BUILDING CONFIDENCE AROUND END-OF-LIFE MANAGEMENT

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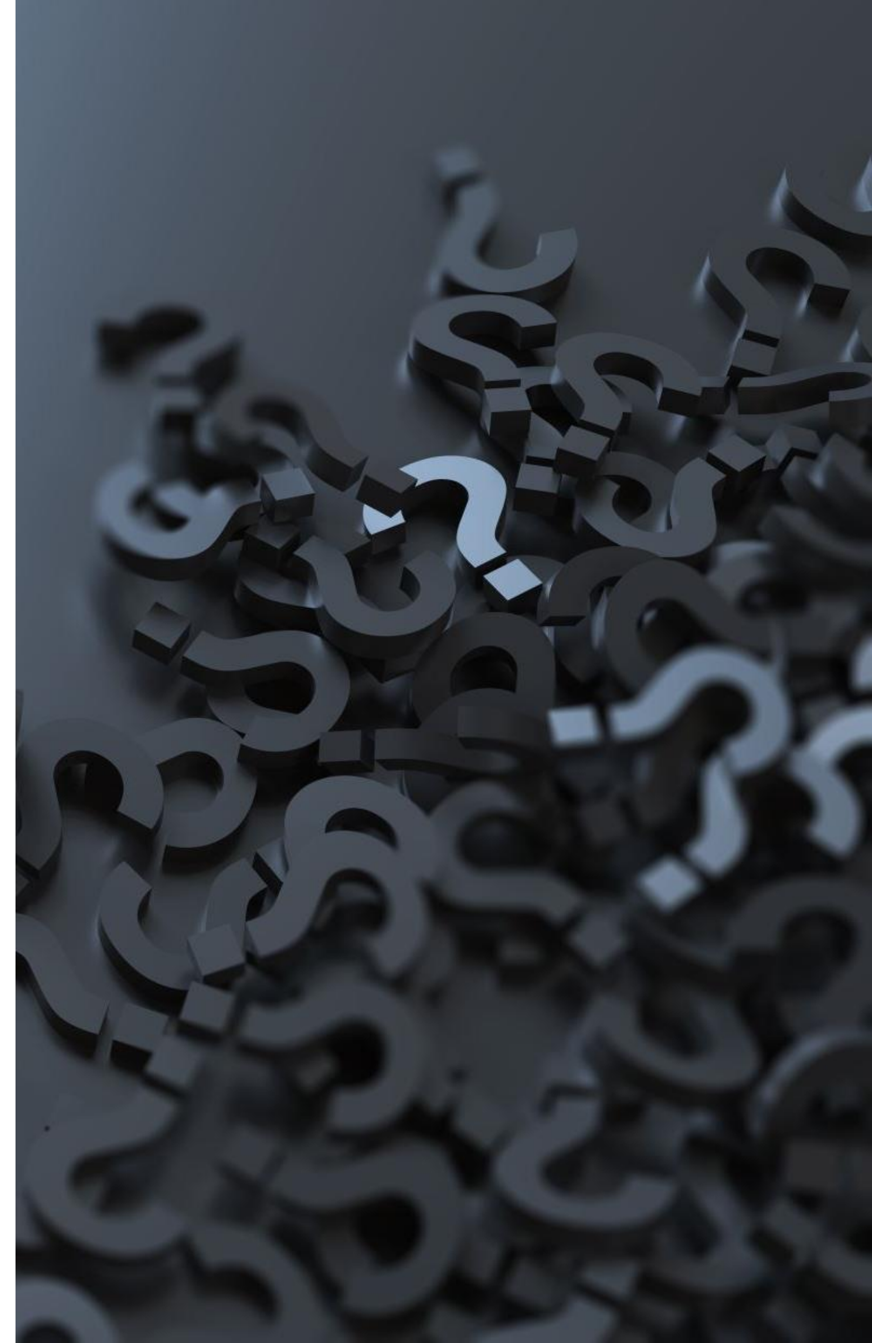
DISCLOSURES

NO RELEVANT COMMERCIAL RELATIONSHIPS TO DISCLOSE.



