Goals of Care Workshop - 2024

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Disclosure

Neither Rory Farrand & Tim Jessick, the faculty for this educational event, have relevant financial relationship(s) with ineligible companies to disclose.

Learning Outcomes

Upon completing this session, participants will be able to:

1. Describe the steps necessary to prepare for GOC conversations and family meetings
2. List potential responses to emotion and strategies to respond to emotions
3. Outline several frameworks to conduct GOC conversations, including delivering bad news, discussing prognosis, and how these may vary based on stage of illness
4. Analyze whether a patient has decisional capacity and list 4 myths related to capacity determination
5. Understand signs and symptoms of moral distress/burnout
6. Expand the ability of participant's organization to deliver GOC conversations successfully and at scale

> You may not control life's circumstances, but getting to be the author of your life means getting to control what you do with them.
>
> *- Atul Gawande*

Workshop Agenda

- **Getting Started:**
  - What is meant by GOC & why do people find GOC difficult
  - How to prepare for & conduct GOC conversations
  - Empathic responses to emotion
- **Discussing Prognostication**
  - Role Play
- **Capacity & ACP (and other legal "stuff")**
- **Basic Frameworks:**
  - Breaking Bad News / SPIKES / Role Play
- **Advanced Strategies & Novel Frameworks**
  - PAUSE & REMAP
  - Tough Talk: Clinical Pearls for Negotiating Goals of Care (AKA: what to say when things get hard) / Role Play
- **The Family Meeting & Managing Conflict** / Role Play
- **Discussing Code Status** / Role Play
- **Self-care / Managing Burnout**
- **Scaling GOC Conversations in Your Organization**

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Goal of Care Conversations

Getting Started

What is the Job of a Hospice or PC Clinician?

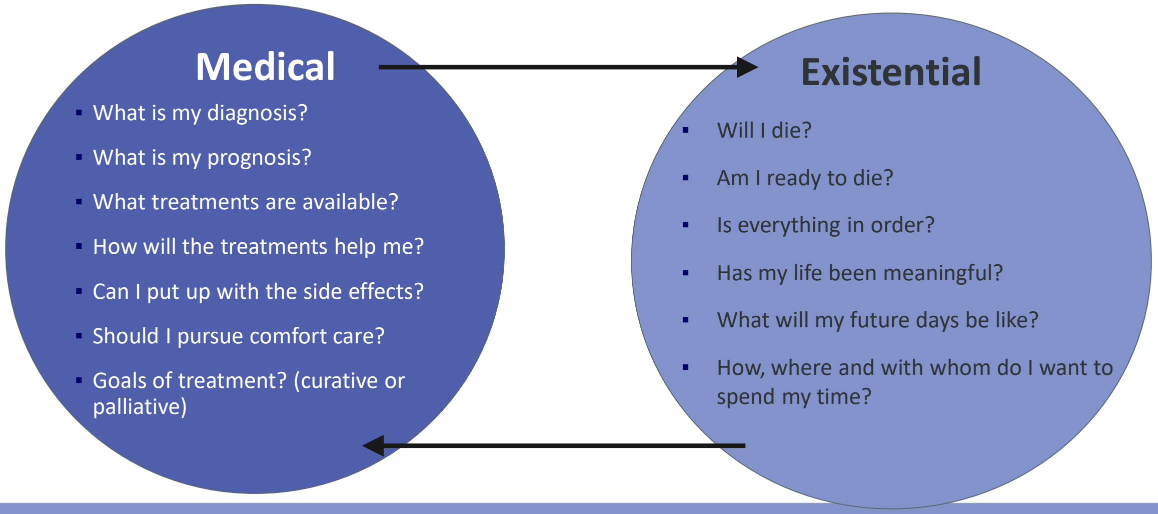
What We Do:

- ***Conduct GOC conversations & advance care planning***
- ***Improve QOL through complex symptom management***
- Prevent ***AVOIDABLE*** hospitalizations through robust care coordination
- Facilitate ***care transitions***, including hospice

How do we do this?

- Coordinate care with attendings/PCPs and other specialists
- ***Facilitate goal-oriented patient care***

The Multiplicity of Decisions



Medical

- What is my diagnosis?
- What is my prognosis?
- What treatments are available?
- How will the treatments help me?
- Can I put up with the side effects?
- Should I pursue comfort care?
- Goals of treatment? (curative or palliative)

Existential

- Will I die?
- Am I ready to die?
- Is everything in order?
- Has my life been meaningful?
- What will my future days be like?
- How, where and with whom do I want to spend my time?

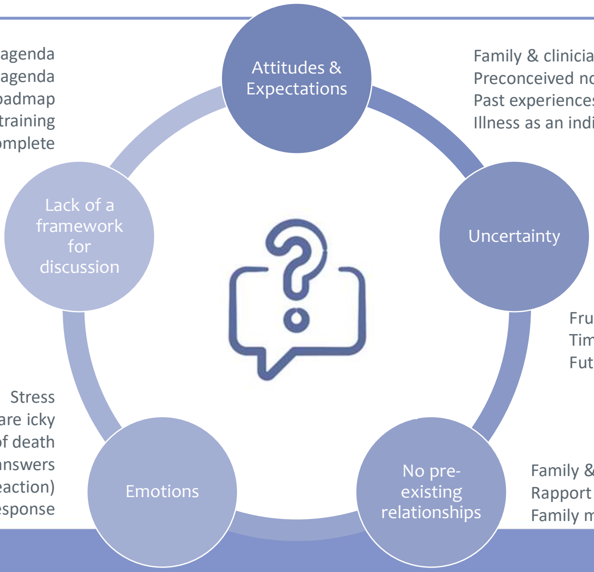
What Are GOALS OF CARE?

Think of GOC *broadly*:

- Establishing actual ***goals*** for care
  - cure vs. comfort, longevity vs. quality
- Decisions about ***treatment options***
- Discussion about ***progression of disease***
- ***Hospitalization*** for severe progressive illness
- Establishing ***code status***
- Discussion about ***imminent death***
- Decisions about ***care after death*** of loved one

Discussions about goals of care should not be limited to goals for **end of life care** (i.e., focusing on death and dying), but as much ***about how the patient wants to live for however much time they have left.***

Why is it so hard?



Attitudes & Expectations

Family & clinician attitudes differ
Preconceived notions about giving “bad news”
Past experiences with serious illness/EOL care
Illness as an indication of failure

Uncertainty

Frustration with lack of goal achievement
Timeline accelerated
Future is unknowable

No pre-existing relationships

Family & clinician are strangers
Rapport & trust can take time to establish
Family may request the clinician withhold info

Emotions

Stress
Feelings are icky
Fear of unknown, fear of death
Fear of not having answers
Discomfort with discomfort (fear of reaction)
Unable to deal with intensity of response

Lack of a framework for discussion

Having an agenda
Not having an agenda
No mental roadmap
Lack of training
Anxiety about the time it takes to complete

Why are GOC conversations important?

- Good communication ***is the cornerstone of quality medical care*** – patients & families demand it
- Can become ***acutely necessary during the course of a life-threatening illness,*** especially when a difficult decision must be made quickly
- Discussions can be ***inherently difficult*** for myriad reasons
- Critical to have a ***systematic approach or framework*** in which to approach the goals of care discussion before a crisis situation arises

Why are GOC important, cont'd

- Facilitates adaptation to the reality of ***living with a serious illness***
- ***Promotes good decision-making and patient-centered care***
- Aligns the care provided ***with what is most important to the patient***

Making things less difficult

- Develop a systematic approach to the ***quality and timing*** about communications about serious illness goals
- Approach a goals of care discussion with ***care and sensitivity***.
- Ensure that the ***setting is appropriate*** and that everyone the patient wants to be there is present.
- Clinicians should ***allot ample time***, and seek to ***eliminate interruptions*** from phones and pagers.

How to Build Rapport & Skillful Communication

> ”
>
> **Begin at the beginning and go on until you come to the end: then stop.**
>
> ***- Lewis Carroll***

Why is establishing good rapport important?

When people like you, **they trust you...**

When they trust you, they listen to you...

When they listen to you, **they follow your recommendations...**

When they follow your recommendations, positive clinical outcomes usually occur!

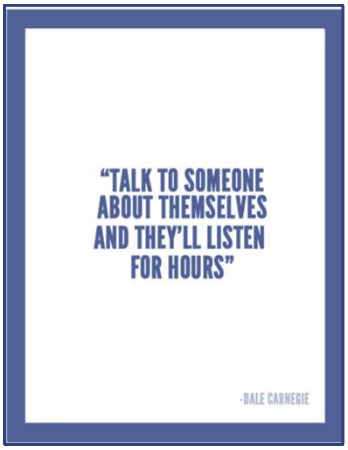
BUT NONE OF THIS HAPPENS
IF THEY DON'T LIKE YOU FIRST!

Why is Good Communication Important?

Communicating Well

Roadmap to Building Rapport

- Engage in a *thoughtful conversation*
- Create a great *1st impression*
- Understand *communication challenges* for persons with cognitive or sensory impairment
- Identify your patient’s preferred *“style”* of speaking & then use it yourself (be aware of cultural differences)
- End on a *high note*



“TALK TO SOMEONE ABOUT THEMSELVES AND THEY’LL LISTEN FOR HOURS”

-DALE CARNEGIE

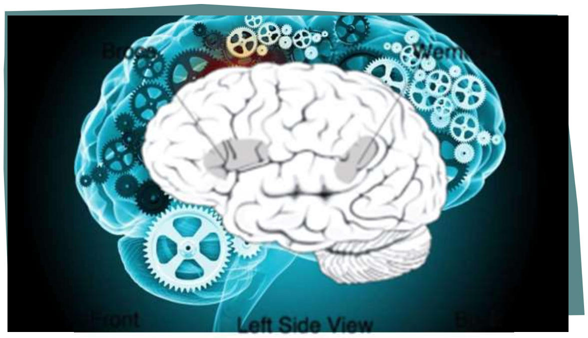
Good Conversations: Best Practices

- *Listen with the intent to understand, not to reply.*
- *Be present. Do not multi-task.*
- *Assume you have something to learn.*
- *Use open-ended questions.*
- *If you don't know, say you don't know. (And work to find out)*
- *Don't equate your experience with theirs. IT IS NOT THE SAME.*

First Impressions Count!

- Focus on *this patient*
- *Have everything you need on hand*
- Demonstrate *genuine enthusiasm*
- *Smile** when you talk!

Communication Barriers



Sensory Issues – i.e., hearing loss

Cognitive Issues
- Medications
- Neurological diseases

Expressive Issues – i.e., speech
- Hearing loss can impede ability to produce intelligible speech
- Changes in dentition & saliva impact ability to speak
- Neurological problems

Adapting Communication for these Challenges

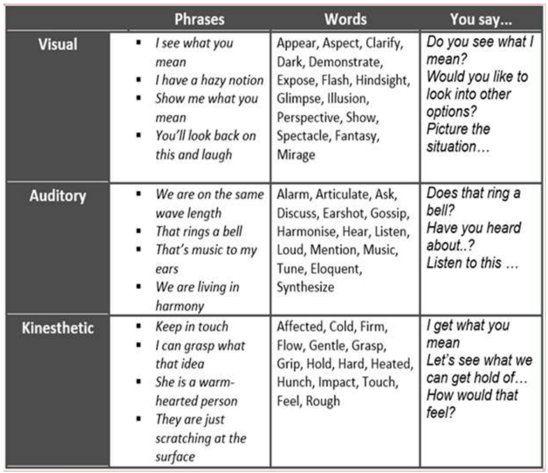
Sensory Issues – i.e., hearing loss
- *Speak more slowly*
- *Drop your pitch, but use normal intonation (not sing-songy)*
- *Enunciate clearly*
- *May need to write things down for them*

Cognitive Issues
- *Use short & direct/concrete sentences*
- *Repeat important information several times (encourage them to write it down)*

Expressive Issues – i.e., speech
- *Allow time for a response: be patient & understanding (give them time to get out what they're trying to say; do not interrupt)*
- *May need them to repeat themselves if inarticulate; can provide alternative word choices*

How Do YOU Like People to Talk to YOU?

- Find ways to build rapport
  - Notice & remember details
  - Use pleasantries
  - Don't complain about your role/job
- Match the pace/pattern/complexity of your speech to theirs
  - Mirror their speaking speed, etc.
  - Avoid jargon
- Speak their "sensory language"



	Phrases	Words	You say…
Visual	▪ *I see what you mean* ▪ *I have a hazy notion* ▪ *Show me what you mean* ▪ *You'll look back on this and laugh*	Appear, Aspect, Clarify, Dark, Demonstrate, Expose, Flash, Hindsight, Glimpse, Illusion, Perspective, Show, Spectacle, Fantasy, Mirage	*Do you see what I mean?* *Would you like to look into other options?* *Picture the situation…*
Auditory	▪ *We are on the same wave length* ▪ *That rings a bell* ▪ *That's music to my ears* ▪ *We are living in harmony*	Alarm, Articulate, Ask, Discuss, Earshot, Gossip, Harmonise, Hear, Listen, Loud, Mention, Music, Tune, Eloquent, Synthesize	*Does that ring a bell?* *Have you heard about..?* *Listen to this …*
Kinesthetic	▪ *Keep in touch* ▪ *I can grasp what that idea* ▪ *She is a warm-hearted person* ▪ *They are just scratching at the surface*	Affected, Cold, Firm, Flow, Gentle, Grasp, Grip, Hold, Hard, Heated, Hunch, Impact, Touch, Feel, Rough	*I get what you mean* *Let's see what we can get hold of…* *How would that feel?*

10 Steps for Serious Illness Conversations

1. Take time to prepare: understand their situation (illness, prognosis, treatment options) includes find & prepare the space (quiet room w/door that closes, tissues, ice water, cups, enough seats)
2. Ask patient who should be there, ensure the meeting happens when those people are available
3. Make introductions & establish ground rules
4. Listen to what they know; don't rush
5. How do they like to get info (Ask #1)
6. Share the one thing you need them to know, then stop (Tell)
7. Ask them what you just shared to ensure they understand (Ask #2)
8. Wait for good timing to ask the tough questions, but DO ask them AND be prepared to answer the tough questions they ask
9. Explain the options; listen (and watch) for emotional content and then respond to it
10. Write down what was discussed

Expect Emotion

Respond to Emotion with Empathy

- *These conversations & their subsequent decisions can be* ***emotional***
- *Attend to emotion* ***BEFORE*** *moving on to anything else*
- *Do not respond to feelings with facts –* ***respond with empathy***

Take out your Empathic Responses handout

– review some of the empathic responses included

NURSE: Acronym for Dealing with Strong Emotions

- The **NURSE acronym** for dealing with strong emotions is depicted in the table.
  - *"I can see you're really concerned about this"*
  - *"I can't imagine what it's been like to hear all this news."*
  - *"Is it okay if we talk a bit more about what this means?"*
- **Therapeutic Silence** ***(least used, most helpful)***
  - Judicious use of strategic silence helps to elicit patients' feelings

ACRONYM	REQUEST	EXAMPLE
N	**Name**	"It sounds like you are frustrated"
U	**Understand**	"I cannot imagine what it would be like to be in this situation"
R	**Respect**	"You are asking all the right questions and doing an amazing job of being an advocate for your husband"
S	**Support**	"I will be around to answer any of your questions"
E	**Explore**	"Tell me more about what you are thinking"

Recognizing Emotion

Patient cues

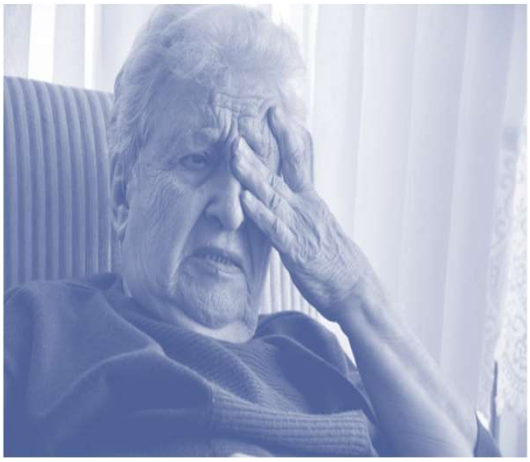
Shutting down/becoming quiet

Body language changes

Intonation changes

Ambivalence/resistance

Questions - especially "why"



Recognizing Other Cues to Emotion

Ambivalence:

"I don't like coming to the hospital, but it makes my breathing better."

"Going to appointments is difficult. But I don't like the idea of people coming into my home."

Resistance:

"I already wrote everything down 20 years ago in my advance directive."

"I don't see why I need to talk about this right now."

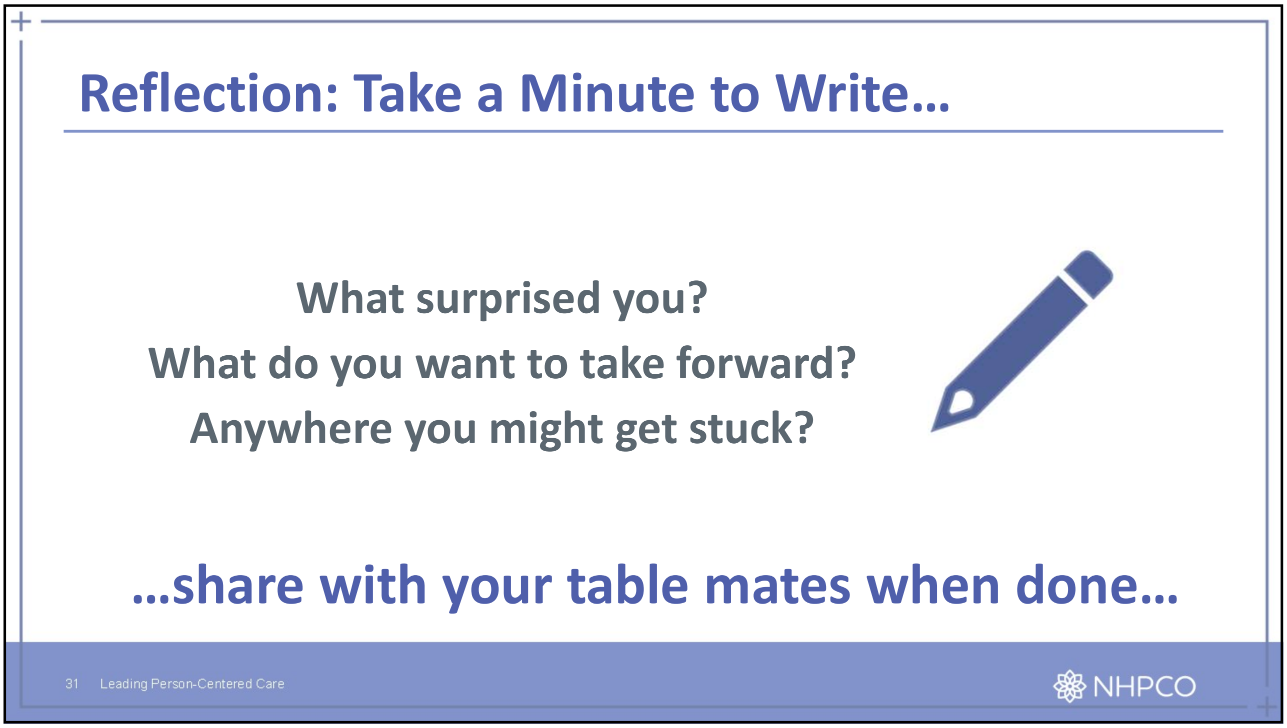
Questions Can Signal Emotion

Watch for questions that are actually expressions of emotion:

> *"Isn't there something else they can do for the cancer?"*
>
> *"Are you sure we've looked into everything?"*
>
> *"Why is this happening to me?"*

Respond to the EMOTION with EMPATHY rather than responding to the QUESTION with FACTS

"It must be so hard to be going through this."



Reflection: Take a Minute to Write…

What surprised you?
What do you want to take forward?
Anywhere you might get stuck?

…share with your table mates when done…

Additional Communication Pearls

- Give the patient and family time to react
- Listen quietly and attentively
- Acknowledge their emotions (name them)
- Remind them that their responses are normal
- Use nonverbal communication to express empathy
- Don't rush them – silence is GOLDEN
- Remind yourself that once the emotion is "spent", most people will be able to move on

"I imagine this is difficult news…"
"You appear to be angry. Can you tell me what you are feeling?"
"How are you feeling in response to this news?"
"Tell me more about how you are feeling about what I just said."
"What worries you most?"
"What does this news mean to you?"
"I wish the news were different."
"Is there anyone you would like for me to call?"

Documentation

- **Document your conversation**
- **State:**
  - Context for the discussion
  - Goals discussed
  - Any decisions made or still pending
  - Follow up needed and/or provided
- **Then, actually follow-up**

Summary

- **Goals of care conversations are important to proactively elicit the patient's values, goals, and preferences, which serve as the basis for treatment decisions**
- **Use key communication skills throughout the goals of care conversation**
- **Recognize and respond to emotion**
- **Remember you are not alone!**

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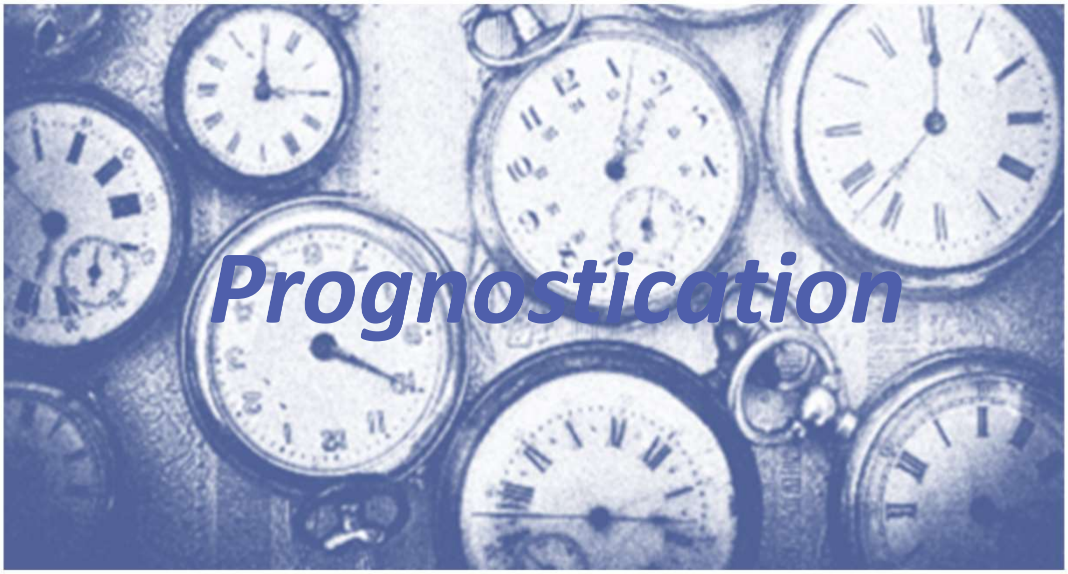
Goal of Care Conversations

Discussing Prognostication and Hospice Eligibility

> “The trouble is
> you think you have time.”
>
> ***- Buddha***



Prognostication

Why We Prognosticate

For advanced illness patients, 74.4% and 88.8%, of patients would forgo treatment if the treatment burden was low but *the probability of severe functional impairment or cognitive impairment* **was high.**

This compares to 98.7% of patients who would want treatment in the treatment burden was low and they were *more likely to return to their previous level of function*.

Terri R Fried MD, et al, *Understanding the Treatment Preferences of Seriously Ill Patients,* NEJM 2002; 346: 1061-66

Of women surveyed (>74 year of age) *80% would rather be dead* than experience the *loss of independence and quality of life* that results from a bad hip fracture and subsequent admission to a nursing home.

Salkeld, G et al, *Quality of life related to fear of falling and hip fractures in older women: a time trade off study,* BMJ 2000; 320(7231): 341-46

Mortality was not the major determinant in patient choice.

