Arthur

- 55 yo with heel wound. H/o Stage IV NSC Lung cancer and poorly controlled diabetes. Immunotherapy on hold due to non-healing wound.
- Initial palliative consultation 11/24/21
  - Physical: Pain in heel, worst in morning, never less than 3 of 10, 7/10 at worst, constant ache with stabbing quality with activity. Dyspnea with activity. Appetite poor, early satiety/feeling of fullness long after meal. Fatigue with fluctuation in glucose. Occasional dysphagia.
  - Emotional: Discouraged re: QOL if surgery needed. Interruption of social services with Covid.
  - PPS 60% - mainly sit/lie, unable to do usual hobbies/housework, minor assist /ADLs, reduced appetite
  - "I have thought about this. To be honest, I'm surprised to be alive. But I love life. I would like to see more of it. But living in excruciating pain is not what I'd want."
  - Advance Directive: Not yet
  - Recommendations: Reconnect with Cancer Center LCSW for Advance Directive and counseling. Outpt palliative clinic. Referral to Chronic Care Management for assist with diabetes resources

Case Study #2 - Carol

- 88 yo female, PMH advanced dementia with R hip fracture 5/22/22, ORIF
- STR 5/26 - 7/29/22 - Did not meet goals
- Home with daughter and Care at Home 7/29
- Palliative consultation 8/10/22
  - Physical: Pressure ulcers x 2, constipation, no obvious pain or SOB
  - Emotional: Agitation
  - PPS: 50% at best, deteriorates as day progresses, FAST 7A, ambulatory ability and trunk control deteriorates as day progresses
  - “She’s a DNR. She never wanted a feeding tube.”
  - Advance Directive: yes, Jane is HCP
  - Recommendations
- 8/18 max potential achieved - referred to hospice
- 8/24 admit to hospice
- Pt pronounced at home 10/22/23

The Smarter Choice for Care

Middlesex Health

QUESTIONS

The Smarter Choice for Care

Middlesex Health