LEARNING OBJECTIVES

At the end of the session participants should be able to

- Estimate prognosis for the seriously ill patient
- Conduct serious illness conversation using the SPIKES model
- Make a medical recommendation about serious illness care
- Feel more comfortable with end-of-life medication options and caring for the actively dying patient

CASE STUDY

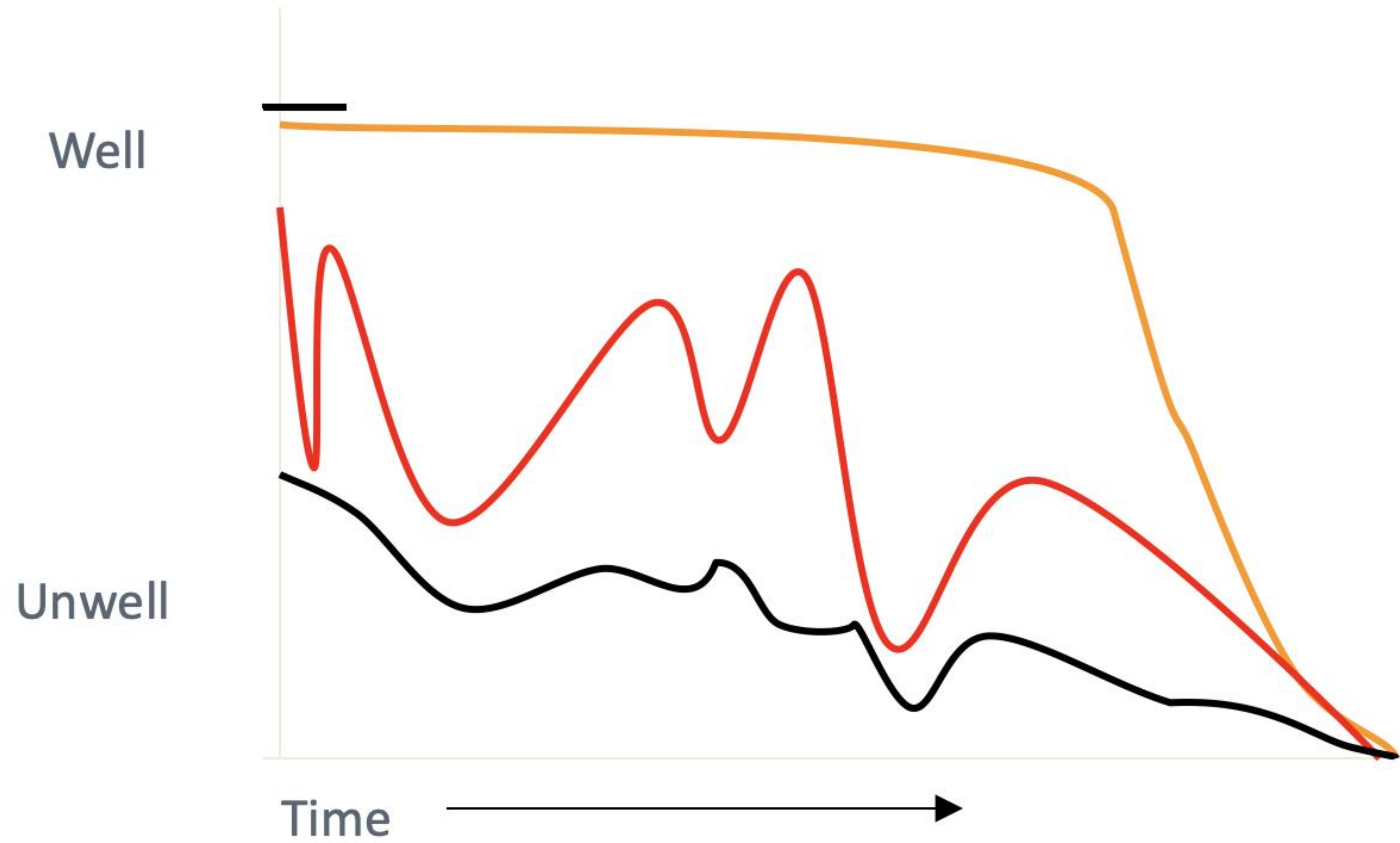
- 85 yo F w/HFpEF, CKD III (GFR 35), COPD (Gold C), DM2, MCI able to live at home with her husband, perform her ADLs but not financial management or driving (no IADLs). Presents with acute SOB and hypoxia to 80% requiring 4L. COVID and flu neg and pro-calcitonin high. CXR w/RLL consolidation.

PROGNOSTICATION

- Rate of Change over time
  - Patients changing in weeks have weeks → days have days → hours have hours.

- Not getting better in the acute care setting = getting worse.