Why We Prognosticate

- Helps patients and families with information to *set goals and expectations of care*
- Guides *appropriate therapy* and recommendations
- Encourages patients to *develop insight in to their dying* & allows for them to attend to EOL tasks (goodbyes, atonement, etc.)
- Assists health care providers in their *decision-making*
- Allows us to *leverage resources*
  - Hospice discharges
  - Upstream discharges

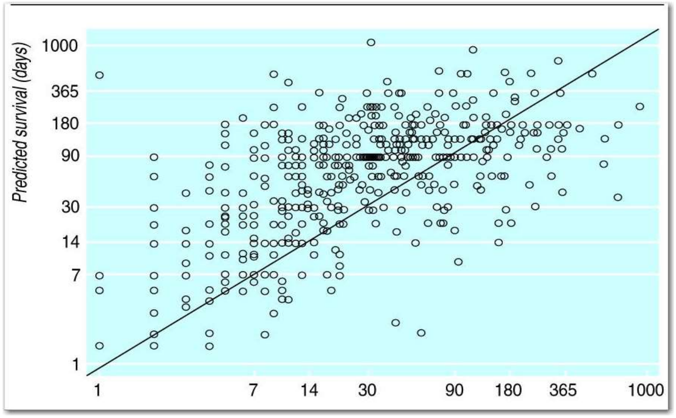
"AS A RESULT OF A FAILURE TO PROGNOSTICATE, LET ALONE PROGNOSTICATE ACCURATELY, PATIENTS MAY DIE DEATHS THEY DEPLORE IN LOCATIONS THEY DESPISE."

Christakis NA. Death Foretold: Prophecy and Prognosis in Medical Care. U of Chicago Press, 1999

Prognostication is both Art & Science

- *Inaccurate science,* but VERY important
- Bias toward *overestimating survival*
  - Survival estimates by physicians usually incorrect and are almost always optimistic
  - Barriers include: *taking away hope and belief that the patient is not ready for conversation*
  - Physicians *off by factor of 2-5X* for advanced cancer
- Study looking at terminally ill patients referred to hospice:
  - *Physician estimated life expectancy 75 days*
  - *What they told patients: 90 days*
  - *Actual life expectancy: 24 days*
- Many other studies produce similar results

Eligibility and Predicting Prognosis



Christakis NA, Lamont EB: Extent and determination of error in physicians' prognoses in terminally ill patients: Prospective cohort study. British Med J 320:269, 2000.

- Predicted versus observed survival in 468 terminally ill hospice patients.
- Diagonal line represents **perfect prediction.**
- Patients **above** diagonal are those in whom survival was overestimated; patients **below** line are those in whom survival was underestimated.

Giving Knowledge = Prognostication

- ➢ Based on clinical indicators & validated tools:
  - ➢ *Disease-specific information*
  - ➢ *Functional and nutritional status*
  - ➢ *Cognitive status*
  - ➢ *Recent hospitalizations and/or complications*
- ➢ Provider experience
- ➢ Patient/family *goals for care* (curative vs. palliative) *& cultural attitudes re: EOL care*

Use all available data to formulate and refine a prognosis

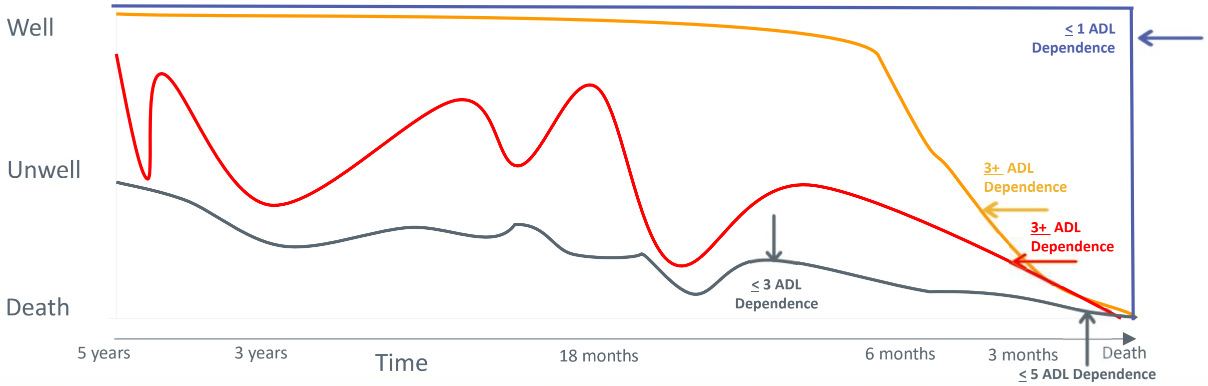
EOL Disease Trajectories and Prognostication – the Big Picture

Sudden death (10%): UNEXPECTED/ACCIDENT

Cancer (25%): Short period of decline

Organ failure (Heart, lung, kidney) – 40%: Slow decline with intermittent acute episodes

"The Dwindles," AKA Frailty & Dementia (25%): Progressive, insidious, long decline



Frailty and dementia (prolonged dwindling) Joanne Lynn, "Living Long in Fragile Health: The New Demographics Shape End of Life Care" Improving End of Life Care: Why Has It Been So Difficult? Hastings Center Special Report 35, no. 6 (2005): S14-S18.

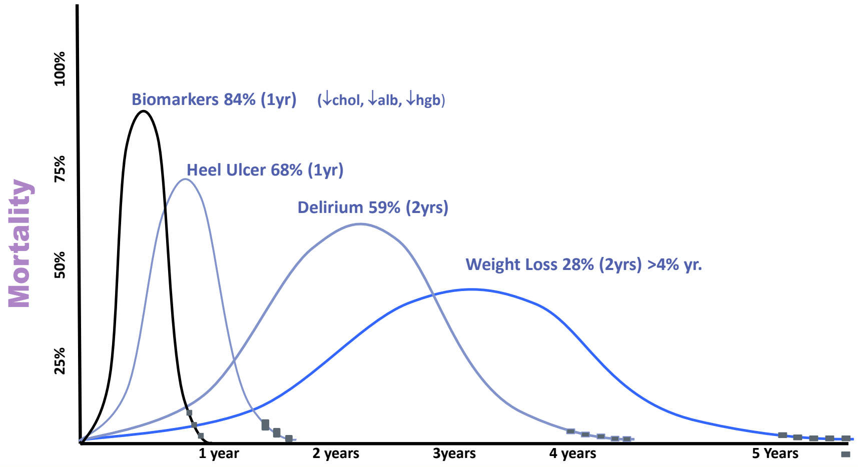
Identifiers of a Pre-terminal patient:

Weight loss
- No loss 11%
- Involuntary loss 28%
- Voluntary loss 36%

Heel ulcer
- Stage 1 or 2, 55%
- Stage 3 or 4, 70%

Delirium
- 30% at 3 mo. to 78% at 34 mo.

Biomarkers
- 84% 1 year mortality for patients with low cholesterol (<160) plus low albumin and hemoglobin



Hoefer, Daniel, MD

Considerations

PCQOs

1. Worsening Symptoms
2. Preventing cognitive decline
3. Preventing Functional decline
4. Preventing Institutionalization
5. Not being an emotional and financial burden to the family.

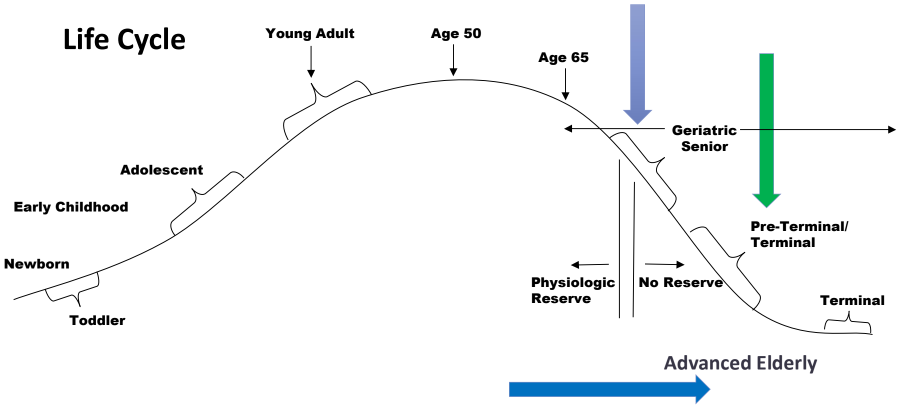
Versus

OSDIs

1. Improving Symptoms
2. Improving Function
3. Maintaining Status

Figure 2. Prognosis is not only about expectations for survival. There are multiple domains that are of varying importance to individual patients. Adapted from Spilker.[38]

Physiology and Goals of Care for the pre-terminal populations are not the same… (nor should they be) for younger and healthier geriatric patients



Communicating Prognosis*

Patients expect open and honest conversations w/their clinician* about prognoses, **however…there is a big gap between what patients want & what happens! You have to ask what they want to know & how much:**

- Some patients want to plan
  - *"Planners" want more details*
- Others are seeking reassurance
  - *Reassurance seekers may want less*
- Avoid precise answers
  - *Hours to days … months to years*
  - *Average life expectancy*
  - *Hope for the best, plan for the worst*
- Cultural factors
- Religious factors

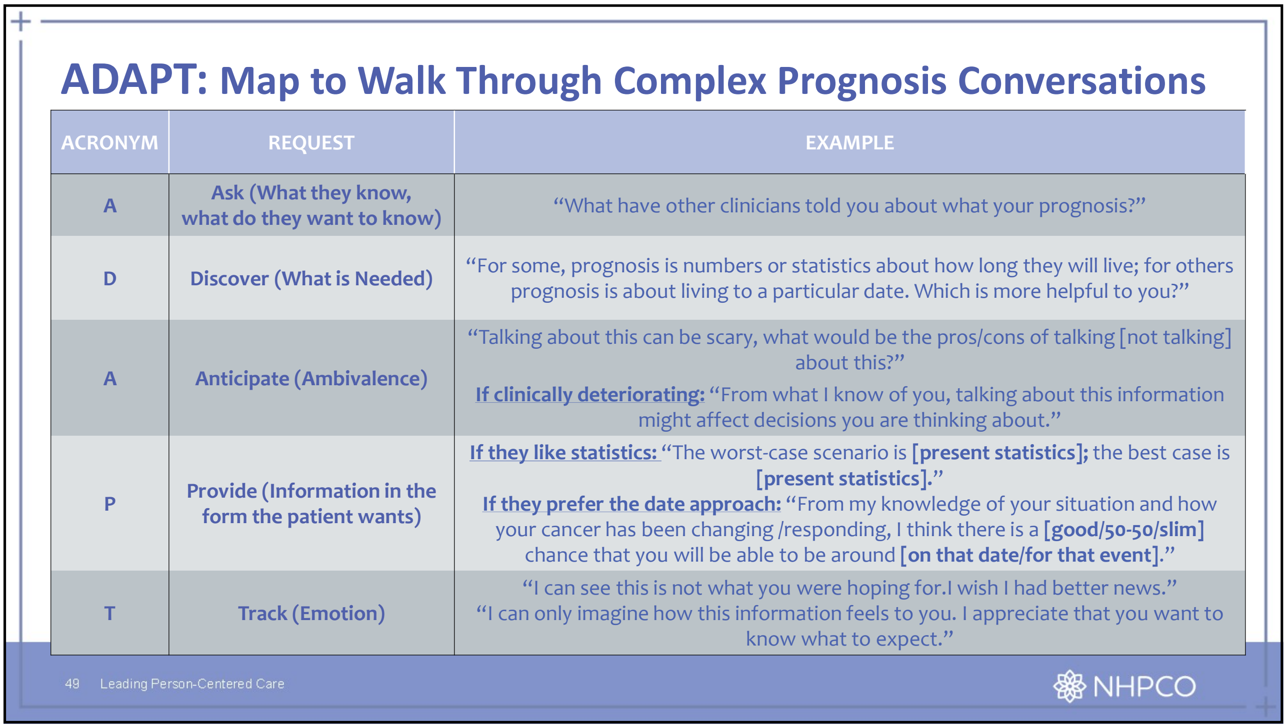
**** Clinician behaviors most important to patients:***

1. ***Offer information about treatments***
2. ***Knowledgeable about the condition***
3. ***Providing reassurance that pain/symptoms would be controlled***

Prognosis - Timelines

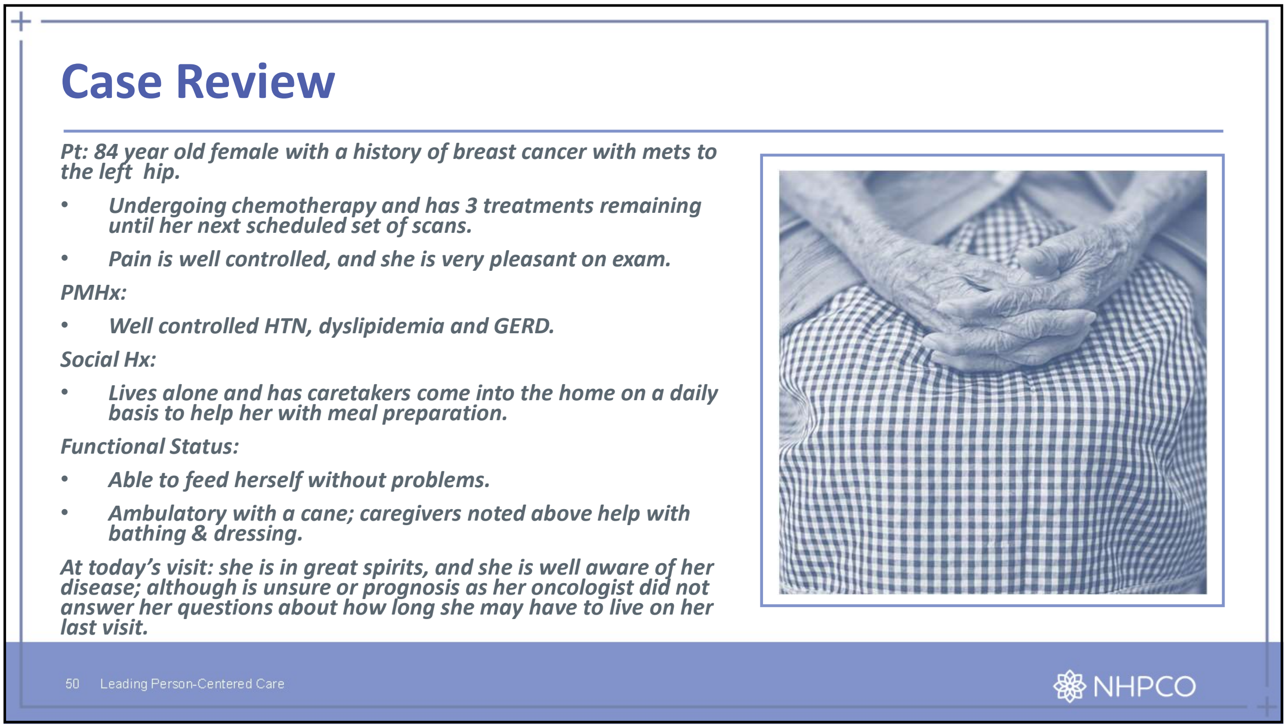
- In theory, if you ask the *question* ***"Would I be surprised if this patient died in the next six months?"*** **when** the answer is ***"No, I wouldn't be surprised."*** ← **YOU SHOULD BE DISCUSSING PROGNOSIS!**

- For every patient you see, consider and determine the prognosis:
  - ***Days to Weeks*** (strongly advocate for hospice transition)
  - ***Weeks to Months*** (advocate for hospice transition when appropriate)
  - ***Months to Years*** (focus on chronic disease management, relationship building, preparation for decline, care planning)
  - ***Years Plus*** (consider eligibility, fit for other programs such as internal health plan case management, virtual CHF/COPD programs, etc..)



ADAPT: Map to Walk Through Complex Prognosis Conversations

ACRONYM	REQUEST	EXAMPLE
A	**Ask (What they know, what do they want to know)**	"What have other clinicians told you about what your prognosis?"
D	**Discover (What is Needed)**	"For some, prognosis is numbers or statistics about how long they will live; for others prognosis is about living to a particular date. Which is more helpful to you?"
A	**Anticipate (Ambivalence)**	"Talking about this can be scary, what would be the pros/cons of talking [not talking] about this?" **If clinically deteriorating:** "From what I know of you, talking about this information might affect decisions you are thinking about."
P	**Provide (Information in the form the patient wants)**	**If they like statistics:** "The worst-case scenario is **[present statistics];** the best case is **[present statistics].**" **If they prefer the date approach:** "From my knowledge of your situation and how your cancer has been changing /responding, I think there is a **[good/50-50/slim]** chance that you will be able to be around **[on that date/for that event]**."
T	**Track (Emotion)**	"I can see this is not what you were hoping for.I wish I had better news." "I can only imagine how this information feels to you. I appreciate that you want to know what to expect."



Case Review

Pt: 84 year old female with a history of breast cancer with mets to the left hip.

- *Undergoing chemotherapy and has 3 treatments remaining until her next scheduled set of scans.*
- *Pain is well controlled, and she is very pleasant on exam.*

PMHx:

- *Well controlled HTN, dyslipidemia and GERD.*

Social Hx:

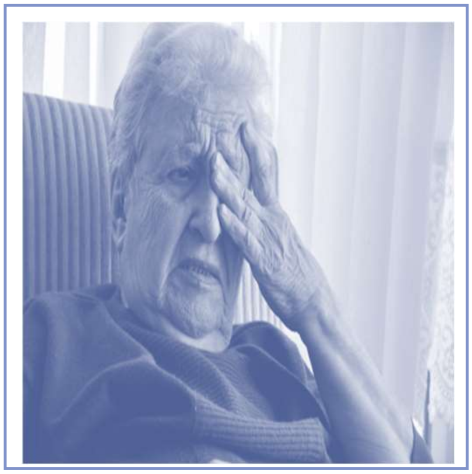
- *Lives alone and has caretakers come into the home on a daily basis to help her with meal preparation.*

Functional Status:

- *Able to feed herself without problems.*
- *Ambulatory with a cane; caregivers noted above help with bathing & dressing.*

At today's visit: she is in great spirits, and she is well aware of her disease; although is unsure or prognosis as her oncologist did not answer her questions about how long she may have to live on her last visit.

Case Review



Pt: 74 year old male prostate cancer with mets to L4.

- *Undergoing a series of injections monthly by his Urologist.*
- *Minimal pain, except w/palpation of L4.*
- *Labs: BMP WNL, HbAIC = 7.2, Calcium of 9.6 and a Hgb of 11.2*

PMHx:

- *DM2, major depression, OA, hypothyroidism, kyphoscoliosis.*

Social Hx:

- *Lives alone, unable to work. No family nearby.*

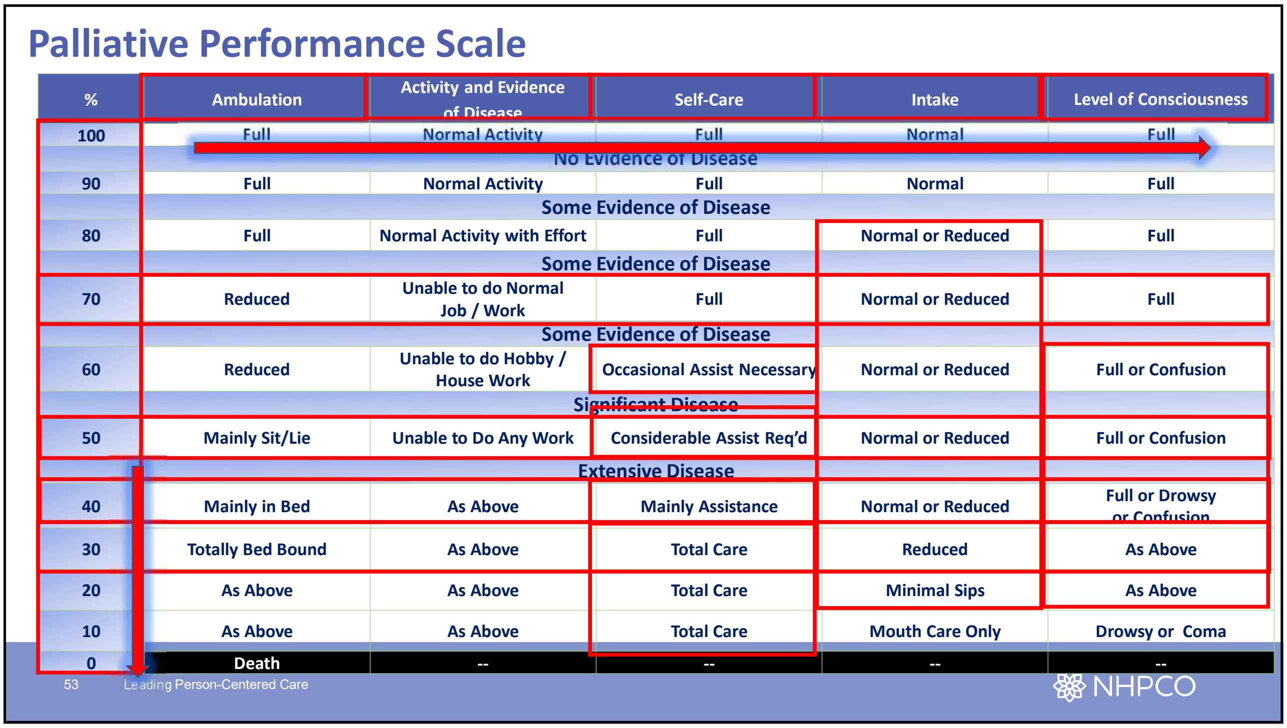
Functional Status:

- *Still active, driving, grocery shopping, etc.*
- *Manages majority of ADLs independently, but slowly*

At today's visit: Plan to review labs, discuss worsening fatigues (napping daily in afternoons). He is wondering about his prognosis as he wants to make a trip to Europe and also wants to get his will in place.