EOL TRAJECTORIES



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.

COVID SPECIFIC NOTES…

Discussing potential decompensation in the face of a disease that is difficult to prognosticate around is HARD.

- Highly functional older patients are potentially not going to be accepting of how ill they can get.
- While most patients > 70 and certainly > 80 do not do well if they require the ICU due to COVID PNA, we have seen a few survive post IPR discharge to go home.

Regardless of COVID, an 80 yo patient w/comorbidities and respiratory complications requiring ICU level care is unlikely to go well.

SPIKES COMMUNICATION TOOL

- The Oncologist. 2000;5(4):302-11.

S	**S**etting up the interview
P	Assessing the patient’s **p**erception
I	Obtaining the patient’s **i**nvitation
K	Giving **k**nowledge and information
E	Addressing **e**motions with **e**mpathy
S	**S**ummary and plan

WHY ARE THESE CONVERSATIONS SO IMPORTANT?

It is a procedure and as delicate as performing one.

These conversations heavily influence the patient's decision making.

It can be a traumatic event.

It impacts the overall physical and emotional well being of the patient and their family.

Compassionate delivery can decrease anxiety & depression

CASE STUDIES

72 yo M w/CHF NYHA IV, COPD (D), HTN, DM and this is his 3rd admission in 3 months for mixed CHF/COPD exacerbation. New Dx of PNA w/RLL consolidation and desaturations to 85% corrected with 4L O2. On 2L O2 at baseline. He is lethargic, febrile and hypotensive.

64 yo F w/metastatic colon cancer to liver and now admitted w/SBO 2/2 to peritoneal carcinomatosis. She has recently started falling at home and is now spending > 50% of the day in bed. BMI now 18 down from 24 3 months ago. She has been discussing enrolling in a clinical trial with her oncologist.

S: SETTING UP THE INTERVIEW

- Schedule a time that all the important players can be present if possible and have seats, space, etc.
- Introduce everyone present and ask permission to speak in front of all present.
- Sit down.
- Be present: Remember only 7% of communication is verbal.

REMEMBER THIS MAY BE THE WORST DAY OF THEIR LIFE AND THEIR ABILITY TO PROCESS INFORMATION IS NOT IDEAL.

P: ASSESSING THE PATIENT'S PERCEPTION AND GOC

- Determine what the patient and family know.
  - "I have read your chart and discussed your case with your other providers. But would you mind telling me in your own words what you understand about your illness and where we are right now?"
  - "Tell me about your loved one and what is important to them."
- Assess for Level of Understanding
  - "What do you understand about how sick your family member is?"
  - "What have the doctors said about your condition?"
  - "Has anyone explained what this latest problem might mean for you?"

P: ASSESSING FOR PERCEPTION OF GOC

Have the family tell the story of the decline themselves: "What was the patient able to do 9 mos, 6 mos and 3 mos ago?"

"What are you worried about?"

"What are you hopeful for?"

"Tell me more about that."

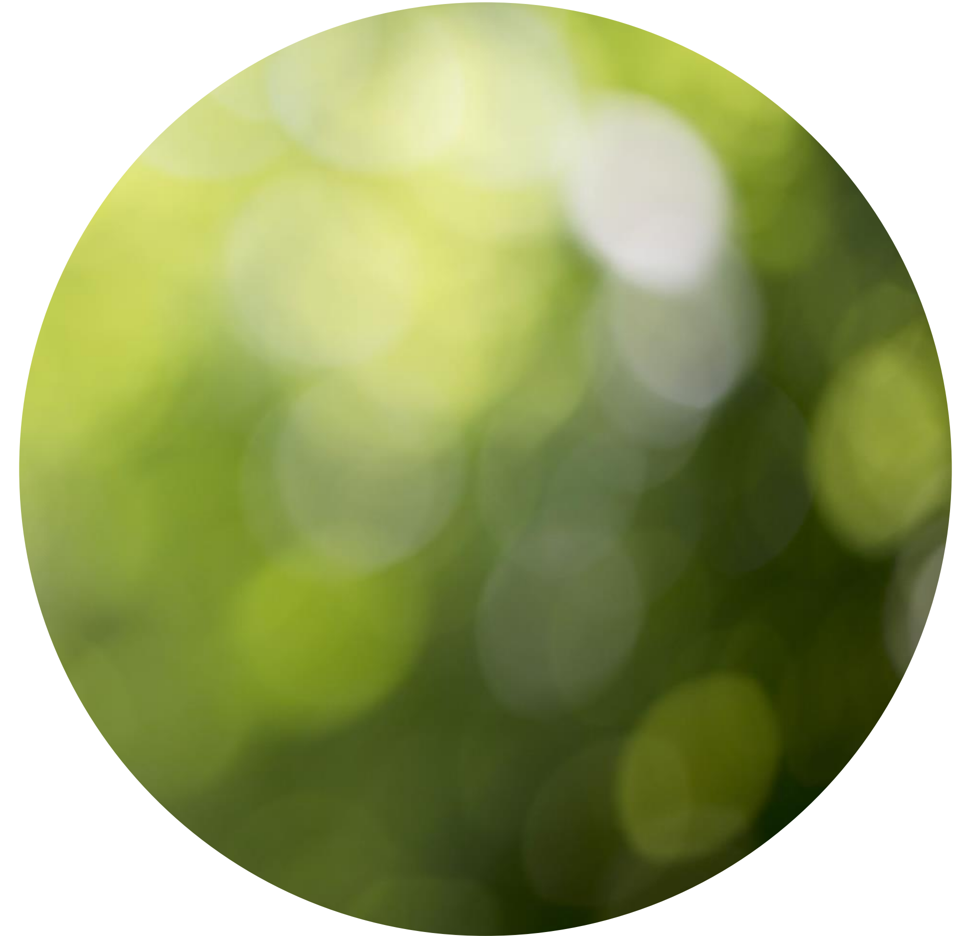
I: OBTAINING AN INVITATION OR ASKING PERMISSION

Ask permission to share a medical opinion

“May I share some information with you?”

"Would you like to know some specific information about where we are?"

"How much would you like to know about your prognosis?"



K: SHARING KNOWLEDGE

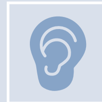
Educate	Educate: Tell the family in clear and simple terms what you understand to be the current state of the patient’s illness and prognosis.
Give	Give information in small chunks.
Observe	Observe how the family is digesting the information.
Check	Check for understanding: "Does that make sense?"

MODELS FOR SHARING INFORMATION

- Hope-Worry-Fear
  - "I am hopeful your father will improve and recover from this pneumonia, but I am very worried about how sick he is. With his chronic illnesses, frequent recent hospitalizations and now this PNA, I am fearful he may not recover from this illness."
  - "I am hopeful we will be able to manage this obstruction and it will not continue to get worse, but I am very worried that we will not be able to. Also given your weight loss and how fatigued you are. I am very fearful you will not get better enough to be eligible for more cancer therapy.
- Assess for understanding: "Is that surprising for you to hear?"

E: ADDRESSING EMOTIONS WITH EMPATHY

Your ability to empathize is the single most important part of delivering difficult news.



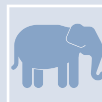
Expect an emotional reaction

Observe, identify, acknowledge and allow expression.

Utilize active listening and reflection.

"Tell me more about that."

Silence is golden



Acknowledge, normalize and validate: Calling out the elephant in the room.

"This is so hard to hear."

"None of this is what you wanted to hear."

Avoid "I" statements

SUGGESTING A PLAN = MAKING A MEDICAL RECOMMENDATION

- "Given what you have told me about his QOL goals combined with how sick he is, I recommend that we continue to support him as we are now with oxygen and antibiotics, but If he gets sicker I do not recommend we transfer him to the ICU and if his heart stops beating and he stops breathing, we should allow him to have a natural death. If what we are doing does not help him in the next few days we should meet again and discuss the plan further."

- "In thinking about next steps – I would recommend we get you more help at home. You need that in the form of symptom management, equipment and also having someone to call so you do not have to come back to the hospital. This next best higher level of care is called hospice… What do you know about hospice?"

CYCLING BETWEEN K AND E

- "Is that surprising for you to hear?"
- "Does that make sense?"
- "Tell me more about that."

S: SUMMARY AND PLAN

Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

SET UP

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"

ASSESS

"What is **your understanding** now of where you are with your illness?"

"How much **information** about what is likely to be ahead with your illness would you like from me?"

SHARE

"I want to share with you **my understanding** of where things are with your illness..."

Uncertain: "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility."

OR

Time: "I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ *(express as a range, e.g. days to weeks, weeks to months, months to a year)*."

OR

Function: "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."