Tools we can use

- Prognostat® http://web.his.uvic.ca/Research/NET/tools/index.php
- Palliative Prognostic Score (PaP)
- Palliative Prognostic Index (PPI)
- Disease Specific Tools – FAST, MELD, NYHA
- BMI/weight
- MMSE, clock drawing test
- **Palliative Prognostic Scale/Karnofsky**
- Eprognosis www.eprognosis.org



Palliative Performance Scale

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Level of Consciousness
100	Full	Normal Activity	Full	Normal	Full
		No Evidence of Disease			
90	Full	Normal Activity	Full	Normal	Full
		Some Evidence of Disease			
80	Full	Normal Activity with Effort	Full	Normal or Reduced	Full
		Some Evidence of Disease			
70	Reduced	Unable to do Normal Job / Work	Full	Normal or Reduced	Full
		Some Evidence of Disease			
60	Reduced	Unable to do Hobby / House Work	Occasional Assist Necessary	Normal or Reduced	Full or Confusion
		Significant Disease			
50	Mainly Sit/Lie	Unable to Do Any Work	Considerable Assist Req'd	Normal or Reduced	Full or Confusion
		Extensive Disease			
40	Mainly in Bed	As Above	Mainly Assistance	Normal or Reduced	Full or Drowsy or Confusion
30	Totally Bed Bound	As Above	Total Care	Reduced	As Above
20	As Above	As Above	Total Care	Minimal Sips	As Above
10	As Above	As Above	Total Care	Mouth Care Only	Drowsy or Coma
0	Death	--	--	--	--

53 Leading Person-Centered Care

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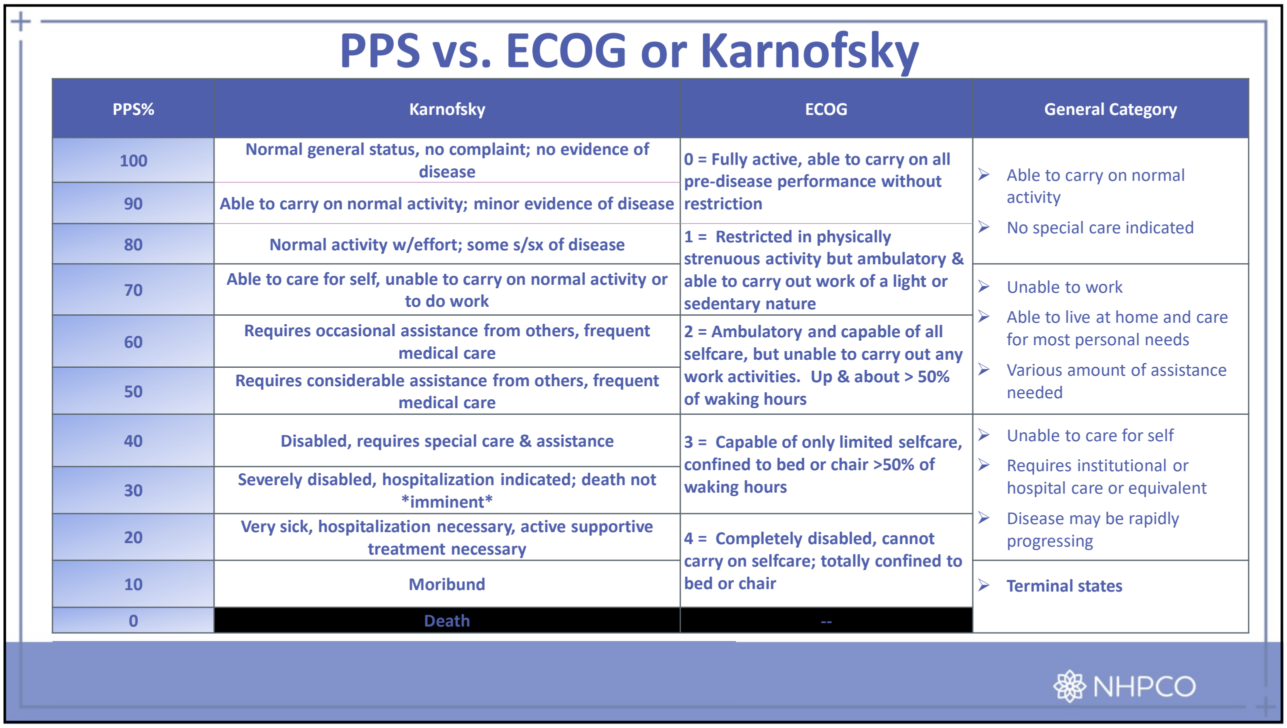

PPS vs. ECOG or Karnofsky

PPS%	Karnofsky	ECOG	General Category
100	Normal general status, no complaint; no evidence of disease	0 = Fully active, able to carry on all pre-disease performance without restriction	- Able to carry on normal activity - No special care indicated
90	Able to carry on normal activity; minor evidence of disease		
80	Normal activity w/effort; some s/sx of disease	1 = Restricted in physically strenuous activity but ambulatory & able to carry out work of a light or sedentary nature	
70	Able to care for self, unable to carry on normal activity or to do work		- Unable to work - Able to live at home and care for most personal needs - Various amount of assistance needed
60	Requires occasional assistance from others, frequent medical care	2 = Ambulatory and capable of all selfcare, but unable to carry out any work activities. Up & about > 50% of waking hours	
50	Requires considerable assistance from others, frequent medical care		
40	Disabled, requires special care & assistance	3 = Capable of only limited selfcare, confined to bed or chair >50% of waking hours	- Unable to care for self - Requires institutional or hospital care or equivalent - Disease may be rapidly progressing
30	Severely disabled, hospitalization indicated; death not *imminent*		
20	Very sick, hospitalization necessary, active supportive treatment necessary	4 = Completely disabled, cannot carry on selfcare; totally confined to bed or chair	
10	Moribund		- **Terminal states**
0	Death	--	

NHPCO

PPS: Predictors* of Survival Times

PPS%	MEAN (DAYS)	MEDIAN (DAYS)	SPECIAL CONCERNS
100			➢ Pt/family education re: disease management, symptom crisis/distress management plan, etc ➢ Optimize function ➢ Psychosocial/spiritual assessments
90			
80			
70	141	63	
60	92	43	➢ Coordination of care and services ➢ Establishment and maintenance of support systems ➢ Education of care givers ➢ Symptom management ➢ End of life planning
50	76	28	
40	39	13	
30	20	5	➢ Ongoing review of medications, likely to discontinue curative treatment(s) if not already done ➢ Aggressive symptom management ➢ Help patient/family prepare for death; get affairs in order
20	7	2	
10	3	1	
0	Death	--	--

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Benefits & Drawbacks

Benefits

- ➢ Tracks functional decline
- ➢ May be useful in helping determine prognosis /help in care planning
- ➢ Can help family members in making tough end-of-life decisions
- ➢ PPS is a good communication tool and a standard reference
- ➢ Communication tool within facilities, between & across care settings

Drawbacks

- ➢ Performance status indicators may not be clear
- ➢ Based on an observer's recording – differences of opinion
- ➢ Multiple variables to remember
- ➢ Another task for staff to complete

NHPCO

Predictors of Survival in Patients with Advanced Cancer

Index Survival	Value	Median Survival (days)
KPS	10 - 20	7 - 16
KPS	30 - 40	8 - 50
KPS	>50	50 - 90
Anorexia	Present	<58
Confusion	Present	<38
Dysphagia	Present	<30
Dyspnea	Present	<30
Xerostomia	Present	<50

Putting it all together

- Remember that ***PERFORMANCE STATUS AND CLINICAL SIGNS/SYMPTOMS*** are most important in predicting survival in terminally ill cancer patients
  - Performance status is a measure of a patient's functional capacity
- ***Biomarkers & progression of illness*** are important in others
- Variety of ***tools*** are available to help make prognostic estimates
- Present prognostic estimate as a range

- Patients and families want to know – but be sure to confirm before telling
  - ***Provide reassurance & support after doing so***

Your Turn To Practice: Role Play

Discussing Prognostication

What did you hear that you liked?
What phrases moved the conversation forward?
Anywhere you might get stuck?

3

Goal of Care Conversations

Core Content
Decisional Capacity and ACP / Documents

> “If you don’t know where you’re going, you’ll end up someplace else.”
>
> *- Yogi Berra*

What is an Advance Care Plan?

- Written **advance care plans** are legal in the US, but laws and forms vary state to state
- Three types of advance care plans:
  - Health care agent/**designated surrogate decision maker** (ie “durable power of attorney” or “power of attorney for health care”)
  - **Living will / advance directives**
  - **POLST**
- Many pre-made forms combine both the healthcare agent and the living will

Healthcare Agent or Designated Surrogate Decision-Maker (DCM)

- Also referred to as a durable power of attorney (DPOA) or power of attorney for healthcare (but above is preferred)
- Allows a patient to **appoint someone to make decisions about his/her *medical care*** if he/she cannot make those decisions
- **Invoked when the patient is no longer able or willing** to make decisions for themselves
- Typically requires witnesses and may require a notarization

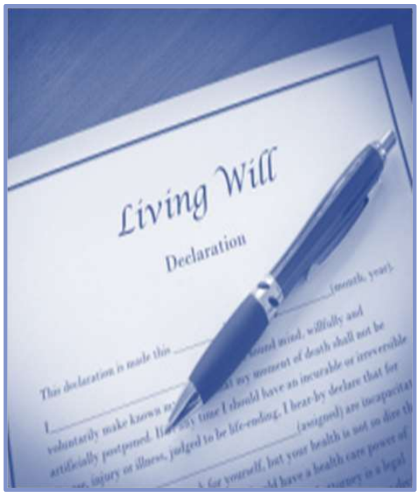
DURABLE POWER OF ATTORNEY
FOR HEALTH CARE DECISIONS
WARNING TO PERSON EXECUTING THIS DOCUMENT
ANT LEGAL DOCUMENT. BEFORE EXECUTING
RTANT FACTS:
THE PERSON YOU DESIGNAT
TO MAKE HEALTH C
SIRES AS STA

Health Care Agent / Designated Surrogate DCM

- May only be completed by a **decisional adult** or appointed by the court
- Ideal agent:
  - Not part of the medical team
  - **Willing and able**
  - Trusted
  - Advocate
  - **Available (quickly)**
- Ends usually at the time of death

when the Executor of your Will takes over

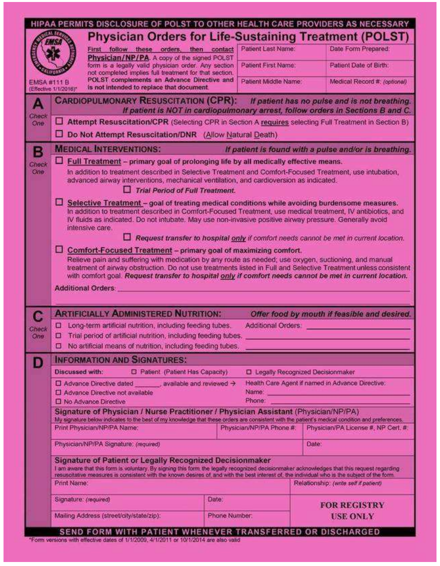
Living Will / Advance Directive



- "Health care directive" is a written document that **describes a patient's wishes regarding medical treatment, is NOT the same as DNR**
- Typically addresses **preferences** for attempting resuscitation, mechanical ventilation, artificial nutrition/hydration, dialysis, comfort care, organ/tissue and body donation
- **Is invoked in the setting of a serious of life-threatening condition when a patient becomes unable to communicate**
- **May only be completed by a decisional adult**
- Typically requires witnesses and some states require notarization

National POLST

- **Portable [out-of-hospital] Medical Orders** for patients who are seriously ill or those who are frail
  - NOT for everyone (if you are healthy, an advanced directive is for you!)
  - A portable order set (they travel with you), applicable regardless of setting of care or if you are home
  - Is completed by the **physician or APP**
  - **Is voluntary**
- **Tells other providers what you want (or do not want)**



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B
(Effective 1/1/2016)*

First follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

Patient Last Name:	Date Form Prepared:
Patient First Name:	Patient Date of Birth:
Patient Middle Name:	Medical Record #: *(optional)*

A *Check One*

CARDIOPULMONARY RESUSCITATION (CPR): ***If patient has no pulse and is not breathing. If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.***

☐ **Attempt Resuscitation/CPR** (Selecting CPR in Section A requires selecting Full Treatment in Section B)

☐ **Do Not Attempt Resuscitation/DNR** (Allow Natural Death)

B *Check One*

MEDICAL INTERVENTIONS: ***If patient is found with a pulse and/or is breathing.***

☐ **Full Treatment – primary goal of prolonging life by all medically effective means.**
In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.
☐ ***Trial Period of Full Treatment.***

☐ **Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.**
In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.
☐ ***Request transfer to hospital only*** *if comfort needs cannot be met in current location.*

☐ **Comfort-Focused Treatment – primary goal of maximizing comfort.**
Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. ***Request transfer to hospital only if comfort needs cannot be met in current location.***

Additional Orders: ____________

C *Check One*

ARTIFICIALLY ADMINISTERED NUTRITION: ***Offer food by mouth if feasible and desired.***

☐ Long-term artificial nutrition, including feeding tubes.
☐ Trial period of artificial nutrition, including feeding tubes.
☐ No artificial means of nutrition, including feeding tubes.

Additional Orders: ____________

D

INFORMATION AND SIGNATURES:

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

☐ Advance Directive dated _______, available and reviewed →
☐ Advance Directive not available
☐ No Advance Directive

Health Care Agent if named in Advance Directive:
Name: ____________
Phone: ____________

Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)
My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

Print Physician/NP/PA Name:	Physician/NP/PA Phone #:	Physician/PA License #, NP Cert. #:
Physician/NP/PA Signature: *(required)*		Date:

Signature of Patient or Legally Recognized Decisionmaker
I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name:		Relationship: *(write self if patient)*
Signature: *(required)*	Date:	FOR REGISTRY USE ONLY
Mailing Address (street/city/state/zip):	Phone Number:	

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009, 4/1/2011 or 10/1/2014 are also valid

Overcoming Obstacles to talking about ACP

Many people think that a financial POA allows them to make medical decisions.

- Usually financial and medical POAs are defined in separate documents

Some people think that if they document an advance directive, they won't get treatment.

- Reassure them that completing an advance directive doesn't mean "don't treat me". It means, "treat me the way I want to be treated".

Providers sometimes find it difficult to begin discussing advance directives.

- Begin with a simple question, "Do you know what an advance directive is? Do you have one?"

Patients may fear that talking about advance directives means they you think they are sicker than they understand themselves to be.

- Respond with, "I ask all of my patients this question, sick or well: the best time to start thinking about this is before something serious occurs."

Overcoming Obstacles Continued

Patients may be fear that once they name a healthcare agent, they will lose control of their own care.

- Explain that as long as they are able to make their own decisions, they retain control of their treatment choices

Some people believe that having an advance directive will save their family from difficult decisions.

- The burden of surrogate decision making can be significant, causing anxiety and tension amongst family members. Encourage the patient to talk with their DPOA/loved ones about what they want and would not want. If appropriate, encourage them to give loved ones permission not to prolong the dying process.

Warm E and Rosielle D. Myths about Advance Directives. Fast Facts and Concepts #`12.
www.mypcnow.org, accessed 7/20/16.

WHY ASSESS CAPACITY?

> *"As our society ages, clinical assessment of higher order functional capacities has become increasingly important. In areas like financial capacity, medical decision-making capacity, medication compliance, and driving, society has a strong interest in accurately discriminating intact from impaired functioning."*

Marson et al. (2000): Archives of Neurology, vol. 57

TERMINOLOGY

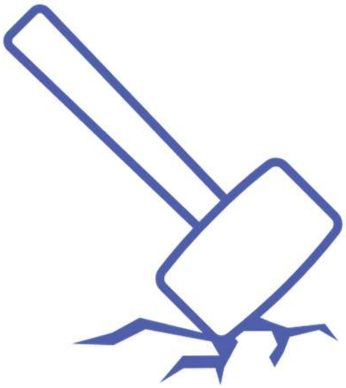
Capacity

- A clinical judgment about a patient's ability to do something
- Considered to be situation- and task-specific
- Reflected in a report after a clinical evaluation

Competency

- Legal status of lacking the ability to handle one's affairs due to mental or physical incapacity
- Usually broader perspective
- Reflected in a court order after a hearing

CAPACITY MYTHS: True or False?



#1 A diagnosis of dementia automatically means lacking in ability to perform a task or to make a decision

#2 Lack of one type of capacity means lacking in all other types

#3 Once capacity is lost, it cannot be restored

#4 Going against medical advice means the person must lack capacity

CAPACITY AT END OF LIFE

- Increased risk of cognitive deficits and impaired decision- making capacity
- Identification and honoring of patients' wishes and values
- Determination of goals of care
- Improved quality of life and comfort at death

Burton, C.Z. et al. (2012). Undetected cognitive impairment and decision-making capacity in patients receiving hospice care. *The American Journal of Geriatric Psychiatry, 20(4),* 306-316.

Kolva, E., Rosenfeld, B., Brescia, R., & Comfort, C. (2014). Assessing decision-making capacity at end of life. *General Hospital Psychiatry, 36(4),* 392-397.

When is DMC important for Hospice Patients?

- Signing election and consent
- Changes in medications?
- Changes in level of care?
- Decisions about taking or not taking antibiotics?
- Whether or not to have a palliative procedure done?
- Electing palliative sedation?
- Others?

MANY CLINICAL CAPACIT*IES*

- Not a unitary construct
- Multiple capacities with emphasis on retaining maximum autonomy
- Individual who lacks capacity to make one decision does not necessarily lack ability to make all decisions

- Making health care decisions
- Determining code status
- Appointing a surrogate decision maker
- Living at a level of the patient's choosing
- Managing finances
- *And more!*

WHO HAS IT?

Adults are presumed to have DMC unless proven otherwise.

- If there are questions about the decisional-capacity of an adult patient, it is the responsibility of the provider to make the capacity assessment

People under the age of 18 are presumed NOT to have capacity, but may consent to certain things

- The capacity necessary to make a decision increases with the increasing complexity and the anticipated consequences of the decision.

DMC must be assessed in relation to the specific decision at hand.

FUNCTIONAL ABILITIES

Four functional abilities:

Understanding
Appreciation
Reasoning
Expression of choice

UNDERSTANDING

Understanding treatment situation & choices

- Ability to paraphrase back the information related to a choice
- Impaired by receptive aphasia, comprehension deficits

Assess understanding by asking:

“Can you tell me in your own words:

- what are the [*factual concept under assessment:* risks / benefits / reasons to do / reasons not to do]?”

APPRECIATION

Appreciating the personal consequences of a choice

- Recognition that the facts (e.g., diagnosis, treatment options) apply to the self
- Ability to relate information to one’s personal situation
- Affected by impaired judgment, lack of insight, psychosis (delusions or pathologic levels of distortion or denial)

Assess appreciation by asking:

“Can you tell me in your own words:

- what is the problem with your health now?” [appreciating the problem]
- what you see as the [benefit/risk] of this decision?” [appreciating risk/benefit]

REASONING

Processing information in a logically consistent manner

- Provide rational reasons for a choice
- Ability to manipulate information, generate consequences & compare them
- Affected by executive dysfunction

Assess reason by asking:

“Can you tell me in your own words:
- How did you decide to accept or reject the recommended treatment?”
- What makes [chosen option] better than [alternative option]?”

EXPRESSION

Evidencing a treatment choice

- Ability to consistently state a choice
- In some ways the simplest standard
- Impaired by intubation, aphasia, anxiety

Assess [consistency in] expression by asking:

“Can you tell me in your own words:
- Have you decided whether to follow your doctor’s [or my] recommendation for [treatment]?”
- Can you tell me what that decision is?”
- [If no decision] What is making it hard for you to decide?”

ASSESSMENT: CONSIDER MANY FACTORS

Capacity evaluations look at the clinical data along with the contextual situation.

- Cognition
- Functional Abilities
- Mental Health
- Physical Health

- Values / History
- Level of Risk
- Ways of Supporting or Enhancing Functioning

Quick Guide to Capacity Assessment

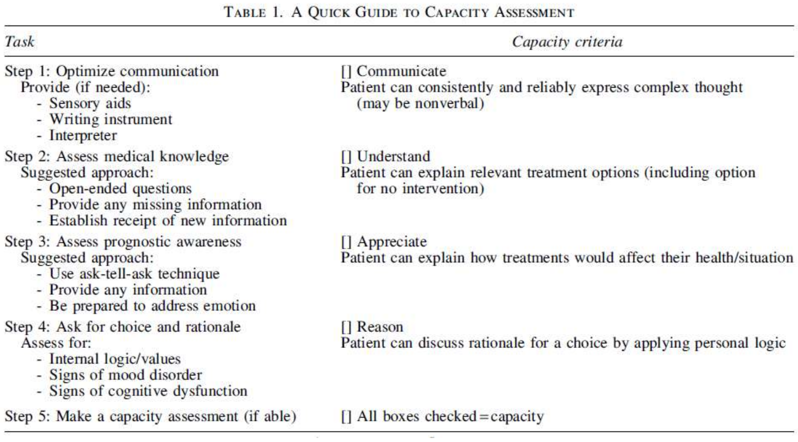


TABLE 1. A QUICK GUIDE TO CAPACITY ASSESSMENT

Task	*Capacity criteria*
Step 1: Optimize communication Provide (if needed): - Sensory aids - Writing instrument - Interpreter	[] Communicate Patient can consistently and reliably express complex thought (may be nonverbal)
Step 2: Assess medical knowledge Suggested approach: - Open-ended questions - Provide any missing information - Establish receipt of new information	[] Understand Patient can explain relevant treatment options (including option for no intervention)
Step 3: Assess prognostic awareness Suggested approach: - Use ask-tell-ask technique - Provide any information - Be prepared to address emotion	[] Appreciate Patient can explain how treatments would affect their health/situation
Step 4: Ask for choice and rationale Assess for: - Internal logic/values - Signs of mood disorder - Signs of cognitive dysfunction	[] Reason Patient can discuss rationale for a choice by applying personal logic
Step 5: Make a capacity assessment (if able)	[] All boxes checked = capacity

Ehrman, et al 2021

Is determining DMC always necessary?

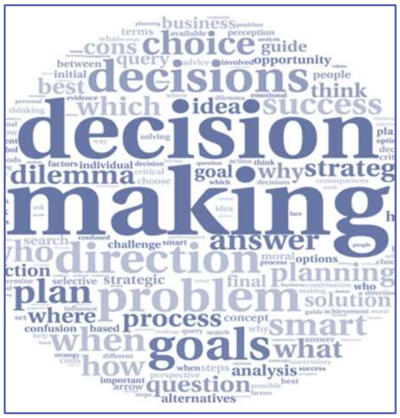
Determination of DMC is not necessary when

- End stage dementia where patient is unable to communicate meaningfully
- Comatose or non-responsive state not induced by medication

It IS necessary when the patient needs to make a choice and:

- DMC is in question – Someone with a brain tumor who is starting to lose words and is occasionally confused
- When DMC is fluctuating – Someone in the middle stages of dementia who is clear sometimes and confused others

Lean on Ethics Councils if needed



Organizational Issues & Challenges

- Does your organization have a **clear policy and procedure** for determination of DMC?
  - Does your organization have (or have access to) an ethics council?
- Does your organization **use an interdisciplinary model** for determination of DMC?
  - Do your hospice physicians participate in determination of DMC or do you look to community physicians?
- Do you have **agreed upon instrument/s** to use in determining DMC for patients?
  - Has everyone been trained on how to discuss capacity in clinical documentation?

Case Examples

Case Study #1

Mrs. Jones is a 68-year-old patient admitted with a diagnosis of cancer of the lung.

She lives alone in her home with 5 cats. The team describes her home as a “hoarder scenario” with animal feces and evidence of rodents present.

She is bedbound, sometimes uses bedside commode while at other times she soils herself in bed and waits for someone from the team to come and clean her up.

She clearly states she wishes to die in her home. Mrs. Jones sees nothing wrong with her living situation.

Question

Which category does Mrs. Jones fall into?

1. Those who clearly have capacity
2. Those who clearly do NOT have capacity
3. Those for whom capacity is questionable and requires as
4. Those who have fluctuating capacity

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Case Study #1 Continued . . .

Mrs. Jones has become increasingly confused as her weakness progresses.

She frequently does not remember who the nurse is or that she had an appointment to visit.

She continues to state that she wishes to stay in her home and refuses any suggestion of placement or level of care change.

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Question

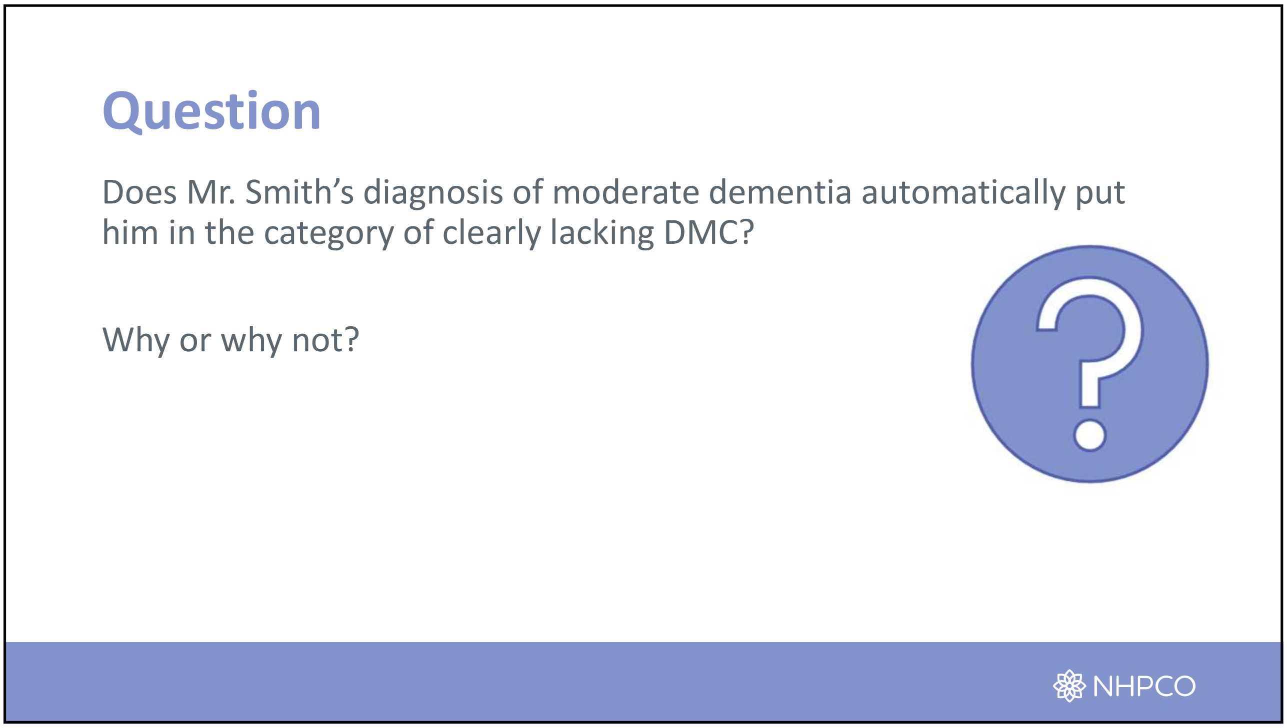
Does Mrs. Jones increased weakness and confusion affect what category she falls under with regard to DMC?