EXPLORE

"What are your most important **goals** if your health situation worsens?"

"What are your biggest **fears and worries** about the future with your health?"

"What gives you **strength** as you think about the future with your illness?"

"What **abilities** are so critical to your life that you can't imagine living without them?"

"If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?"

"How much does your **family** know about your priorities and wishes?"

CLOSE

"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your treatment plans reflect what's important to you."

"How does this plan seem to you?"

"I will do everything I can to help you through this."

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MAKING A MEDICAL RECOMMENDATION OR OBTAINING "INFORMED ASSENT"

ETHICAL PRINCIPLES: AUTONOMY VS. BENEFICENCE, NON-MALEFICENCE AND JUSTICE

Autonomy: Patients have the right to refuse care, but they do not have an unqualified right to demand care.

Beneficence: providing help and benefit to the patient

Non-Maleficence = Do no harm

- Hippocratic corpus, The Art: "Whenever a man suffers from an illness, which is too strong for the means at the disposal of medicine, he surely must not expect that it can be overcome by medicine."
- The ancient Greek healers suggested that among the 3 goals of medicine was the refusal to treat those "overmastered by their illness," and patients were warned not to ask healers to attempt that which was impossible to medicine.
- To attempt a futile treatment is to display an ignorance that is "allied to madness."

Justice: being a steward of the appropriate use of healthcare resources

TYPES OF FUTILITY = MEDICALLY INAPPROPRIATE CARE

- Brain Death
- Physiologic Futility
  - The intervention cannot achieve its purpose
- Quantitative Futility
  - Percentage Measures
  - Standard of Probable Effectiveness
- **Mediated Futility: Disease progression will render the treatment futile over time for the stated goals of treatment**
- Qualitative Futility
  - Shift from asking if the treatment can obtain the GOC to questioning the appropriateness of the goals
  - 3 Forms
    - (1) Risks > Benefits
    - (2) Benefits are not worth the required resources
    - (3) treatment cannot provide the patient a quality of life worth living, i.e., provider perception the patient cannot appreciate the benefit of the tx or it does not support reasonable tx goals.

NAVIGATING MEDICAL INAPPROPRIATENESS AND INEFFECTIVENESS: MAKING A RECOMMENDATION

The law is the fence on the baseball field. We would prefer to catch the ball in the outfield rather than needing the fence to stop it.

To do that, medically ineffective care at the EOL needs to be conceptualized and communicated as such. The appropriate care is then offered as a recommendation or you seek to obtain "informed assent."

INFORMED ASSENT

- "By informed assent, we envision a process in which clinicians provide full information about the risks and benefits of treatments, convey specific recommendations about the medically proposed course, and clearly indicate that the patient and family are entitled to defer to the clinicians' judgment. As an abstract matter, this is no different from the conventional conception of informed consent: a fully informed patient or family surrogate can always make an affirmative choice to accept clinicians' recommendations. But as a psychological proposition, informing the patient or family surrogate that they are entitled to accept those recommendations can convey to them the information that the clinicians are prepared to relieve them of unwanted burdens of making life-or-death decisions."

CHEST® JOURNAL

EDITORIALS POINT/COUNTERPOINT EDITORIALS | VOLUME 132, ISSUE 3, P748-751, SEPTEMBER 01, 2007

Point: The Ethics of Unilateral "Do Not Resuscitate" Orders

The Role of "Informed Assent"

Curtis J. Randall, MD, MPH, FCCP • Burt Robert A., JD

DOI: https://doi.org/10.1378/chest.07-0745

"CHOICE ARCHITECTURE"

- The way you choose to frame and present ACP choices influences what people choose.
- 2016 Study from Anesi & Halpern. *Choice architecture in code status discussions with terminally ill patients and their families*
- Patients given 3 different versions of an ACP document
    - Standard
    - One with a comfort default and an opt out
    - One with a full care default and an opt out
- Patients then followed up to let them know about the different versions and most all stayed with original choices

MAKING A MEDICAL RECOMMENDATION IS NUDGING… BUT THAT'S OK

You are an "architect of decision making" as a provider. You are an expert in a point of power making recommendations in a way that will influence decisions. You are not and cannot be neutral and that's ok.

What is imperative is to make sure you are being thoughtful about assessing goals and the way you present information.