Case Study #2

Mr. Smith is a 73 year old man with an admitting diagnosis of Congestive Heart Failure and a secondary diagnosis of dementia. He currently resides in an assisted living facility memory unit.

In a routine visit to the facility, the Ombudsman asked Mr. Smith about the care he was receiving and Mr. Smith clearly articulated that he wanted to go on unaccompanied walks. The Ombudsman advocated for him with the facility administrator, saying that there was no reason not to let him take walks by himself.

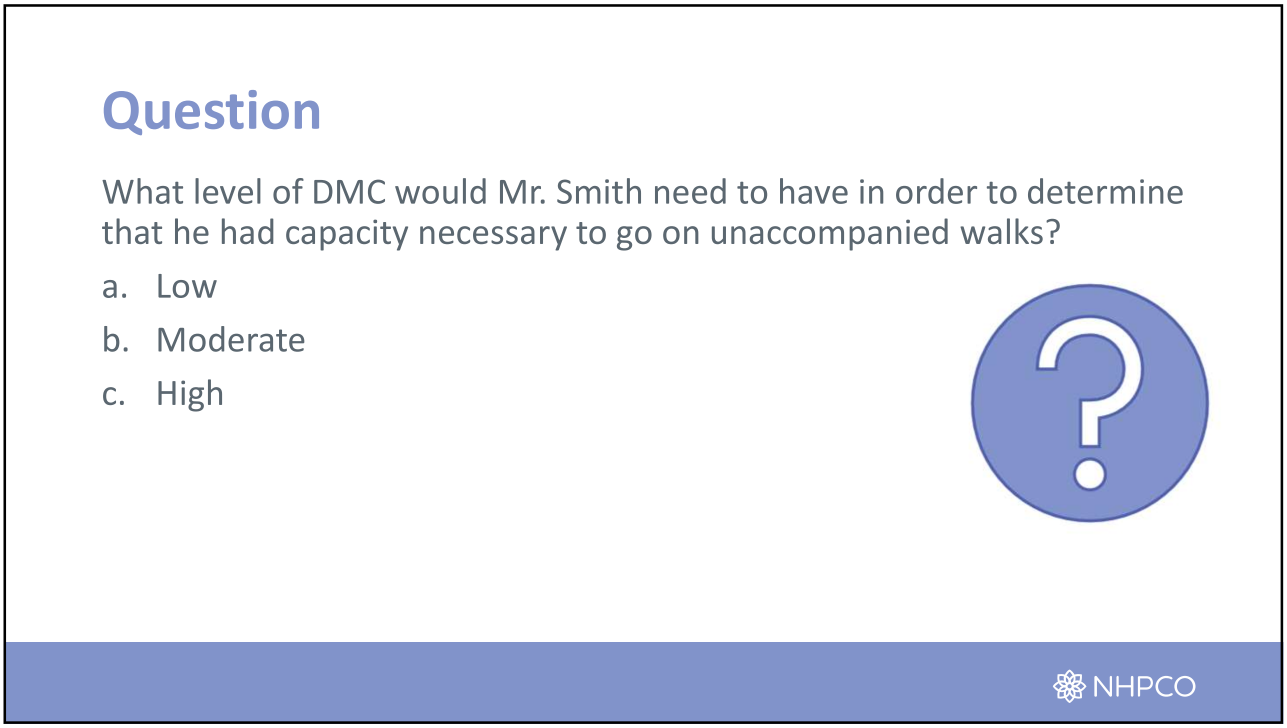
The care team, however, was concerned that Mr. Smith might get confused and may get lost or have a fall or walk out in traffic and get seriously hurt.



Question

Does Mr. Smith’s diagnosis of moderate dementia automatically put him in the category of clearly lacking DMC?

Why or why not?



Question

What level of DMC would Mr. Smith need to have in order to determine that he had capacity necessary to go on unaccompanied walks?

a. Low
b. Moderate
c. High

Conclusions

Patients with serious illness face many difficult decisions and encounter many clinical situations that may undermine decisional capacity.

Many older patients with serious illness can engage in end-of-life discussions and can make autonomous decisions about preferred end-of-life care.

Comprehensive assessment will aid clinicians in their responsibility to balance respect for patient autonomy with their responsibility to protect patients from harm resulting from impaired decisional capacity.

Consult and referral services such as ethics and psychiatry can help with treatment decisions and with assessing underlying psychosocial and psychiatric conditions. Decisional capacity may fluctuate and requires a variable amount of decisional ability depending on the clinical situation; hence, it is time-specific and decision-specific.

4

Goal of Care Conversations

Basic Communication Framework (SPIKES)

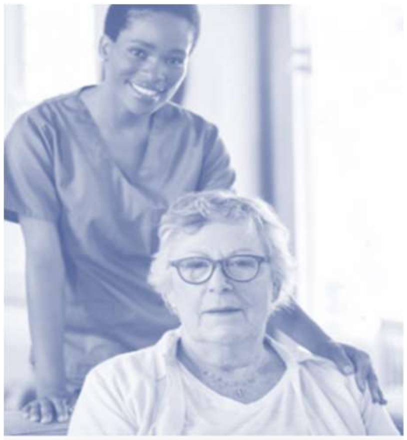
SPIKES – Brief History

Surveys of physicians in the 1950s to 1970s found that they thought it was *inhumane & damaging* to share "bad news" re: cancer diagnosis/prognosis

Advancements in treatments may equate to increasing hope, but creates a *paradoxical need to have increased skill* in sharing *other* types of "bad news"

- *Disease recurrence and/or metastases*
- *Treatment failure*
- *Presence of permanent side effects*
- *Positive results of genetic tests*
- *Raising the issue of poor prognosis*
- *Discussing futile treatments and/or resuscitation*
- *Introducing hospice/EOL topics*

What is "bad news?"



Any news which may adversely and seriously affect and individual's view of his/her future = *in the eye of the beholder*

Impacts of "bad news" cannot be determined in a vacuum, but requires:

- *Recipient's expectations*
- *Recipient's understanding*
- *Recipient's response/feeling about the news*

Remind me why this is important??

- Frequent, but stressful task
  - *(for both patient & clinician)*
- Patients Want the Truth
  - *Both diagnosis and prognosis*
  - *Want forthright information about potential side effects of treatment(s)*
- Ethical and Legal Imperatives
  - *Informed consent, patient autonomy*
- Clinical Outcomes
  - *QOL*
- "Don't Kill the Messenger" / the "MUM" effect
  - *Anxiety and/or fear*
  - *Burden of responsibility*

SPIKES Protocol

- *Systematic & structured approach to conversations*
- *Moves care planning forward*
- *Facilitates shared-decision making*

Setting up the interview/meeting
Patient perception
Invitation
Knowledge
Explore emotions & empathize
Strategy and summary

Meet the patient: MJ

- 69 y/o male, appears older than stated age
  - *Presents with pneumonia, RUQ pain, & weight loss*
- Essentially homeless with social support of a brother
  - *History of ETOH abuse*
- Pneumonia slow to respond to treatment
  - *CT chest through liver finds RUQ mass*
  - *Consistent with HCC*
- Providers on case include hospitalist, oncology, palliative care, and hepatobiliary service

S: Setting Up the Interview

- Coordinate with primary/consulting services and other key interdisciplinary team members
- Review clinical information
  - What is the prognosis? what is medically appropriate?
  - Consider future interventions (benefit vs. burden)
- Determine who should be present for the discussion
  - *"Is there anyone you rely on to help you make important decisions?"*
  - *"Who would you like to be here with you when we discuss your plan of care?"*
- Identify & prepare the physical setting
- Manage time constraints/reduce interruptions

MJ: Family Meeting

- All think mass c/w HCC
  - *Recommend a biopsy of mass after patient nutrition and function optimized and patient not abusing alcohol*
- None of the specialists feel the need to attend the meeting
  - *Hospitalist and palliative care to be present*
  - *MJ wants brother to be present*
- Set up a private room and coordinate time to meets need of family/guest and patient

---

P: Perception - Before you tell, *ask*

- Patient’s perception of the medical situation
- Open-ended questions
  - *“What is your understanding of …”*
- Correct misperceptions
- Assess acceptance of illness
  - Denial?
  - Wishful thinking?
  - Unrealistic expectations?
  - Leave out important facts about illness?

MJ Perception

Clinician: *"How have things been going in the hospital?"*

MJ: *"Overall I feel better, but still very weak and tired. My belly and legs are much bigger than when I came into the hospital. I know something else is going on b/c my pneumonia isn't getting better & I had that CT scan."*

Clinician: *"What is your understanding of the CT scan results?"*

MJ: *"They said that I have a mass. I think that it might be cancer…but no one has really told me anything else."*

I: Obtaining the Patient's Invitation

- Determine how they would like to receive information
    - Orally and/or written down?
- Inquire how much the patient wants to know about diagnosis, prognosis, treatment decisions, and recommendations and at what level of detail
    - Titrate information accordingly
        - Changes over the course of an illness
    - Opportunity to assess patient's coping mechanisms
    - If appropriate, offer to discuss with a family member or friend
- Determine who else patient wants to know what information, specifically what/how much, and then document that you received this consent (be specific).

MJ Invitation

Clinician: *"We were going to go in further detail about the CT scan results and what it means for your care. How much of the information are you ready to hear?"*

> **MJ:** ***"I want to know everything doc. I may need you to repeat it a few times, or give me something to read, but don't keep things from me. If it's bad, I want to know."***

Clinician: *"How much do you want your brother to participate or know?"*

> **MJ:** ***"He can stay for everything. He is the person I am closest to, and he's been helping me out these past years. He should be included in the conversations, all of it."***

K: Knowledge and Giving Information

- **Warning patient of the "news" may lessen the shock & facilitate understanding**
  - ***"Unfortunately I have bad news…"***
  - ***"I'm sorry to tell you that…"***
- **Avoid jargon, speak to level of patient and family**
  - **Spread vs. Metastasis**
  - **Spots on the liver**
- **Avoid excessive bluntness**
  - ***"You are going to die within days."***
- **Give information in chunks and check understanding**
  - **Observe acceptance, denial, and understanding; is there conflict around decision making? What if someone asks you to "not tell?"**
- **When prognosis is poor, avoid phrases like "there is nothing more we can do…"**
  - ***Inconsistent w/palliative practices of good pain control & symptom relief***

Knowledge MJ

Clinician: *"I am very sorry to have to confirm your suspicions, MJ. While your pneumonia has gotten just a bit better, the pain you have been having here (points at location) is most likely related to a mass. The mass at this point seems most consistent with a cancer.*

We will not know for sure what the mass is until we do a biopsy or a procedure to get a piece of it. However, because you are so weak physically and your liver is not working normally because of the alcohol, the liver and cancer doctors want you to get stronger before the biopsy is done. After the biopsy we can see under the microscope what it is and what can be done."

- Make good eye contact, await response (most likely emotional, so wait for it so you can acknowledge & address)

"I know this isn't what you had hoped to hear."

E: Explore the Patient's Emotions with Empathic Responses

- Recognize patient emotions
  - Most clinicians (not us though!) generally overlook emotional cue & make few empathetic responses
- Identify that patient's emotion by naming it
  - If silence, query to what patient feeling
- Identify the reason for the emotion
  - Acknowledging (whether verbally or nonverbally), naming & validating the emotional response = empathy
  - Empathy decreases patient anxiety!
- Connect the emotion with the reason
  - Opportunity continued assessment of patient & family

More Empathic Responses

Empathic statements	Exploratory questions	Validating responses
"I can see how upsetting this is to you."	*"How do you mean?"*	*"I can understand how you felt that way."*
"I can tell you weren't expecting to hear this."	*"Tell me more about it."*	*"I guess anyone might have that same reaction."*
"I know this is not good news for you."	*"Could you explain what you mean?"*	*"You were perfectly correct to think that way."*
"I'm sorry to have to tell you this."	*"You said it frightened you?"*	*"Yes, your understanding of the reason for the tests is very good."*
"This is very difficult for me also."	*"Could you tell me what you're worried about?"*	*"It appears that you've thought things through very well."*
"I was also hoping for a better result."	*"Now, you said you were concerned about your children. Tell me more."*	*"Many other patients have had a similar experience."*

NHPCO

MJ Emotion and Empathy

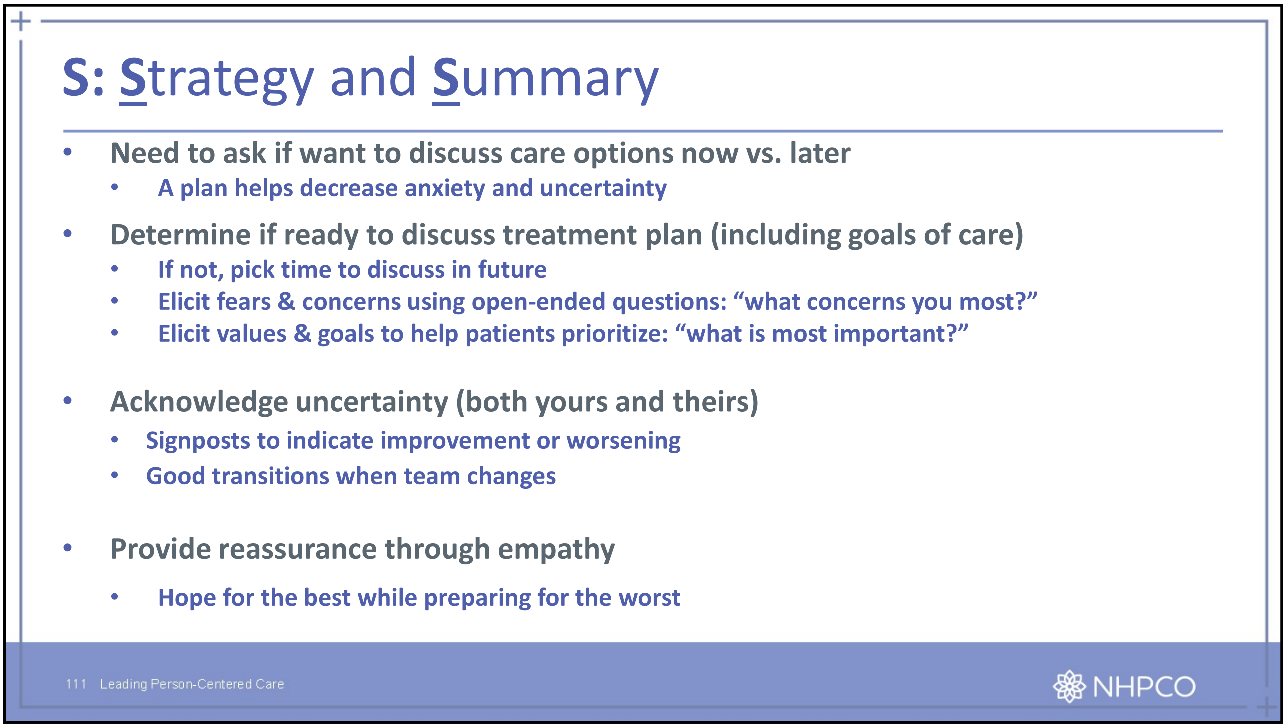
Clinician: *"You are really quiet; can I ask what you are thinking?"*

> **MJ:** *"I am just so angry and disappointed with myself. I know part of this is because of my drinking and I have tried to stop and never could. I want to try and get better, but I am so tired & weak. My brother has always been here for me, and now this. I can't expect him to carry me through this, too!"*

[MJ's brother protests & promises support]

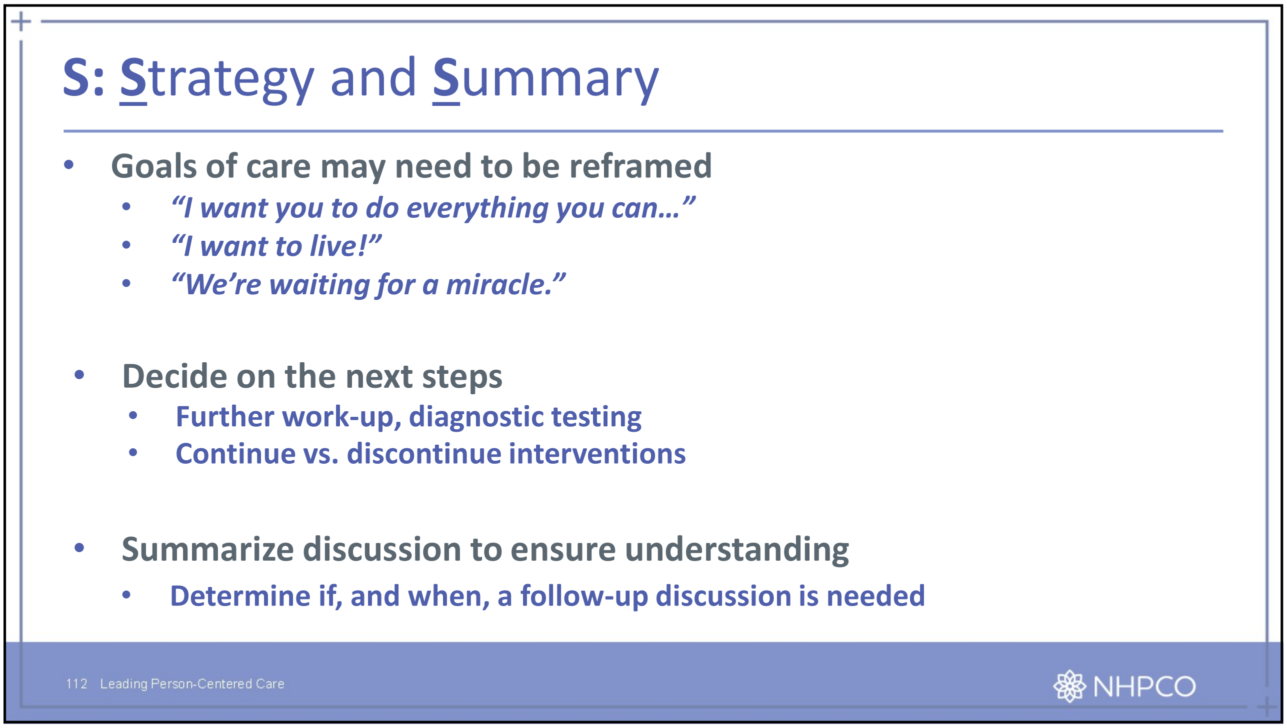
> **MJ:** *"What happens now? You said I should get stronger so I can get the biopsy done, and then maybe…be strong enough to get treatment for the cancer…if that is what it is?"*

NHPCO



S: Strategy and Summary

- Need to ask if want to discuss care options now vs. later
  - A plan helps decrease anxiety and uncertainty
- Determine if ready to discuss treatment plan (including goals of care)
  - If not, pick time to discuss in future
  - Elicit fears & concerns using open-ended questions: “what concerns you most?”
  - Elicit values & goals to help patients prioritize: “what is most important?”
- Acknowledge uncertainty (both yours and theirs)
  - Signposts to indicate improvement or worsening
  - Good transitions when team changes
- Provide reassurance through empathy
  - Hope for the best while preparing for the worst



S: Strategy and Summary

- Goals of care may need to be reframed
  - *“I want you to do everything you can…”*
  - *“I want to live!”*
  - *“We’re waiting for a miracle.”*
- Decide on the next steps
  - Further work-up, diagnostic testing
  - Continue vs. discontinue interventions
- Summarize discussion to ensure understanding
  - Determine if, and when, a follow-up discussion is needed

MJ: Strategize and Summary

Clinician: *"Do you feel up to talking about how we can work to get you stronger?"*

MJ: ***"Yes, I want to know so I can start working on whatever I need to do."***

Clinician: *"One of the best ways to get stronger is exercise. We are going to have a physical therapist come evaluate you for strength and endurance. The therapist often will recommend going to another place for a couple of weeks after you leave the hospital where they work on getting you stronger. After that we will decide what to do next."*

MJ: ***"Sounds good doc, I'm ready."***

MJ Case Resolution

- Transferred to skilled facility for rehabilitation
- Overall condition weakens over ensuing weeks
  - Clinician continues to have follow-up conversations (GOC)
  - Signs DNH, DNR orders
  - After discussion w/brother, elects to transition to hospice for comfort care
- Develops refractory ascites, GI bleed, becomes encephalopathic
  - ***POLST is honored & he does not return to hospital***
  - Dies a few weeks later in the nursing home with hospice support, and his brother at bedside

Deliberate Practice: Skill Attainment

- Set time to review the encounter & clinicians should debrief
  - What worked
  - What went wrong
  - How can I improve?

- Review provider emotions: unexamined emotions over time
  - Physician distress
  - Disengagement
  - Burnout
  - Poor decision-making

- Find a mentor
  - Provide supervision of practice
  - Offer constructive feedback
  - Help identify areas need improvement

Summary

If communicating bad news is done ***poorly,***
patients and family members ***may never forgive us…***

However, when we do it ***well***, they will ***never forget us***.

5

Goal of Care Conversations

Role Play: Delivering Difficult News

Your Turn To Practice: Role Play

Delivering Difficult News

What did you hear that you liked?
What phrases moved the conversation forward?
Anywhere you might get stuck?

6

Goal of Care Conversations

Advanced Strategies & Novel Frameworks – PAUSE/REMAP, Negotiating Goals

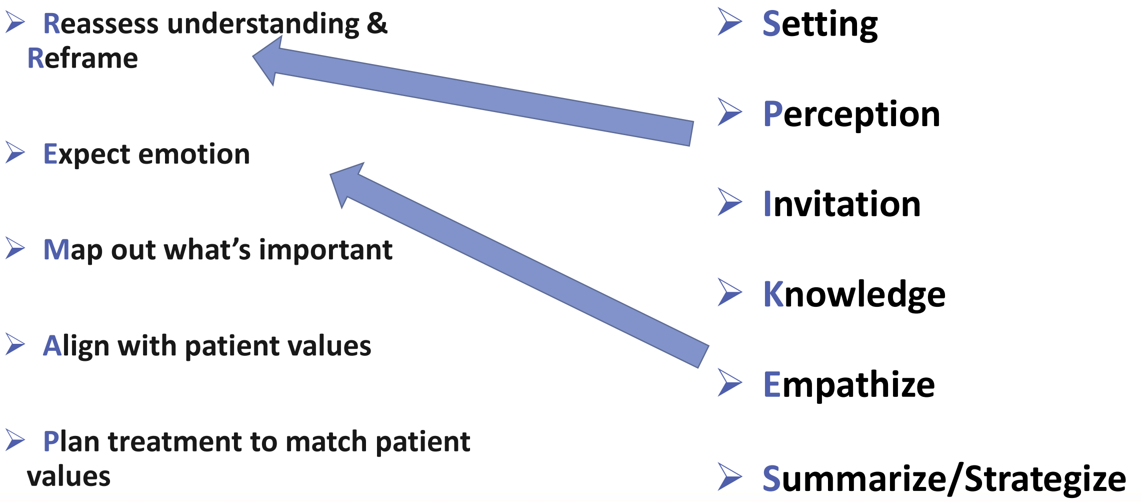
> "It is NOT about hard choices. It is about what they want and how they want to live."
>
> ***Atul Gawande, MD***

PAUSE: Discussing (Early) Goals of Care

Early Goals (PAUSE) vs. Late Goals (REMAP): An ‘early’ goals of care conversation is earlier in an illness or one where a clinical decision *is not imminent*.

STEP	What you say or do (examples):
P – PAUSE Make time to introduce the topic	*“There is something I’d like to put on our agenda today.”*
A – ASK: Ask permission and explain why you are bringing up this topic.	*“I would like your opinion on something. Occasionally one of my patients gets sick suddenly and I can’t talk to them. Then I worry that I can’t provide the best care for them. For example, one of my patients told me that they would never want to be a vegetable. That’s very important for me to know, even when that person is far from being that sick. What do you think about that?”*
U – UNDERSTAND: Get a sense of your patient’s big picture values.	*“If the disease was getting worse and might take your life, what would be most important to you?” “Some people think that we should focus on comfort, others say adding days to your life is the most important. What do you think?”*
S – SUGGEST: Choosing a surrogate decision maker.	*“Have you ever thought about who would be the best person to make medical decisions if you were too sick to make them yourself?”*
E – EXPECT/EMOTION: Respond to emotion empathically.	*“I can see this is making you feel concerned.” [names the emotion]* *“What I am hearing you say is you want to keep fighting.” [Reflects the patient’s words back]*

REMAP: Discussing (Late) Goals of Care



- **Reassess understanding & Reframe**
- **Expect emotion**
- **Map out what’s important**
- **Align with patient values**
- **Plan treatment to match patient values**

- **Setting**
- **Perception**
- **Invitation**
- **Knowledge**
- **Empathize**
- **Summarize/Strategize**

Palliative Transitions: Triggers for GOC

SPIKES: Sharing Serious News

- Discussion of diagnosis (new)
- Discussion of disease progression

ADAPT: Talking Map

- Discussion of prognosis

PAUSE: Early Illness GOC

- Clinical decisions are not imminent

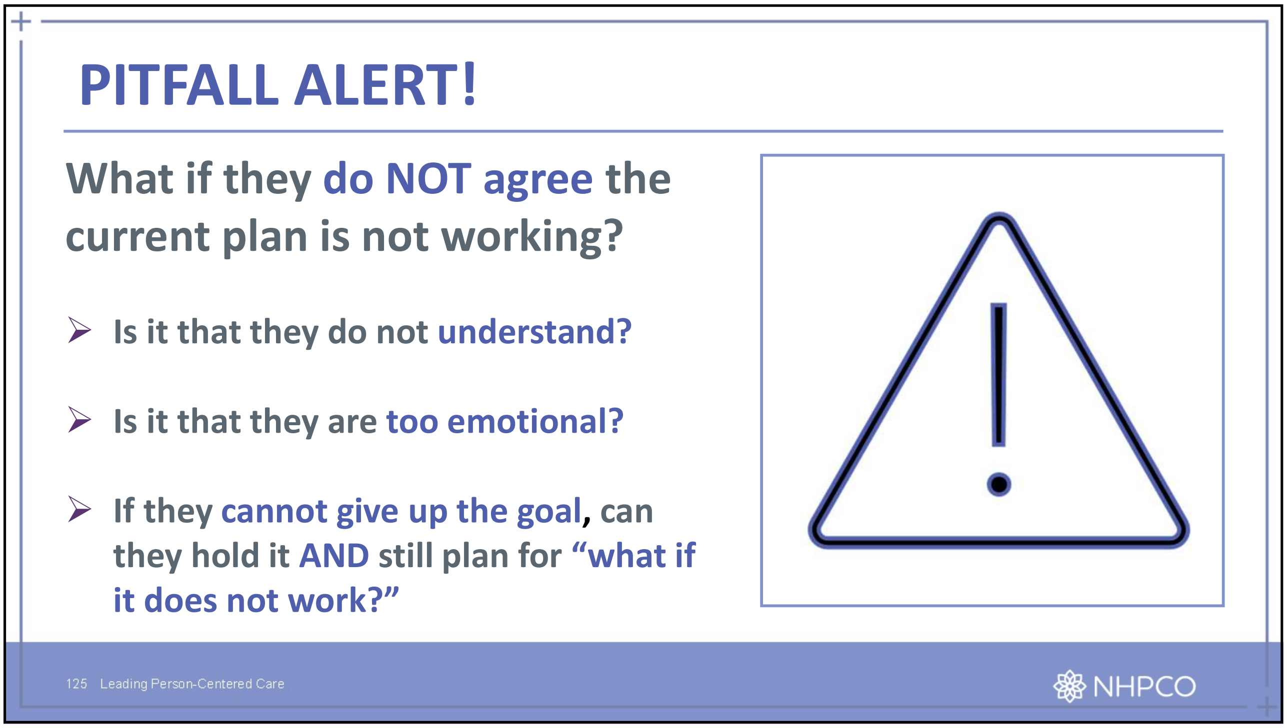
REMAP: Recommendations) (Later Stages of Illness

- Discussion of how treatments have helped or failed
  - *Outcome is thought to be poor or different than expected*
- Time for the discussion of future care
  - *Needing to or discussing transitions away from life-prolonging treatments*
- Re-evaluate goals with patient
- Ethical variables begin to affect care
  - Suffering
- Patient symptoms change

REMAP: Reassess Understanding and Reframe

"Given where you are in your illness, it seems like a good time to talk about where to go from here."

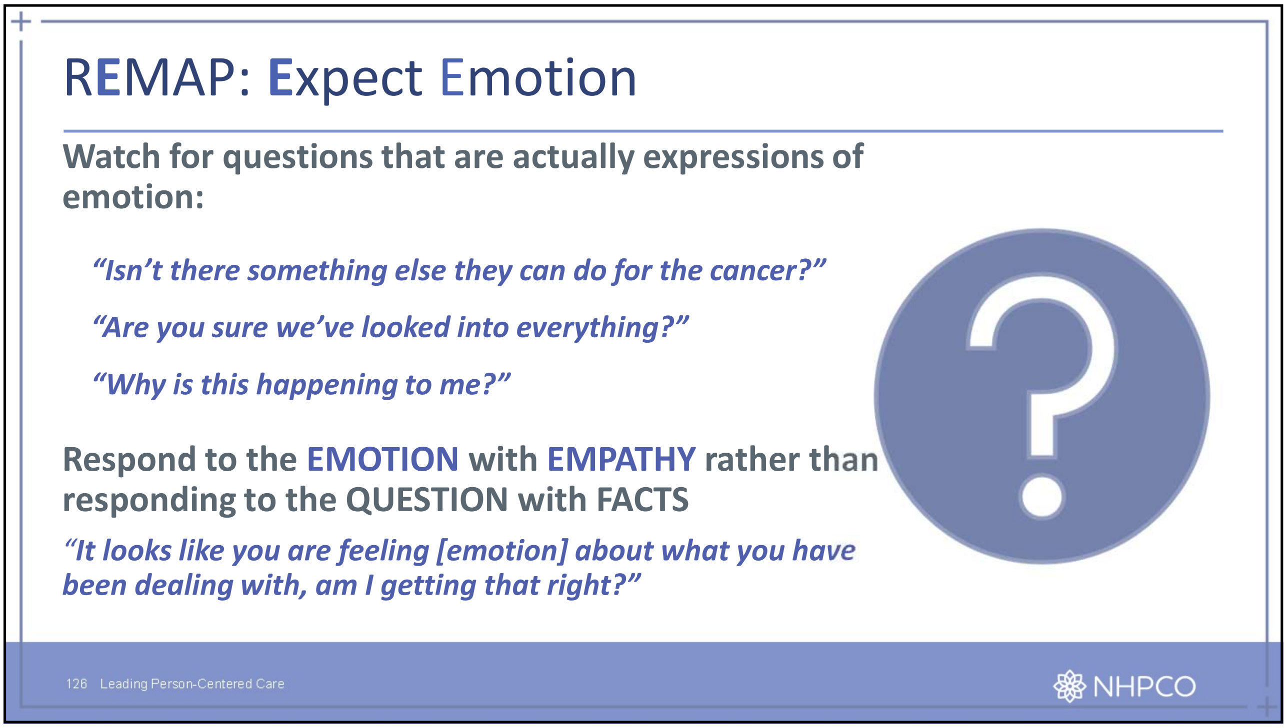
"Based on what you've just told me, it seems like a good time to talk about what to do now."



PITFALL ALERT!

What if they do NOT agree the current plan is not working?

- Is it that they do not understand?
- Is it that they are too emotional?
- If they cannot give up the goal, can they hold it AND still plan for "what if it does not work?"



REMAP: Expect Emotion

Watch for questions that are actually expressions of emotion:

"Isn't there something else they can do for the cancer?"

"Are you sure we've looked into everything?"

"Why is this happening to me?"

Respond to the EMOTION with EMPATHY rather than responding to the QUESTION with FACTS

"It looks like you are feeling [emotion] about what you have been dealing with, am I getting that right?"

REMAP: Expect Emotion

- Remember your tools for responding to emotion:
  - Name
  - Acknowledge
  - *“I wish”* statements

“I can see that you are really concerned”

“I get a sense that this is not what you were expecting to hear today”

“I wish you weren’t having these kidney problems.”

- Ask permission before moving on

“Is it OK for us to talk about what this means?”

REMAP: Map Out What’s Important

- You must know the patient’s goals and values before creating a plan
- Only way to know is by asking
- If asked correctly, the question makes sense and isn’t scary
- Need to separate from strategy…what are their *goals?*

“Can we step back and think about what you are hoping for and that will let us come up with the right choice for you?”

“Given what you have told me matters the most to you, my recommendation is that we…”

Map Out What's Important (more examples)

"Given this situation, what's most important to you?"

"Knowing that time may be limited, what things are most important?"

"As you think about the future, what do you want to avoid? What do you want to make sure does not happen to you?"

"As you look at the future, what seems more important, the quality of your life or how long you live?"

"Have you ever written a living will?"

"Have you ever thought what you would do if things do not go the way you want?"

"Have you ever had to face issues like this with anyone in your family?"

"What kinds of things do you enjoy doing?"

"How do you envision spending your time, with whom & doing what?"

REMAP: Mapping Tips

- Be curious
- Ask multiple exploratory questions
- Don't have an agenda or respond with judgment
- Don't "rank" their goals (yet)

REMAP: Mapping with Surrogate

- What is most important to the patient - NOT to the surrogate?

"If your dad was sitting here, what would he say is most important?"
"What would your mom be worried about in this situation?"
"If your son was sitting here and could hear what we are saying, what would he hope to avoid?"

- Do not ask what they would "want," ask what matters to them

"Did your mom ever discuss how she expected things would be at the end?"
"How did she say she wished to spend her final days/hours?"

- Provide choices you are comfortable with (only)
- Offer recommendations
- Focus on what you can do (the positive)

Other Strategies for Mapping

Strategy	Example
Asking about advance directives	"Have you ever completed a living will?"
Asking about values directly	"What's most important to you now, with what you know about your illness?" "What else?"
Reflecting on emotion	"You feel sad thinking about the possibility that you won't see your children grow up. It sounds like time with your children is one of the most important things for you now."
Exploring worries	"As you think about the future, what concerns you?" "What do you want to avoid?"
Exploring life outside the hospital or clinic	"What kind of things do you like to do when you're feeling stronger?"
Personal experience with medical interventions	"What has chemotherapy been like for you?"
Family/friend experience with medical interventions	"Has anyone close to you been in the intensive care unit or on a breathing tube? What was that like?"
Exploring recent quality of life	"How has your life been for the past year since you've had more health problems?"

REMAP: **Aligning with** Patient Values

- **Repeat what patient has just told you is most important**
  - **Helps you make sure you've got it right**
  - **Helps the patient feel understood**

"As I listen to you talk, it sounds like what is important to you is…"

"You said staying in your home was something you valued; I think we can help you to do that by…"

"By planning ahead, we can avoid things like…"

Plan treatments that match values

AFTER EMOTIONS HAVE BEEN ADDRESSED…

- **Transition from stated values to specific treatments or care plans that match agreed-upon goals.**
  - *"It sounds like quality of life is the most important issue for you right now. Did I get that right?"*
  - *"Now that I have a better understanding of what's important to you, let's talk a bit more about the options for treatment"*
  - *"Here are some things we can do now…"*

- **Give a recommendation that flows *only from the patient's goals.***
  - *"Would it be helpful for me to offer a recommendation?"*
  - *"From what you've told me about what's most important to you, I recommend…How does that sound to you?"*

REMAP: Aligning with Patient Values (Example)

PATIENT:

"This has all been so hard, and I'm tired. I'm really worried that the pain might get worse. I don't want to end up on a breathing machine like the last time I was in the hospital – I never want to go through that again. And I haven't been able to really enjoy time with my husband and my kids. I'd like to do that…maybe go on a vacation with them."

CLINICIAN:

"As I listen, it sounds like what's most important to you is that you stay out of pain and spend more time with your family. It also sounds like you would not be willing to go through things that will cause you a lot of pain and suffering, like being on a breathing machine again. Does that sound right?"

PITFALL ALERT!

What if they are hoping for a miracle?

- Join with them

  "I hope we get one too…"

- See if you can help them expand their hope portfolio

  "What else can you hope for?"

- Can they consider what if a miracle does not happen?

The patient responds to the question "what is most important," with…*"TO LIVE LONGER!"*

Acknowledge, *"I hear you…*
…and what else?
…and what if this is unlikely?"

REMAP: Plan Treatments that Match Values

- **Ask permission** to make a recommendation to help the patient meet their goals. Focus on:
  - what can be achieved
  - what might be possible
  - what not to do because it won't help meet the patient's goals
    - do not offer bad options which lead to poor outcomes!
- Ask patient or family **whether the plan seems right**
- Conclude with **specific expression of support**
- Confirm they understand

REMAP: Plan Treatments that Match Values (Example)

"Would it be ok if I offered a recommendation? Given what you've told me is most important, there's a lot we can do to help. We'll focus on keeping you out of pain. We can also get some services into your home to help you stay there and spend more quality time with your family. We'll work toward that vacation, and we'll have a better idea of how possible that is after we see how you feel on the new medication. Does that sound ok?"

"I also recommend that we don't do further scans or blood draws, because they won't help identify the best way to take care of you. I recommend we avoid using life-support like a breathing machine, or CPR if your heart were to stop, because at this point they won't help you achieve your goals. How does that sound to you?"

REMAP: Plan Treatments that Match Values (Example)

"I want to be sure I understand your goals. Given what you've told me is most important, it sounds like you would want to pursue any treatment that would give you a chance of living longer, even if that means your life might be supported by machines (or the intervention may be painful). Does that sound right?"

"Is there any situation you can imagine when you wouldn't want your life to be supported by machines?"

REMAP: Align (and Defer Planning)

- Sometimes, it may not be possible to immediately formulate a recommendation. If so…DEFER
  - Map out goals and make aligning statement
  - Respond to emotions
  - Inform team of the patient's goal
  - Return later with recommendations

PITFALL ALERT!

Patient	Clinician
Does this mean you're giving up on me?	*Absolutely not. Tell me, what do you mean by giving up?*
Are you telling me I'm going to die?	*Hearing all of this must be really scary. I wish I could tell you something different.*
Is there any hope?	*There is always hope. Tell me about what worries you.*

Summary:

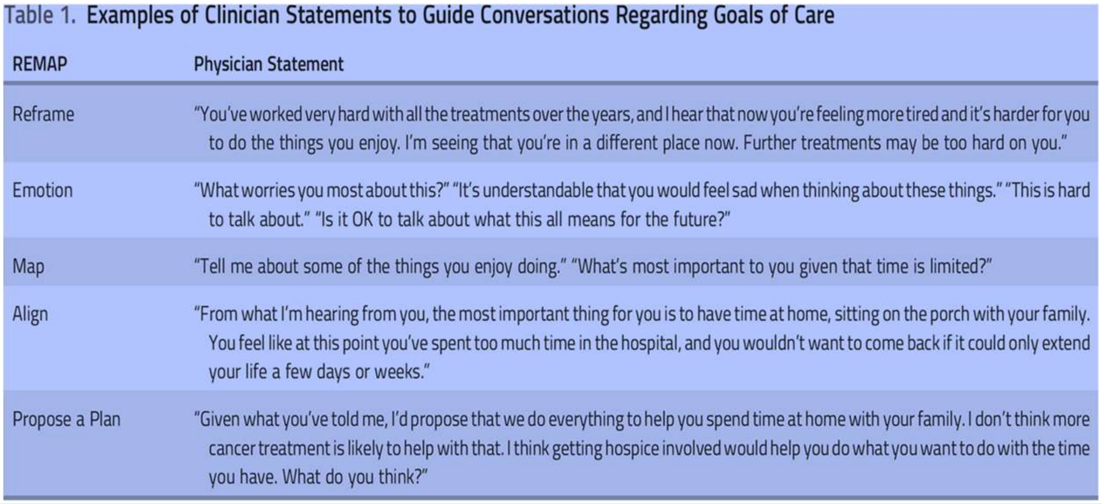


Table 1. **Examples of Clinician Statements to Guide Conversations Regarding Goals of Care**

REMAP	Physician Statement
Reframe	"You've worked very hard with all the treatments over the years, and I hear that now you're feeling more tired and it's harder for you to do the things you enjoy. I'm seeing that you're in a different place now. Further treatments may be too hard on you."
Emotion	"What worries you most about this?" "It's understandable that you would feel sad when thinking about these things." "This is hard to talk about." "Is it OK to talk about what this all means for the future?"
Map	"Tell me about some of the things you enjoy doing." "What's most important to you given that time is limited?"
Align	"From what I'm hearing from you, the most important thing for you is to have time at home, sitting on the porch with your family. You feel like at this point you've spent too much time in the hospital, and you wouldn't want to come back if it could only extend your life a few days or weeks."
Propose a Plan	"Given what you've told me, I'd propose that we do everything to help you spend time at home with your family. I don't think more cancer treatment is likely to help with that. I think getting hospice involved would help you do what you want to do with the time you have. What do you think?"

Closing the Meeting: Summarize the Plan

- Express your appreciation for their willingness to talk about the topic
- Ask the patient for their understanding of what was discussed and what the next steps are
- Discuss, in detail, your next steps to help them accomplish their future goals

---

Recap: Our Roles in GOC conversations

Ensure patients receive treatment consistent with their values and goals by helping them…

- ➢ Define what is important to them
- ➢ Understand the possible outcomes of treatment
- ➢ Make informed decisions to support their goals

…it’s not easy, but can be learned & practiced

PITFALL ALERT!

- Responding to distress with more ICU care
- Not responding to empathetic opportunities
- Talking too much
- Not speaking to their "language" (cultural, education level)
- Address specific treatments rather than goals and values
- Distancing/blocking behaviors
- Feeling that you must "figure out a plan," or expecting too much too soon
  - Sometimes goals are never achieved
- Struggling to respond to conflict
- Not Taking time to REFLECT

Time to Take Action: Advanced Communication Skills

➢ Negotiation: resolving of disagreements; the reaching of agreement through discussion and compromise

- Identify *potential barriers and sources of conflict* (disconnects) that arise when negotiating goals of care
- Describe different *concepts* that explain why patients and families may be considered *"in denial"*
- Discuss *practical strategies* for employing the presented ideas in clinical situations

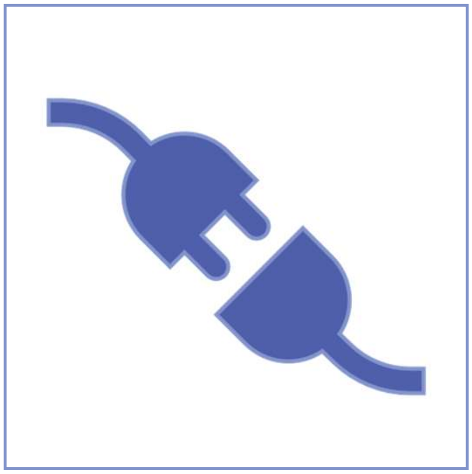
Meet the patient: MB

- MB: 39-yo mother of four
  - Children ages 8,13, 15 and 21
  - Divorced, no contact with ex-husband
  - MB's mother lives with them, helps with childcare/household tasks
  - College graduate
  - Employed by the state helping enroll potential beneficiaries in state programs
  - Active in local evangelical church
- Developed weight loss and abdominal pain
  - Workup revealed stomach cancer
    - Surgery removed some tumor
    - Chemotherapy to reduce tumor size
    - More surgery planned to remove remainder
  - At second surgery, tumor widespread
    - "opened & closed" surgery
    - Sent home with NG tube in place and hospice called

Meet the patient: MB

- MB identified the following goals of care
  - Relief from pain and nausea
  - Eat & drink enough to get stronger
  - Return to work to provide for family
  - Watch her children grow up
  - Continue in her strong Christian faith
  - Make the tumor go away
  - Wants to "know everything" but…
  - …does not want any "negative talk"

Disconnect #1:



- **Clinician’s perspective:**
  - Medical decisions are primarily guided by medical factors
  - Believes his or her job is largely cognitive:

    “If I educate the patient or family well, they will make a rational medical decision.”
- **Patient’s/family’s perspective:**
  - Social and emotional factors often dominate over the medical factors

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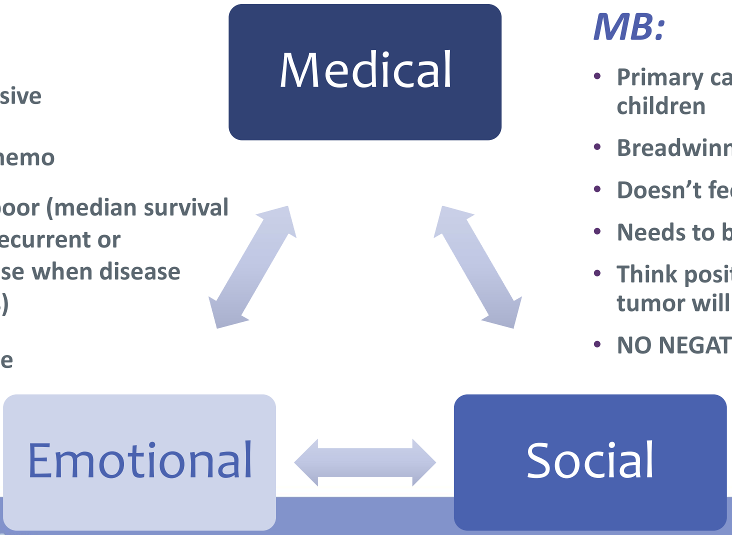
Decisions are Multifactorial



Clinicians:

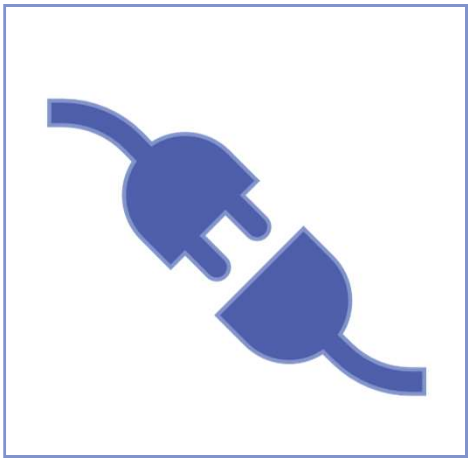
- Tumor is aggressive
- Grew despite chemo
- Outcomes are poor (median survival < 6 months w/recurrent or refractory disease when disease free < 6 months)
- Pt needs hospice