PUTTING IT ALL TOGETHER

- 85 yo F w/Alzheimer's Dementia (FAST 6E down from FAST 5 in 11/2020) with acute decline in the last 3 months. BMI in 11/2020 was 24 and now is 18. She is eating 25% of her meals and was eating 75% in 11/2020. She has required hospitalization x2 for cystitis with fever and failure to thrive and is now admitted for aspiration PNA. She has fallen x2 and is now spending > 50% of the day in bed and in 11/2020 was out of the bed most of the day. She has a Stage III pressure ulcer on her buttock. She has had increasing agitation and pain requiring increasing use of antipsychotics and opiates.

- Establish what functional status and QOL are important to the patient and whether the therapy being offered will help achieve that goal.
- Use HOPE-WORRY-FEAR to help communicate your recommendations
- ”I hear from you that it was very important to your mother to be able to live independently and participate with the grandchildren. I am hopeful she will continue on as she is and start to improve. But I am very worried if she becomes sick enough to need a higher level of care, she would likely not survive to discharge and I am fearful if she did, it would not be to live independently at home again.”

YOU WANT TO HELP THE FAMILY GET THE CARE THEY NEED TO GET TO THE QOL THEY WANT.

MAKE YOUR RECOMMENDATION AND OFFER MEDICALLY EFFECTIVE CARE

Given what we have discussed and having heard what is important to her, I would recommend that we do everything we can with oxygen and support where we are, but I do not recommend transferring her to the ICU.

I also would recommend if her heart stops beating and you/she stops breathing despite all the support we can give her, we allow a natural death.

I am concerned she is uncomfortable now and I would like to add some medicines to help make her feel less short of breath.

GOC: DISCUSSIONS WITH OTHER PROVIDERS

- Part of a GOC discussion process is having the conversation with other providers and helping specialists support the process.
  - When you know the ICU transfer is not going to result in a patient who will go home to live independently, and that is the goal, but the family says do everything…
  - The conversation with the ICU can be asking for a specific answer
    - ”I am going to go speak with the family about their decompensating loved one. My assessment is an ICU transfer would not change this outcome given how frail the patient is. I wanted to ask if you agreed with my assessment and see if you had anything to add or specific reasons/data I might bring with me to the conversation with the family."
- The Goal
  - To engage the specialist to help support the recommendation so you neither own it 100% nor are you giving it away to someone else. It is a shared message by the team.
  - It also gives the specialist the opportunity to say they will take the patient.

SETTING EXPECTATIONS FOR YOUR SELF…

- The goal is not to achieve a specific outcome like DNR or no ICU escalation. The goal is to have an informed conversation w/the patient or family to ensure they are aware of the risks and the care is aligned w/the desired outcome.
- Most of these conversations will go well. You will remember the ones that do not and that anecdotal bias can cloud our perception of how valuable having these conversations is.
- Often death is for the living. The family has to survive with the knowledge of how their loved one died and escalation may be what they need.

REMEMBER TO REMEMBER

- Many patients and families remember more about how difficult information was communicated than anything else about their care.
- Be calm, present, compassionate and clear.
- Be open, honest and empathetic.

CARING FOR THE PATIENT TRANSITIONING TO COMFORT

DIAGNOSING DYING

- Rearranging deck chairs on the titanic
    - Fixing one problem only to cause another one…
- I have fixed “all the things”…
    - This is usually a case of poor initial functional reserve and the body could not tolerate the acute illness even if the acute problem has resolved.
- Signs and symptoms
    - Irreversible delirium = Terminal Delerium
    - Hypotension, decreasing UOP, tachycardia, mottling of the skin, cool extremities, irregular breathing, palor
- Rise above the trees and see the forest

Symptom	First Line	Second Line	Third Line
Pain	opiates	Steroids (dexamethasone)	Neuropathic agents, ketamine, lidocaine
Dyspnea	opiates	Ativan w/opiate	Cool fan
Agitation/ Terminal Delirium	Treat pain and dypsnea	Haldol	Ativan
Secretions	Robinul	Scopolomine patch	Levsin, atropine
Nausea	Haldol	Phenergren, compazine	Ativan, steroids

SYMPTOM MANAGEMENT AT EOL

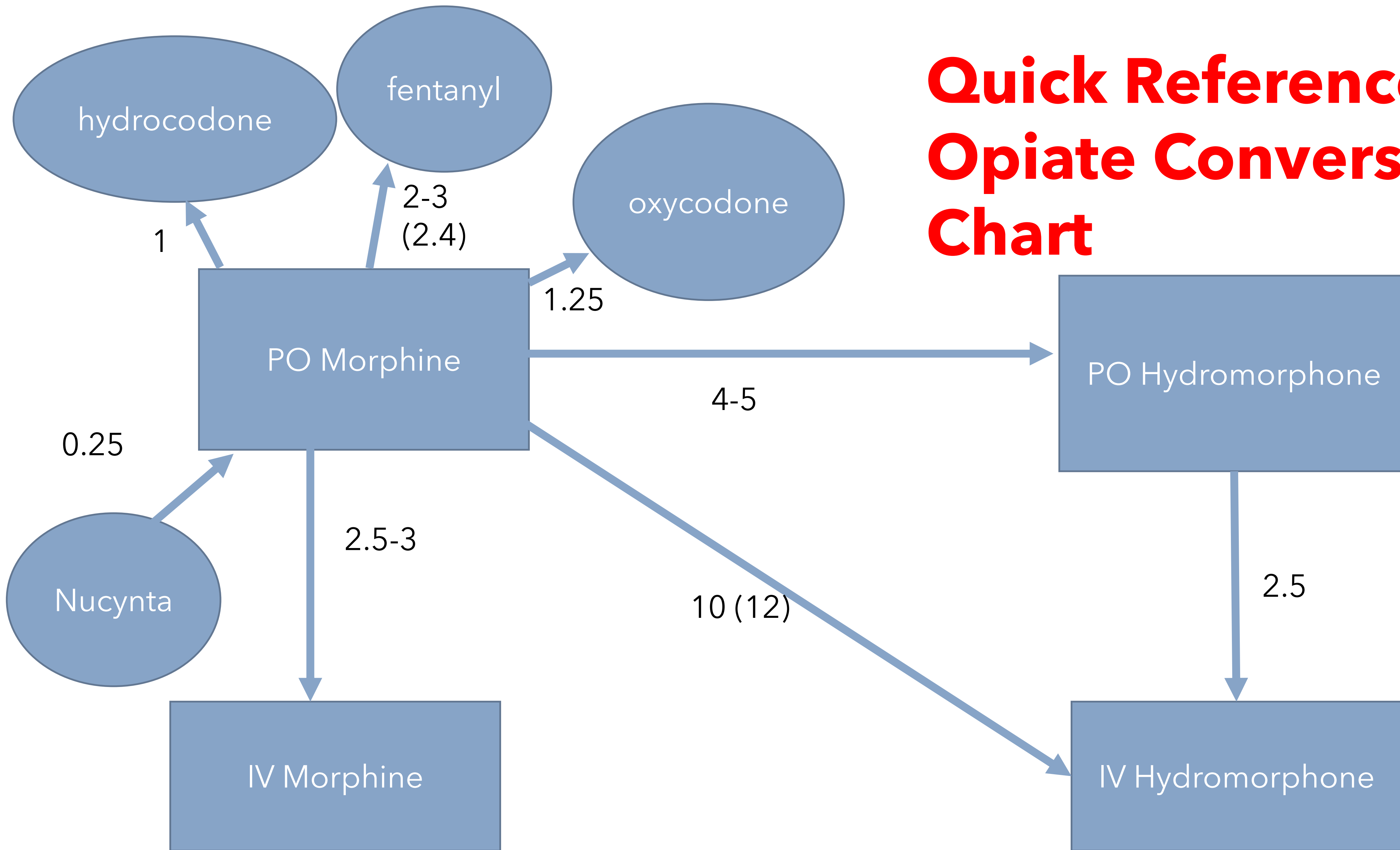
Symptom	Agent	Initial Dosing	Escalation
Pain	IV or SQ Morphine IV or SQ Hydromorphone Liquid Morphine (Roxanol) *Time to onset is 5-10 min for IV and 30+ min for PO; PO has a longer half life	2-4mg q1-2 hr 0.5-1mg q1-2hr 5mg po q2-3h	- Ask if it is not working or not lasting long enough - Add up what they have had over time to decide on dose increase. - Can increase dose and decrease interval.
Dyspnea	See Pain above; write PRN order for pain or dyspnea		
Agitation	IV or SQ Haldol IV Ativan	0.5-1mg q1-2h 1-2mg q1-2hr	- Can give together - Can double dose to increase at q15-q30min intervals
Secretions	IV or SQ Robinul Scopolomine patch Levsin	0.4mg q6h Apply patch q72h 0.125-0.5mg po q4h (crush and slurry)	
Nausea	IV or SQ Haldol Phenergen, Compazine, Zofran Benadryl/Ativan/Dex (BAD) pump	0.5-1mg q6h call pharmacy	