MB:

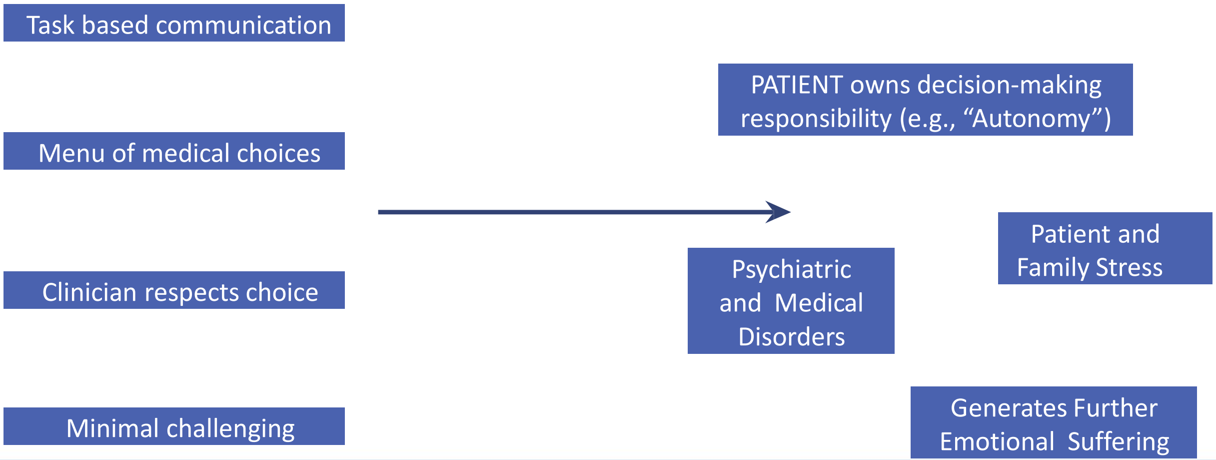
- Primary caregiver with young children
- Breadwinner for family
- Doesn’t feel well/weak
- Needs to be able to eat/drink
- Think positively & have faith & tumor will go away
- NO NEGATIVE TALK

Disconnect #2:

- **Clinical Dilemma:**
  - Pressure to “get” the patient/family to accept the fact that the patient is dying
  - Since resuscitation is the default mechanism, more pressure to “get” the DNR
- If the patient/family do not achieve acceptance
  - Must be “in denial”
  - **Fails to consider normative grief and conflict**



Old vs. New Perspectives on Decision Making



Task based communication

Menu of medical choices

Clinician respects choice

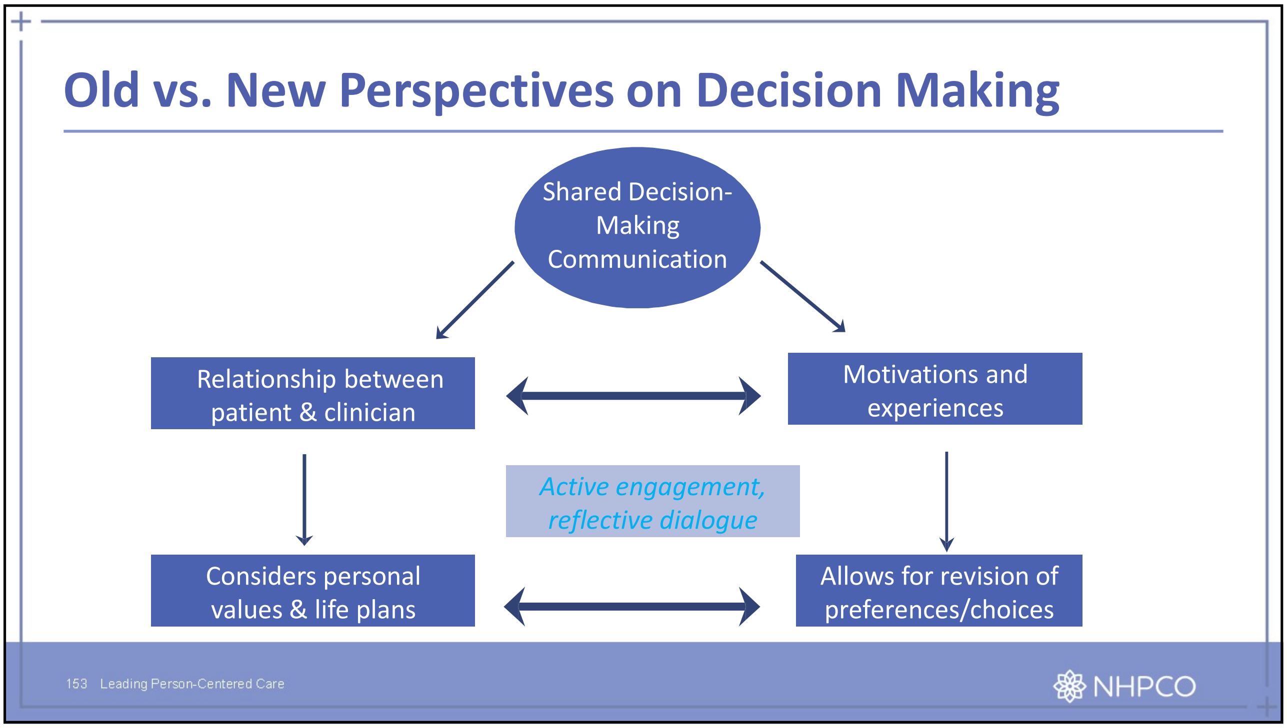
Minimal challenging

PATIENT owns decision-making responsibility (e.g., “Autonomy”)

Psychiatric and Medical Disorders

Patient and Family Stress

Generates Further Emotional Suffering



Old vs. New Perspectives on Decision Making

Shared Decision-Making Communication

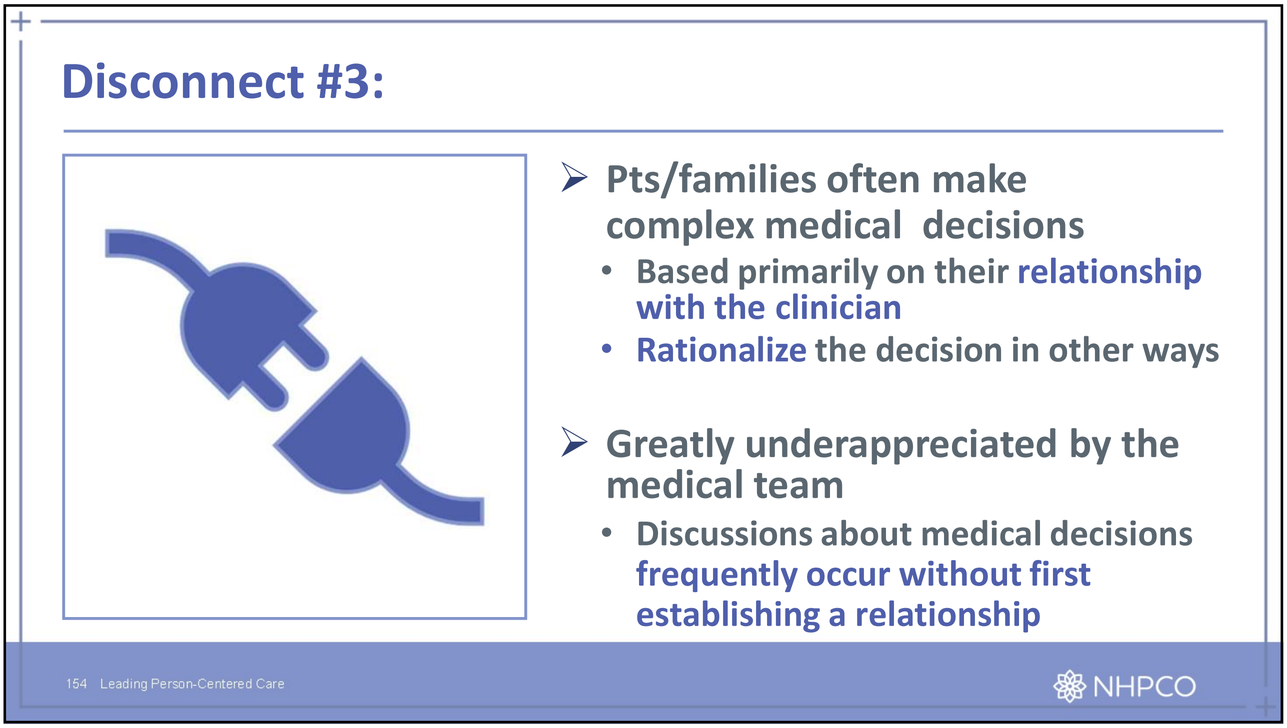
Relationship between patient & clinician

Motivations and experiences

Active engagement, reflective dialogue

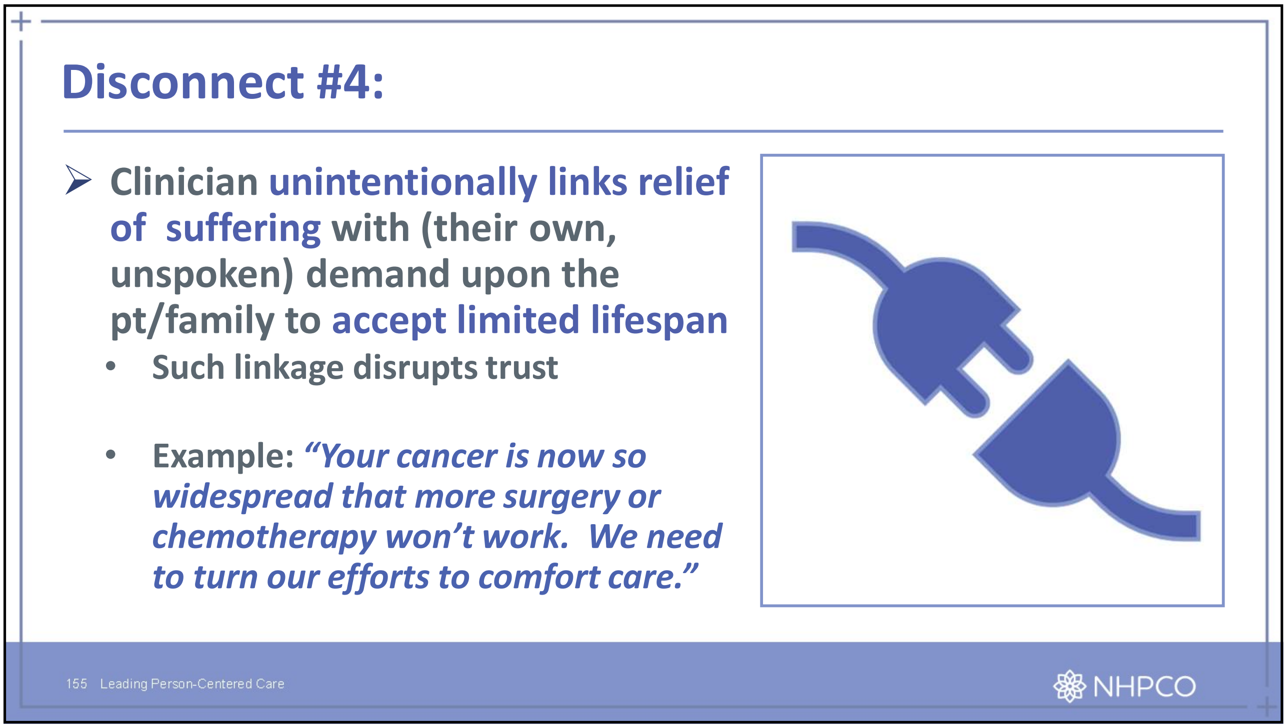
Considers personal values & life plans

Allows for revision of preferences/choices



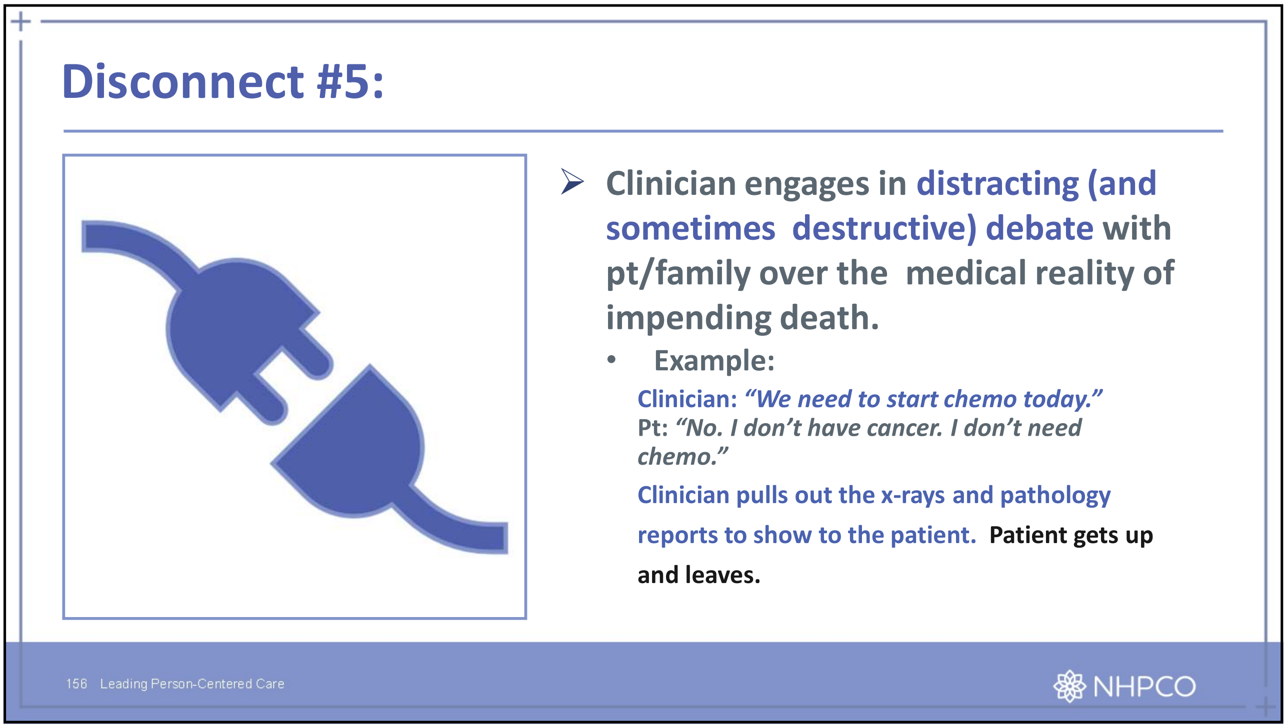
Disconnect #3:

- Pts/families often make complex medical decisions
  - Based primarily on their **relationship with the clinician**
  - **Rationalize** the decision in other ways
- Greatly underappreciated by the medical team
  - Discussions about medical decisions **frequently occur without first establishing a relationship**



Disconnect #4:

- Clinician unintentionally links relief of suffering with (their own, unspoken) demand upon the pt/family to accept limited lifespan
  - Such linkage disrupts trust
  - Example: *"Your cancer is now so widespread that more surgery or chemotherapy won't work. We need to turn our efforts to comfort care."*



Disconnect #5:

- Clinician engages in distracting (and sometimes destructive) debate with pt/family over the medical reality of impending death.
  - Example:

Clinician: *"We need to start chemo today."*
Pt: *"No. I don't have cancer. I don't need chemo."*

Clinician pulls out the x-rays and pathology reports to show to the patient. Patient gets up and leaves.

Negotiating Goals

- The steps are the same as delivering bad news…except…
  - You must come up with a plan of care

- Why Negotiate?
  - Gain greater understanding of the other side's motives, objectives, and constraints (their side)
  - Share some of <u>your</u> motives, objectives, constraints (your side)
  - Seek common ground (Win/Win) (the 3rd side)

Negotiating Goals

- Paradigm Shift:
  - From a "message delivery" stance:
    - Prove a point
    - Give a piece of our mind
    - Get our way
    - Persuade other to do or be what we want
  - To a "learning" stance:
    - Understand what happened from the other's point of view

Negotiation as it applies to Goals

➢Some examples of BAD questions/statements that can have unintended consequences include:

- *Do you want us to do everything possible?*
- *Will you agree to discontinue care?*
- *We'll refrain from extraordinary measures.*
- *It's time we talk about pulling back.*
- *I think we should stop aggressive therapy.*
- *I'm going to make it so he won't suffer.*

- What are you expecting?
- What do you most want to accomplish?
- What is most important in your life right now?
- What are you hoping for?
- What do you hope to avoid?
- What do you think will happen?
- What do you expect the outcome to be like?

Reminder: MB

- ➢ Inoperable, terminal gastric cancer with inability to provide nutrition by mouth or tube
- ➢ Patient demanded TPN
  - ➢ Clinician attempted to explain how this would not prolong life and could likely shorten life

"You're talking negative! Leave!"

- ➢ Attempted to debate with the patient
- ➢ MB lost trust with clinician, and kicked him out of the room

Assessing Readiness

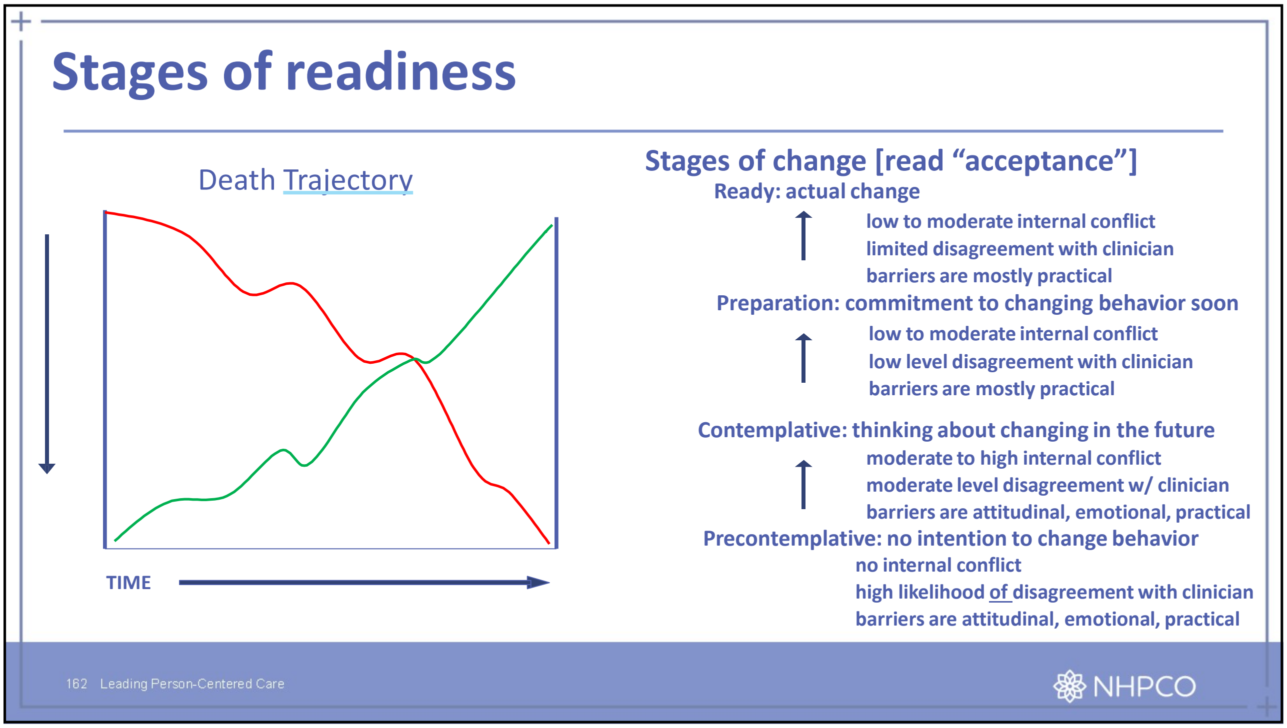
WHY?

- Understand **who the patient** is
  - Medical, social and emotional elements
- Allow the patient to **appreciate your understanding**
  - Form a trusting relationship
- Understand the **broader forms of suffering** (patient defined)

HOW?

- Stages of change: **precontemplation, contemplation, preparation, (action) and readiness**

Stages of readiness



Stages of change [read "acceptance"]

Ready: actual change
↑
low to moderate internal conflict
limited disagreement with clinician
barriers are mostly practical

Preparation: commitment to changing behavior soon
↑
low to moderate internal conflict
low level disagreement with clinician
barriers are mostly practical

Contemplative: thinking about changing in the future
↑
moderate to high internal conflict
moderate level disagreement w/ clinician
barriers are attitudinal, emotional, practical

Precontemplative: no intention to change behavior
no internal conflict
high likelihood of disagreement with clinician
barriers are attitudinal, emotional, practical

Example:

Stage:	Patient's POV:	Clinician's POV
Precontemplation	"Exercise and diet will cure me." "You don't know what you're talking about. I'm not coming back here!" "I'm not sure…have you ever just not done chemo?"	***Denial response:*** "You need to start chemo as soon as possible." ***Precontemplative response:*** "Tell me more about what you're thinking, and how will we know if it works."
Contemplation	"I doubt I'll benefit from chemotherapy. Plus, I usually don't trust doctors; should I get a second opinion?" [Patient fires doctor]. "I have to think it over."	***Denial response:*** "You should, but they will say the same thing." ***Contemplative response:*** "You're doing great with diet and exercise. I fear it just may not be enough by itself. Could we hope for it to succeed if we supplement it with chemotherapy? Are there any other factors you need to consider as you prepare to make that decision?"
Preparation	"I would be open to chemotherapy, but who would watch my children while I'm in the hospital?" [Thinks doctor is insensitive jerk] "I think that would be beneficial, I need some help."	***Denial response:*** "You can worry about that when the time comes." ***Preparatory response:*** "It sounds like you're worried about your family. Would it be helpful if I asked our social worker to speak with you?"
Ready	"I know that I need this therapy, but I'm just so scared."	***Readiness response:*** "I can tell that this has been a lot for you, and I appreciate your willingness to share that with me. How can I help you prepare to speak to your family?"

Reminder: MB

- Inoperable, terminal gastric cancer with inability to provide nutrition by mouth or tube
- Patient demanded TPN
  - Clinician asked MB to explain more about what she was thinking.

"I don't think I can get well without nutrition."

  - Clinician recognized precontemplative stage of change, negotiated intermittent IV fluids (with significant protest expressed by other family members).

Precontemplative: no intention to change behavior
no internal conflict
high likelihood of disagreement with clinician
barriers are attitudinal, emotional, practical

The power of the time limited, goal oriented trial

- If the goal seems unrealistic or you are unsure if it may be appropriate, it is ok to start a trial and readdress based on agreed upon outcomes
    - Feeding Tubes/IVs
    - Dialysis
    - Breathing support

For example:

"Based on your goal to attempt to get back home. I am comfortable with attempting a time trial of tube feeding for two weeks to see if we can achieve the functional goals to get you independent. Let's reconvene in two weeks."

- Focus on relationship of patient/family goals
    - Treatment, goal to be achieved, endpoints, period of time

---

Reminder: MB

- Pain meds via IV and transdermal patch
    - Comfort treatment separated from discussion of mortality
- Hospice chaplain services declined
    - Had own pastoral support
    - Often there "watching" during staff visits
    - Insisted God would heal
        - Precontemplative
- Social worker did develop some rapport
    - Had to be careful about 'talking negative'
    - Did get patient & mom to allow SW to talk with children (monitored)
        - Contemplative

Reminder: MB

- Nurse managed to provide all necessary clinical care
  - Completely avoided discussion beyond the "here and now"
  - Separated caring from facing mortality
- Physician visits
  - Purpose was to discuss goals
  - Opened discussion with

"I understand that you want to know everything, and I've got some new information. Would you like to review it now?"

  - Trying to gently move from one stage to the next

Reminder: MB

- Then reviewed what was obvious & would give information until told he was getting "too negative"
  - *Contemplative*
- Each visit, conversation got a little farther along
  - *Contemplative towards Preparation*
  - As symptoms progressed and function declined, MB accepted her terminal prognosis & elected hospice
  - *Preparation & eventually, Ready*
- MB died *7 weeks after coming onto hospice*
  - Family relatively accepting of her death: *"God took her home"*

Summary

- The act of negotiating goals of care is…in fact…*a negotiation*
- Negotiation doesn't happen **without dialogue**
- Diagnosing "denial" **blocks dialogue**
- Assessing stages of readiness allows for **open dialogue and stage-appropriate negotiation**
- Whatever the stage or goal, **we can still care**

> *"The secret to patient care is caring for the patient."*
>
> Peabody – JAMA 1927

7

Goal of Care Conversations

Role Play: The Family Goal Setting Meeting – Managing Conflict

Basic steps for GOC Conversations – also apply to the Family Meeting

Set the stage & start off slowly

- An appropriate setting and significant people the patient wishes to have are present
- Provide a calm presence and build rapport

Know the basic information & explain the topic

- Explain why you are raising the topic now

Elicit *their* understanding

- What the current medical situation is and what the future is likely to bring

Then review what you know & assess *their* comprehension

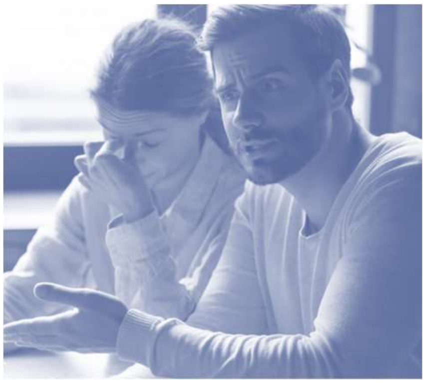
- Make sure the family understands the discussion & plan

Contributors to Conflict in the Family Meeting

Four primary factors complicate the management of frequently occurring team-family conflicts

- Diagnostic and prognostic uncertainty
- Families' strong negative emotions
- Families' limited health literacy
- Families' burden of responsibility

While doctors mainly use content-oriented strategies to resolve these conflicts, empathic strategies appear to be more effective *- especially if conflicts linger on*



Basic Steps to Manage Conflict in the Family Meeting

DO:

- Acknowledge emotions & uncertainty
- Ask open-ended questions & encourage *ALL* points of view
- Provide honest/factual answers & be supportive
- Check in to ensure understanding

TRY TO AVOID:

- Extensive clarifying of a (your) point
- Taking the moral high ground
- Redirection to skirt emotion

Only when necessary:

- Postponing the conversation (ok if necessary to de-escalate)
- Turfing to another (ok when a specific/different resource is appropriate)

Your Turn: Role Play

The Family Goal Setting Meeting

What did you hear that you liked?

What phrases moved the conversation forward?

Anywhere you might get stuck?

8

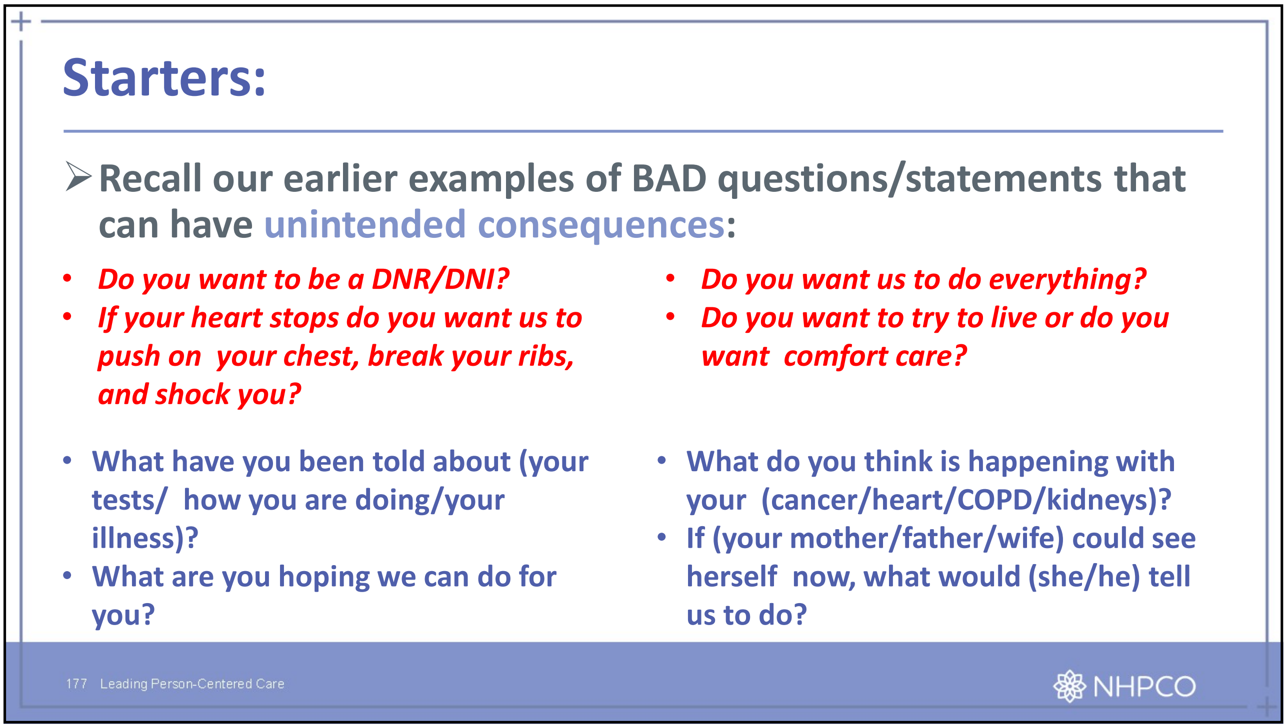
Goal of Care Conversations

Discussing Code Status and Role Play

Meet the patient: Martha

- 87-year-old female, advanced COPD, admitted with CAP. History includes DM, PVD, CHF with EF 45%
- Has had 3 admissions in last 4 months prior to this one
- Has been on solu-medrol, multiple antibiotics, nebulizers, etc. x 5 days, requiring 6L 02, not improving, and having some non-sustained VT on telemetry
- ICU doc consulted you for "goals of care"
- No AD on file, so full code by default

WHERE DO YOU START?

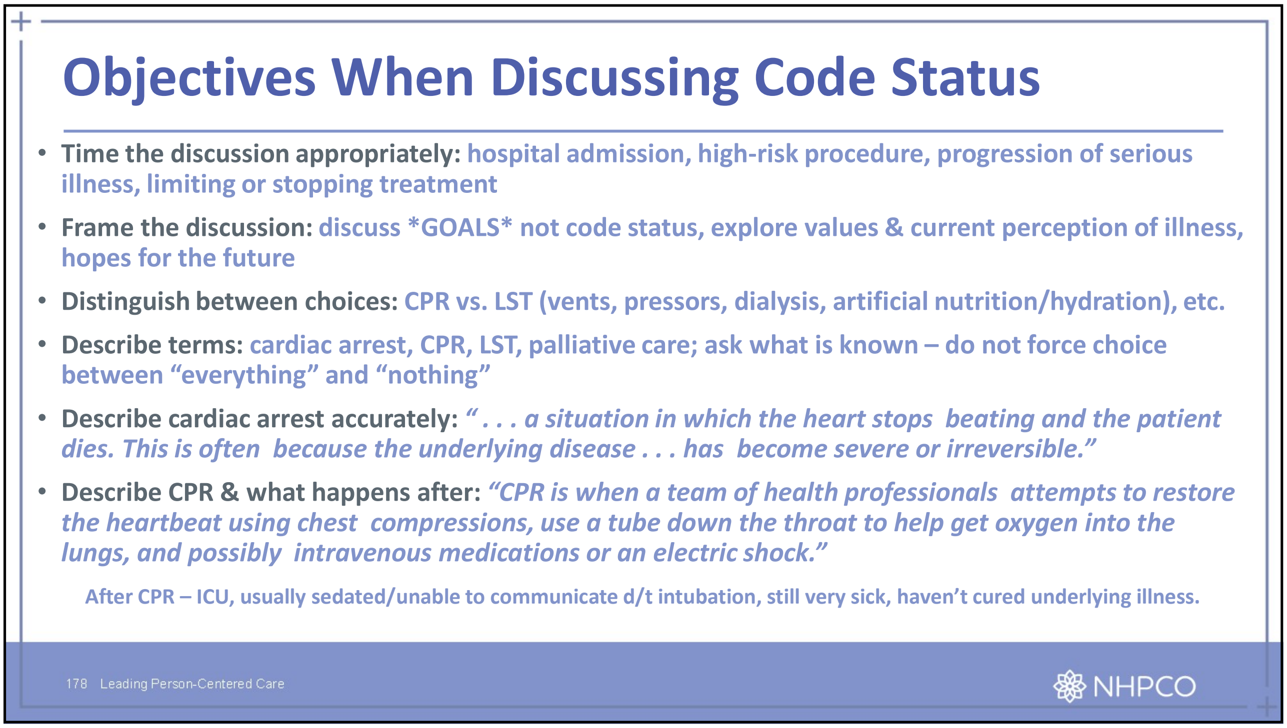


Starters:

➢ Recall our earlier examples of BAD questions/statements that can have unintended consequences:

- *Do you want to be a DNR/DNI?*
- *If your heart stops do you want us to push on your chest, break your ribs, and shock you?*
- *Do you want us to do everything?*
- *Do you want to try to live or do you want comfort care?*

- What have you been told about (your tests/ how you are doing/your illness)?
- What are you hoping we can do for you?
- What do you think is happening with your (cancer/heart/COPD/kidneys)?
- If (your mother/father/wife) could see herself now, what would (she/he) tell us to do?



Objectives When Discussing Code Status

- **Time the discussion appropriately:** hospital admission, high-risk procedure, progression of serious illness, limiting or stopping treatment
- **Frame the discussion:** discuss *GOALS* not code status, explore values & current perception of illness, hopes for the future
- **Distinguish between choices:** CPR vs. LST (vents, pressors, dialysis, artificial nutrition/hydration), etc.
- **Describe terms:** cardiac arrest, CPR, LST, palliative care; ask what is known – do not force choice between “everything” and “nothing”
- **Describe cardiac arrest accurately:** *“ . . . a situation in which the heart stops beating and the patient dies. This is often because the underlying disease . . . has become severe or irreversible.”*
- **Describe CPR & what happens after:** *“CPR is when a team of health professionals attempts to restore the heartbeat using chest compressions, use a tube down the throat to help get oxygen into the lungs, and possibly intravenous medications or an electric shock.”*

After CPR – ICU, usually sedated/unable to communicate d/t intubation, still very sick, haven’t cured underlying illness.

Objectives When Discussing Code Status

- **Describe palliative as a valid treatment plan:** active treatment focused on symptom management and QOL - *not "doing nothing," not "keeping you comfortable"*
- **Modify/tailor approach:** maintain sensitivity to cultural beliefs, ensure approach is appropriate to clinical status, acknowledge discrete goals, tailor to education/knowledge/level of understanding
- **Offering a prognosis/discuss likelihood of success:** *"A cardiac arrest is usually a sign of severe illness; very few people are able to survive it long enough to leave the hospital."*
- **Correct misconceptions regarding success of CPR as portrayed in popular media with reality/probability for this patient:** discuss "survival to what?" SNF, reduced functional status/permanent disability, etc.
- **Making a recommendation:** may offer guidance; this may help relieve some of the burden of decision-making; remember the power of time-limited trial
- **Aim for trust and rapport:** avoid medical jargon, check frequently for understanding, allow time to process and ask questions/initiate dialogue,

Reminders:

- CPR was originally intended for patients who were not in the terminal phase of illness; it is also the ***only medical intervention in the US provided without consent***
- At best, resuscitation at the end stages of a terminal illness returns patients to a dying state
- You can still tell the truth without removing hope

UNDERSTAND THAT THESE DISCUSSIONS MAY REQUIRE TIME, COLLABORATIONS WITH FAMILY MEMBERS AND MULTIPLE CONVERSATIONS

THE BEST INTERVENTION IS HAVING ROBUST GOALS OF CARE CONVERSATIONS, OFTEN AND EARLY

And now, a musical interlude to drive this home

https://youtu.be/1B3otefmrjA?feature=shared

Your Turn: Role Play

Discussing Code Status

What did you hear that you liked?
What phrases moved the conversation forward?
Anywhere you might get stuck?

9

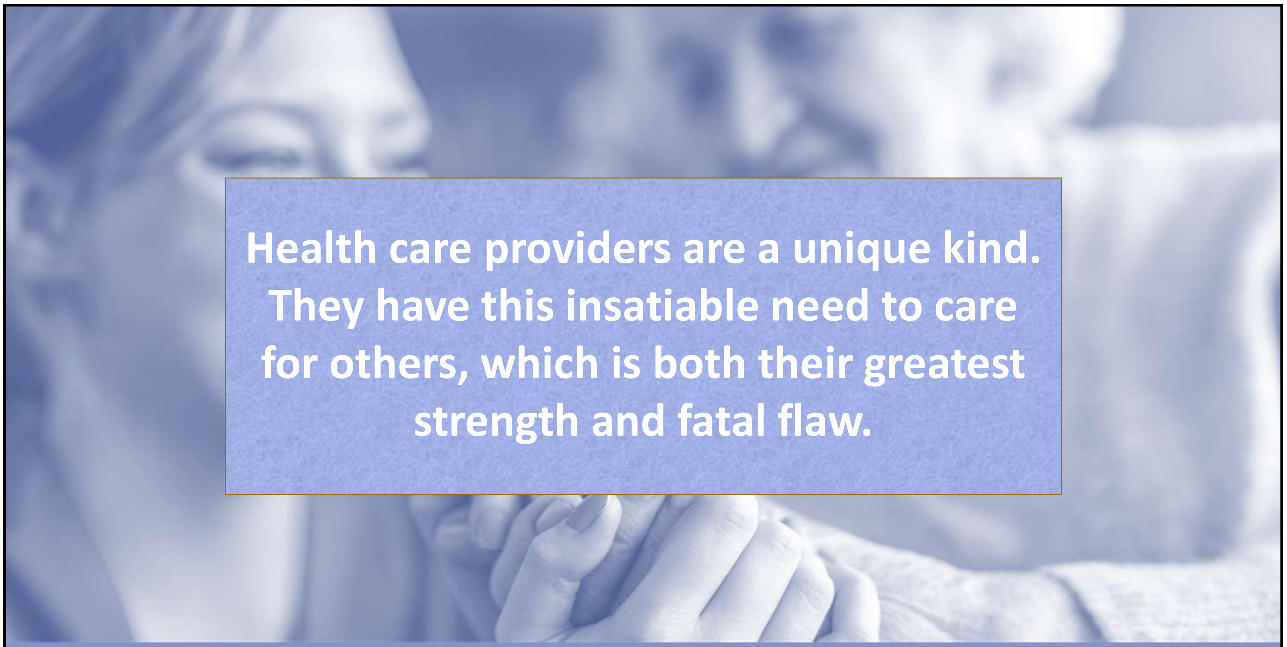
Goal of Care Conversations

Self Care: Recognizing Moral Distress & Managing Burnout

> ”
>
> The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.
>
> *Kitchen Table Wisdom*

Overview

- Identify moral distress and strategies for reducing distress
- Differentiate moral distress from compassion fatigue
- Identify how moral distress affects clinicians, managers and organizations
- Discuss use of case consultation, ethics committees and ethical frameworks to develop strategies to approach complex cases
- Identify strategies to manage and survive distress to avoid burnout



Health care providers are a unique kind. They have this insatiable need to care for others, which is both their greatest strength and fatal flaw.

Definitions of Terms

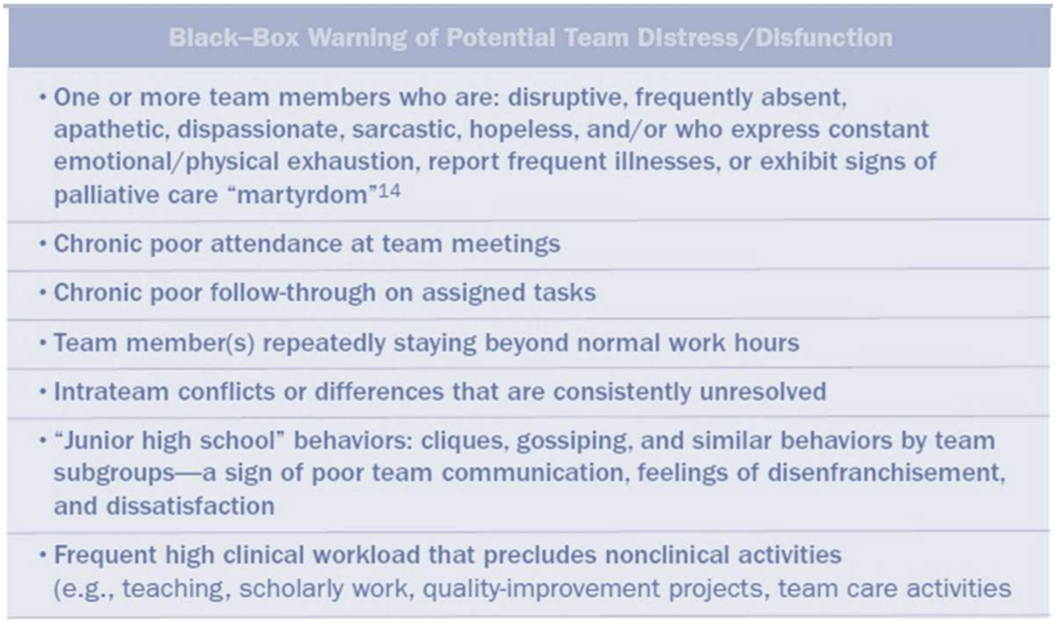
- **Burnout (BO)**, an emotional and behavioral impairment that **results from the exposure to high levels of occupational stress**, has been described as a combination of three factors: emotional exhaustion, depersonalization and personal accomplishment.
- **Compassion fatigue (CF)** has been defined as **a state of physical or psychological distress in caregivers**, which occurs as a consequence of an ongoing and snowballing process in a demanding relationship with needy individuals.
- **Moral distress (MD)** is the **pain or anguish affecting the mind, body or relationships** in response to a situation in which the person is
  - aware of a moral problem,
  - acknowledges moral responsibility, and
  - makes a moral judgment about the correct action;

  yet, as a result of real or perceived constraints, **participates in perceived moral wrongdoing**

The Crescendo Effect

- **Repeated and unaddressed situations** of moral distress over time cause a **gradual crescendo of moral residue**, the lingering feelings of distress that may continue to months.

Crescendo effect can undermine the professional commitment and integrity of the provider



Black–Box Warning of Potential Team Distress/Disfunction
• One or more team members who are: disruptive, frequently absent, apathetic, dispassionate, sarcastic, hopeless, and/or who express constant emotional/physical exhaustion, report frequent illnesses, or exhibit signs of palliative care "martyrdom"[14]
• Chronic poor attendance at team meetings
• Chronic poor follow-through on assigned tasks
• Team member(s) repeatedly staying beyond normal work hours
• Intrateam conflicts or differences that are consistently unresolved
• "Junior high school" behaviors: cliques, gossiping, and similar behaviors by team subgroups—a sign of poor team communication, feelings of disenfranchisement, and dissatisfaction
• Frequent high clinical workload that precludes nonclinical activities (e.g., teaching, scholarly work, quality-improvement projects, team care activities

> We must be watchful of the manner in which our own need for meaning and a sense of transcendence may function as a method of managing the feelings of anxiety and horror that accompanies our bearing witness to suffering that is unrelieved.
>
> ***Browning***

Find Your Passion

What do you like to work on, what areas, what dimension of your professional do you enjoy?

Spending at least 20% of professional effort on the dimension of work (you) find most meaningful lowers risk for burnout!

Shanafelt, Noseworthy, 2017

Self Care

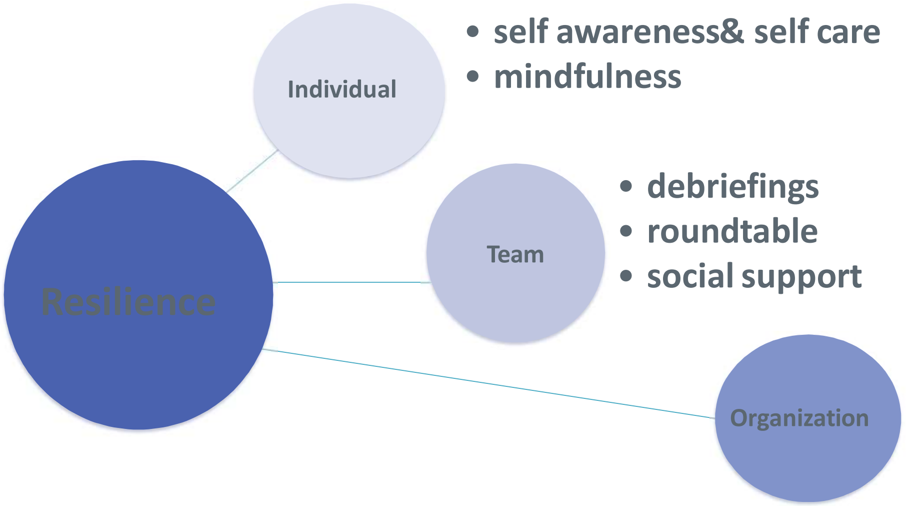
Includes any intentional actions you take to care for your physical, mental and emotional health

Nutrition, Exercise, Rest, Social Support

Many approaches

- General fitness and exercise
- A balance in rest and sleep
- Dietary – various diets
- Personal hygiene
- Stress reduction through avoidance of substances – tobacco, alcohol and drugs
- Personal development
- Engagement in life through hobbies and interest

Three Prong Approach



Resilience

Individual
- self awareness& self care
- mindfulness

Team
- debriefings
- roundtable
- social support

Organization
- leadership
- support
- materials

Your Responsibility: Be the Role Model!

- → Take time to think about how your actions and reactions impact those around you
- → Are you modeling good resilience strategies?
- → Are you “pausing” after a difficult situation to debrief with your colleagues?
- → Are you encouraging folks to take a day off, take time for themselves, etc.?
- → Are you (subconsciously) rewarding overworking or over-involvement?

10

Goal of Care Conversations

Scaling GOC with Your Team: Why It Matters

Incorporating Goals of Care Conversations into Standard

Dr. Tim Jessick
timjessick90@gmail.com

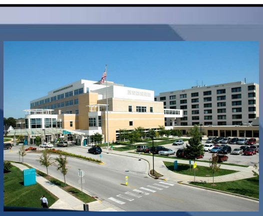
Why is this important?

Truisms

- ✓ The real work of the future is to improve care decisions long before the “terminal” admission.
  - ✓ There will never be enough palliative care specialists.
    - ✓ Improving the work of <u>generalist clinicians</u> is essential to a broad based movement to improve patient-centered care.

Who are generalists?