OPIATE CONVERSION TABLE (2018)

Drug	Parenteral	Oral
Morphine	10	25
Codeine	100	200
Fentanyl	0.15	N/A
Hydrocodone	N/A	25
Hydromorphone	2	5
Oxycodone	10	2
Oxymorphone	1	10
Tapentadol	N/A	100
Tramadol	100	120

McPherson, Mary Lynn. Demystifying Opioid Conversion Calculations: A guide to effective dosing, 2nd Edition. 2018.

Quick Reference Opiate Conversion Chart



WHAT ARE THE OPTIONS IF WE DO NOT ESCALATE CARE?

Non-escalation

- Adding comfort meds but not stopping anything else.
- "We will continue doing exactly what we are doing to support the patient, but if they get worse, we will not be transitioning to the ICU and if their heart stops and they stop breathing we will allow them a natural death."

De-escalation

- Peeling off somethings but keeping others.
- "We will stop some unnecessary medications and things that are just causing a burden right now and not changing the overall prognosis."

Transition to Comfort

- "We are going to change around the medications for your loved one to focus on the ones that will help them the most right now and keep them comfortable. We will be decreasing the oxygen some too as tolerated and eventually stop it."
- Make sure comfort meds are on board before removing O2

USING MORPHINE AND O2 TOGETHER

- Leaving the O2 and adding morphine = non-escalation.
- Consider stopping po meds the patient cannot take.

- If you want to bring up de-escalation, focus on "quality awake time."
  - "I do not want to change anything about your loved one's oxygen at this time because they are still having some good awake time with you. However, if they are no longer waking up we can discuss decreasing or stopping the oxygen."

- **Note:** Leaving on the O2 will prolong the dying process, so it is worth considering stopping in the right circumstance.

CASE STUDY

- 85 yo F w/HFpEF CKD III (GFR 35), DM, MCI and RLL PNA, DNR/DNI after your discussions and now on 15L nc. Nursing reports she is tachypneic to the 30s, tachycardic to 120 and grimacing.

  - Symptoms to address: dyspnea, pain and agitation
  - Ask about baseline opiate usage so you know where to start
    - i.e., 10mg Lortab PRN = 10mg morphine = 3.3mg IV morphine; reduce for cross tolerance so can start at 2mg IV morphine
  - Order
    - 2mg IV morphine q30 min for pain or dyspnea
    - 0.5mg IV Ativan q30min for agitation

CASE STUDY CONTINUED

- Nursing calls back in 2 hours and says she has had 3 doses of morphine and 2 doses of Ativan and it helps some but doesn't seem to be working as well as it could.
  - Increase to 4mg morphine and 1mg Ativan
  - Add IV Haldol 0.5mg q1h

- Nursing calls back in an hour and has given 2 more doses of each with good effect but now the patient is asleep and they are worried about their respiratory status.
  - Provide reassurance

THE GOAL = TITRATION TO COMFORT

- The goal is to get the patient resting comfortably.
- It is very possible this will result in them being asleep for the remainder of their life.
- That is OK!! It is titration of the medication to comfort. It is not…
    - Palliative Sedation
    - Physician Assisted Death

- Principle of Double Effect
    - It is highly unlikely you will hasten death with titration to comfort.
    - However, even if you hypothetically did, it is still ethically sound because the intention is to relieve suffering and that good intent outweighs potential harm.

ADRENERGIC RESPONSE AT EOL

You will hear families say that the "dose of morphine killed" the loved one because when the patient finally became comfortable they passed away quickly.

We think this may be because the adrenergic tone was high when they were uncomfortable, but when their suffering was relieved, the tone decreases and they pass peacefully.

You can actively make it a point to address this with nursing and families.

- "It is possible that once we get your loved one/patient comfortable they may pass quickly. This is normal and because their body cannot keep up any more. It is not because of the medication, but because they are no longer struggling."

TAKE HOME POINTS

Prognosis is rate of change over time. Its important to see the forest for the trees.

Communicating difficult news in serious illness is about providing space and empathy.

Patients and families appreciate your candor and want a medical recommendation.

Medications at the end of life are treatment and the most compassionate treatment.

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