- Primary Care, Oncologists, Hospitalists, Pulm/CC, Nephrology, Neurology etc.
- Ward/ICU/ED/Clinic nurses
- Unit social workers/DC planners
- Hospital chaplains



SETTING

- Aurora Healthcare
  - Largest health system in Wisconsin/Northern Illinois
  - 16 hospitals
  - 13 hospitals w/ palliative care clinicians/programs
- Aurora West Allis Medical Center (AWAMC)
  - Second largest system hospital - 350 beds
  - Community focused Med/Surg – 140 beds
  - Specialty Palliative Care since 2010

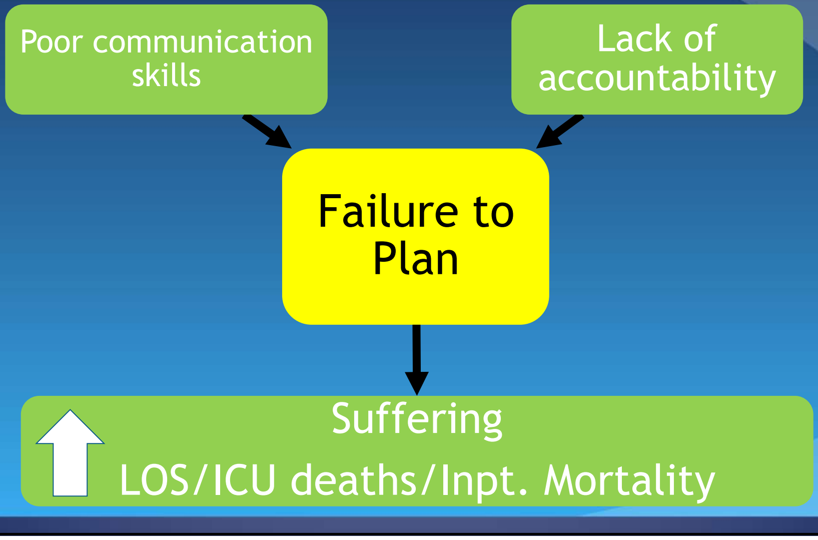
The Burning Platform

- Peer Review Case clusters – deaths associated with failure to plan/rescue/communicate
- Cases of “full code” conversions to “comfort care” within a few hours of death
- High proportion of hospital deaths in ICU
- Low % documentation of Advance Directives or designated HCPOA’s

Mortality Review: 50 charts

- ✓ No screening of patients at high risk for unmet palliative needs
- ✓ Too many ICU deaths
- ✓ Comfort care orders written < 24 hours from death
- ✓ Goals of care discussions not completed early in the stay
- ✓ Advance directives completion poor
- ✓ DNR orders not always followed
- ✓ System failures

What was Broken?



Poor communication skills

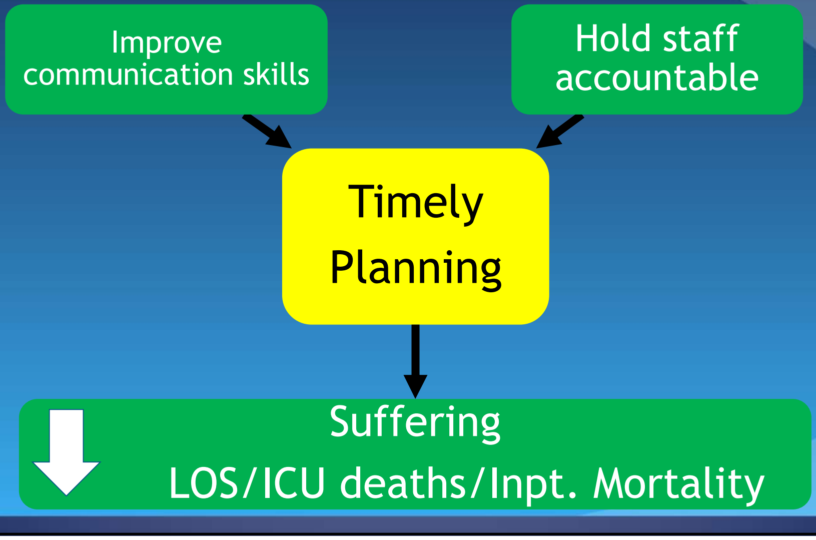
Lack of accountability

Failure to Plan

↑ Suffering

LOS/ICU deaths/Inpt. Mortality

Solution



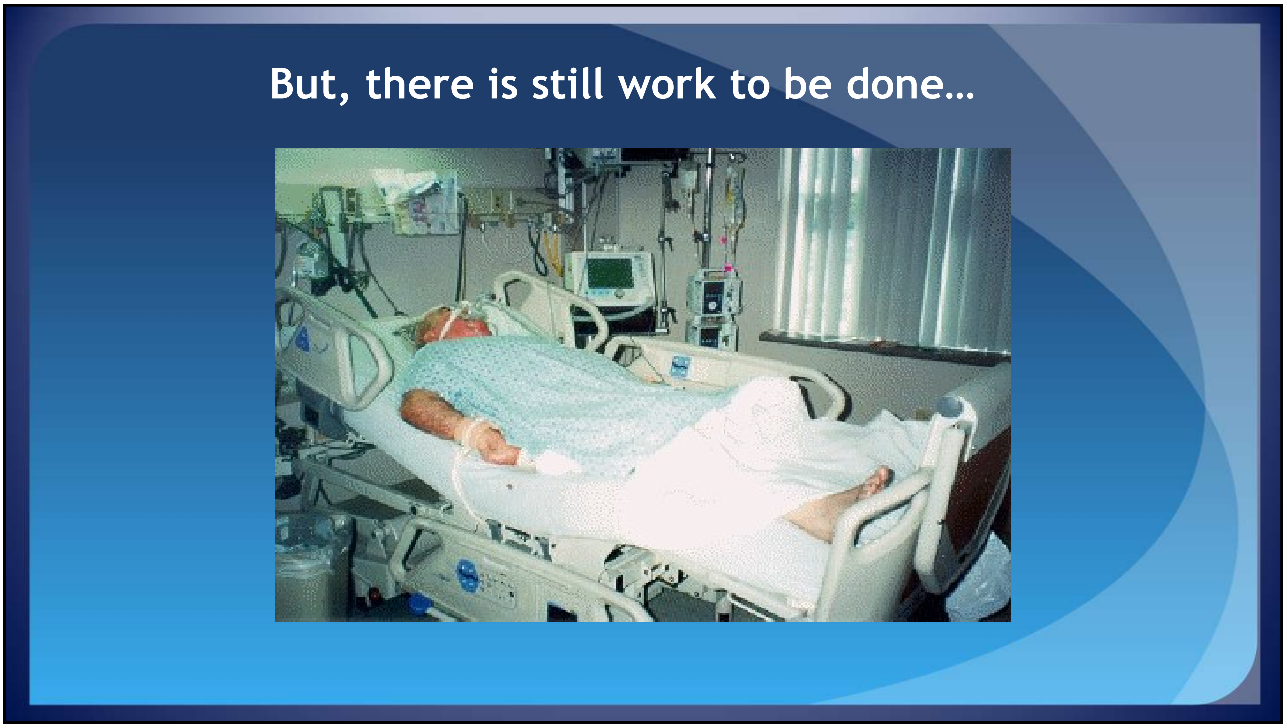
Improve communication skills

Hold staff accountable

Timely Planning

↓ Suffering

LOS/ICU deaths/Inpt. Mortality



But, there is still work to be done…

We Needed a New System!

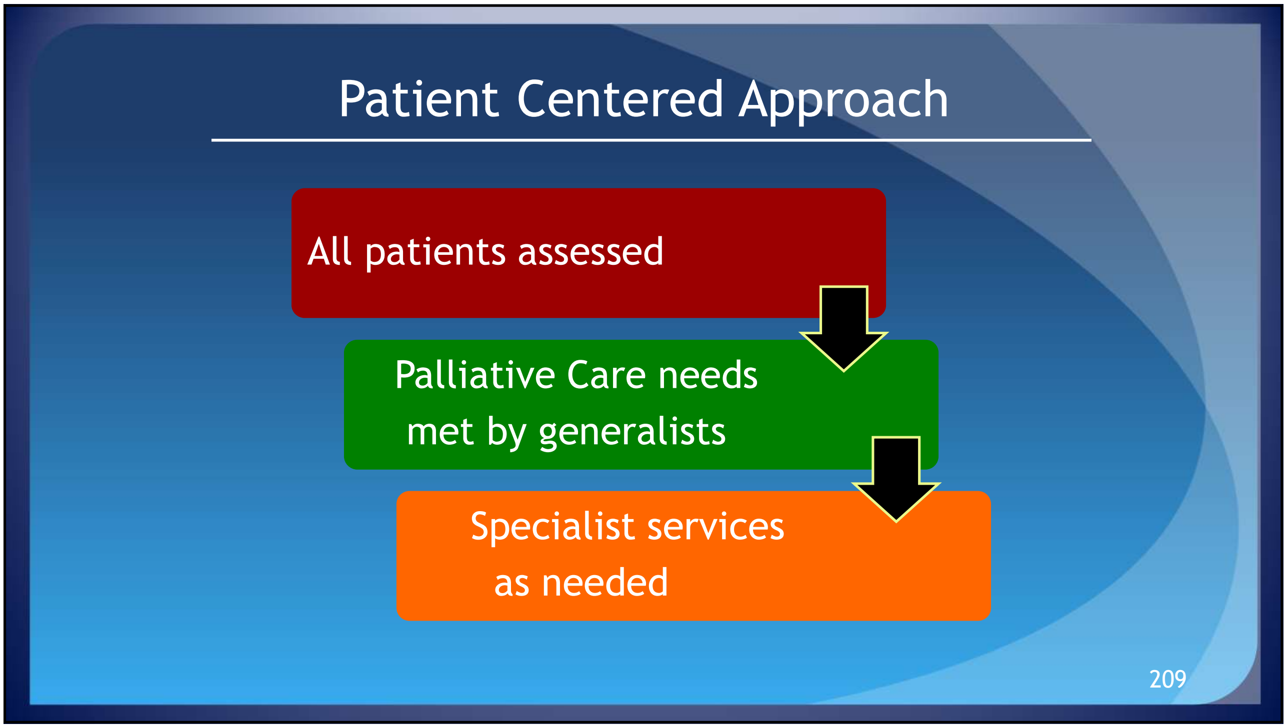
Case Study

- Aurora West Allis Hospital, Milwaukee Wisconsin
- 3 year project to improve care for seriously ill patients
- Goal: Reduce Failure to Communicate, Plan and Rescue
  - ✓ Improve patient satisfaction
  - ✓ Reduce Inpatient Mortality
  - ✓ Reduce ICU deaths
  - ✓ Increase hospice referrals

Is Palliative Care Beneficial?

Key Outcomes:

- ✓ Reduction in symptom burden
- ✓ Improved patient and family satisfaction
- ✓ Reduced ICU days
- ✓ Reduced inpatient mortality and readmissions
- ✓ Reduced health care costs
  - $200-600/hospital day post consultation
- ✓ Survival advantage?



Patient Centered Approach

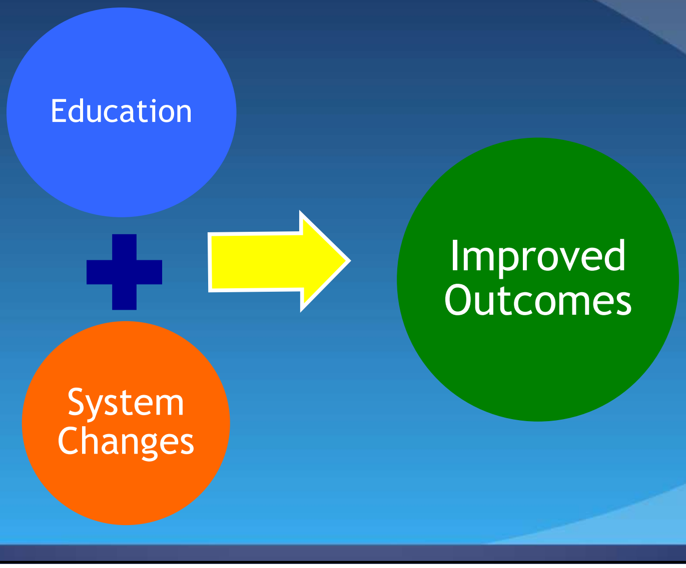
All patients assessed

Palliative Care needs met by generalists

Specialist services as needed

What did we do?

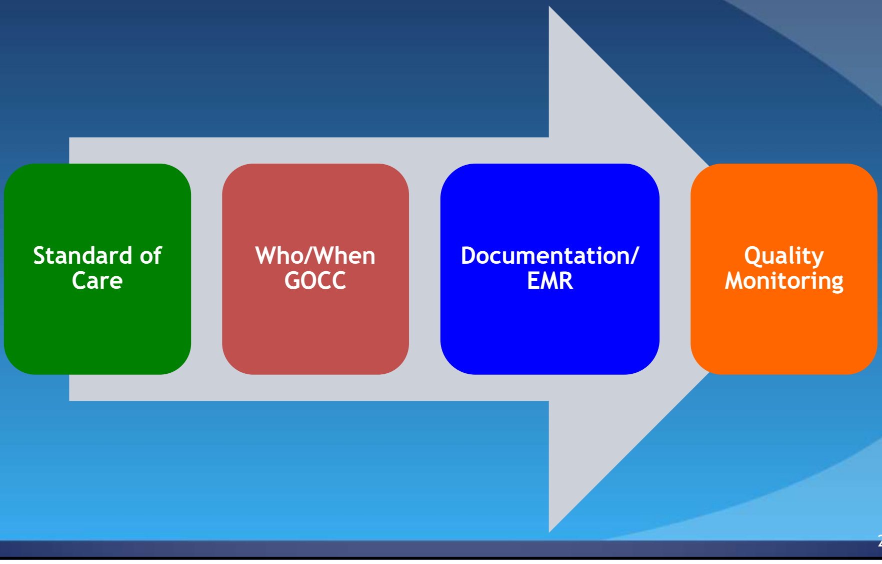
Guiding Principle



What to teach?

- Teaching focused on communication skills for generalists:
  - Primary focus on the *Goals of Care Conversation (GOCC)*
  - ***Supporting information***
  - Goal: not perfection
    - Awareness of personal attitudes
    - Awareness of personal deficiencies
    - Awareness of an organized step-wise approach

Embedding the GOCC into Practice



Standard of Care

Who/When GOCC

Documentation/ EMR

Quality Monitoring

Goals of Care Documentation Example

- **Advance directives:**
  - HCPOA in EMR; Daughter is POA. DNR/DNI; Rationale: Poor prognosis, family preference
- **Decisionality:**
  - Patient Is not decisional
- **Goals of Care:**
  - 85 y/o with DM, dementia and weight loss, with new infection, possibly sepsis; patient very likely to die within 12 months.
  - POA wants to try antibiotics and fluids to reverse infection. Re-evaluate progress and goals with family q24 hours.

Training Principles

- Small group learning environment (< 20)
- Time to discuss personal attitudes that impede communication; cognitive re-framing
- Time to practice different words using role playing
  - Focus on microskills
- Didactic information:
  - ethics and legal issues, advance directives, prognostication.

Training Agenda

Giving Bad News	**Role Play**
Prognostication: cancer and non-cancer factors	Readings/Group discussion
Decision Making Capacity	
Advance Directives: clinical responsibilities/protections	
Informed consent: emergency exception	
Hospital policies	
Family Goal Setting meeting-Part 1	Group Discussion
Family Goal Setting meeting-Part 2	**Role Play**
Conflict management	**Role Play**
DNR/CPR	**Role Play**

Teaching Primary Palliative Care

- Initially trained the Medical Executive Committee members
  - Internists, Surgeons, ED, Cardiology, Ortho
- To Date: >700 hospitalists, ED physicians, specialists, medical students, Skilled Nursing Home APC’s, case managers, CNS’s, CNO, CMO and Director of Quality

Physician Follow-Up

- Two, one hour mentoring sessions
  - Observed goals of care discussions
- Assistance in documentation
  - Implemented goals of care template
- Chart review
  - Looked for presence of and quality of the goals of care notes

January 2014 to June 2015 Analysis

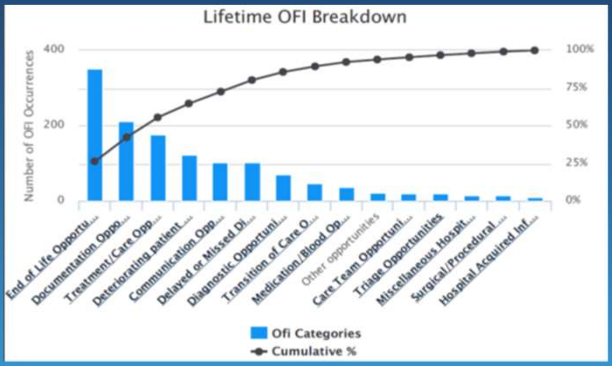
Early Effective ***Goals of Care*** Discussion Improves patient
centered care & In-Hospital Mortality at AWAMC

AWAMC Outcomes: 2013-2015

Mortality Outcomes 2015

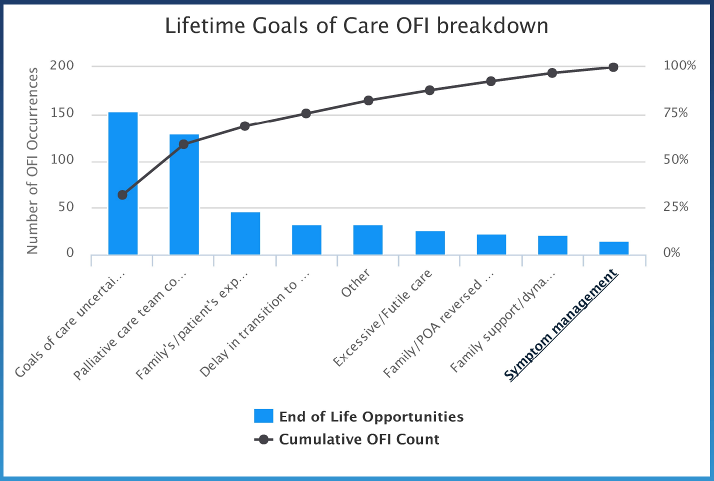
- 30 Day Readmissions - ↓ 7%
- Hospital Deaths - ↓ 27%
- Hospice referrals - ↑ 14%
- Advance Directive completion - ↑27 points
- Restraint usage - ↓ 6%
- Palliative Medicine Consults - ↓9%

System OFI Breakdown



Lifetime Cases
Finalized:
1321

Lifetime
Number of
OFIs: 1336
from 645 cases



AdvocateAuroraHealth

ThedaCare

Waupaca Collaboration

Waupaca Pilot- readmission/mortality reduction/LOS

LAST REV 6/28/2022

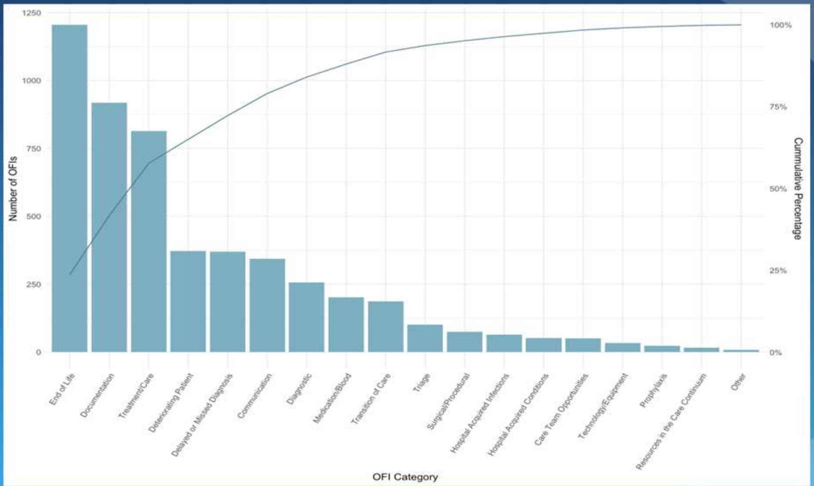
Timeline & Process Measures

TIMELINE:	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec
Convene workgroup	▨	▨	▨	▨								
Establish Baseline Data				☐	▨	▨						
Develop EMR Documentation	▨	▨	▨	▨								
Conduct Provider Clinician Training					▨	▨						
Develop/Test Quality Improvement Plan						▨	▨	▨	▨			
Establish Post Training Outcome Metrics						▨						
Communicate test of change expectations						▨						
Gather Outcome Metrics							▨	▨	▨	▨	▨	▨
Develop plan for training new Clinicians									▨	▨		

Acute Care Pilot Scope: Patients with RED LACE + Score and RED End of Life Index
Process Measure Baseline:

- 65% of patients have and Advanced Care Plan on file at Discharge
- 35% of identified patients have GOCC completed in ACP navigator

Pareto of Opportunities for Improvement (OFIs)



How do we do this?

How do I replicate this here?

- Gather data on the problem
- Form a change committee with C-suite involvement
- Education planning
- Systems change planning
  - Standards
  - Documentation
  - Data
  - Quality improvement
- Mortality review process

Find your Partners

- President of the hospital
- CMO,CNO, Director of Quality
- Risk Management
- Skilled Nursing Facilities
- Medical Executive Committee/Medical Staff

Keys to System Change

- Top down support
- Have Leadership take a communication training course
- The Mortality review process
  - Mortality/Readmissions committee
- Strategic planning
- Data
- Accountability

The Dream Scenario

- Patient centered care is the norm for all patients
- Goals of care are completed and then documented for all appropriate patients in all settings
- Goals of Care Conversations are a credentialing requirement
- Patient care is concordant with their wishes

Thank You!

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www.mypcnow.org

For More Information

http://www.VitalTalk.org

Ariadne Labs – Serious Illness Conversation Guide

Fast Facts – www.mypcnow.org/fast-facts

CAPC

HPNA

AAHPM

Stanford Palliative Care

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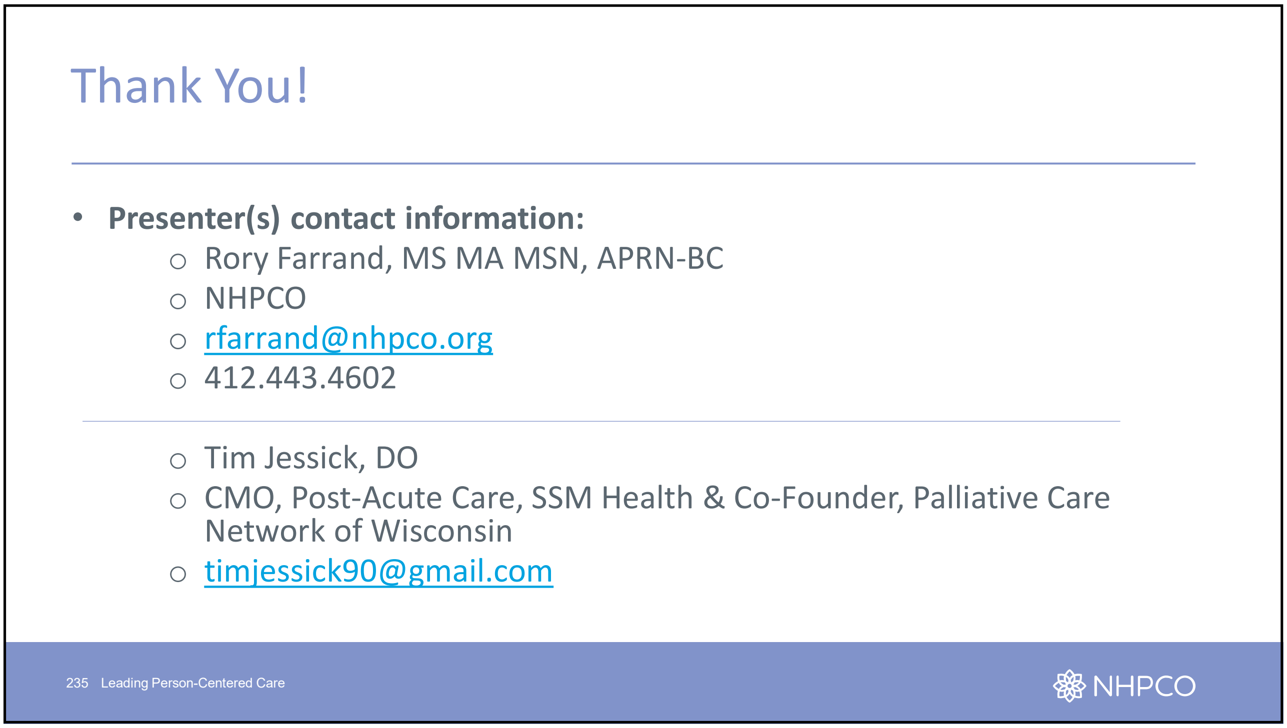
Questions



Thank You!

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