

GOALS OF CARE DISCUSSIONS DURING COVID-19: TALKING ABOUT WHAT EVERYONE IS FINALLY TALKING ABOUT

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Learning Objectives

- Define goals of care
- Understand why goals of care and code status discussions are perhaps more important now than ever before
- The conversations don't have to be long or difficult
- Ensure comfort and control
- Develop scripts for discussions with patients and families
- R.E.M.A.P.: an adaptable framework for having difficult discussions with patients and their family members
- Identify appropriate patients to target for these conversations



 Which patients are at the highest risk of death from COVID-19?

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- Patients with rapidly progressive symptoms



- What does REMAP stand for?
- A. Relay information, Elevate, Map out goals, Align, Propose Plan
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- **B.** Specialists
- C. Emergency Physicians
- All health care providers share this important responsibility



The case – Rose Johnson

- A 78 y/o female with HTN, DM, and CHF presents to the ED with four days of fever, shortness of breath, and myalgias. Her vitals are BP 112/74, HR 106, RR 22, T 100.8, and O2 sat 86% on room air, improved to 95% on 3 L. She has mild increased work of breathing and bilateral patchy infiltrates on CXR. Her rapid COVID-19 test is positive, and she is being admitted to the medicine floor.
- She currently has the capacity to make her own medical decisions. She does not have a POA listed.



Asking about code status

- The old way: "If your heart stops or you stop breathing, do you want us to push on your chest to restart it and put a breathing tube in to breathe for you?"
- "...or do nothing and just let you die?"



A BETTER WAY

A script for starting the conversation with high risk patients



A sample Script

- I want to talk with you ahead of time about how COVID might affect you
- This is a very difficult conversation, and I don't mean to scare you, but I think it's an important conversation to have
- What we know from our experience in taking care of patient's with COVID, is that because of your age group and medical problems, there's a high risk that if you need life support or a breathing machine, that things won't go well
- Depending on what you read, up to 80% of people who die from from disease are in same category you're in
- We're going to continue doing everything were doing
- We're going to support you and take care of you no matter what
- Ensure you are as comfortable as you can be



Script, continued

- But if something catastrophic does happen, our ability to have success with things like CPR at the time of your death is minimal
- At this point, its not something really that we normally recommend, as it's not something that we think will be successful in letting you to continue live in a way you'd like to
- If you have trouble or your breathing starts to fail, we will care
 for you and give you oxygen, but if we have to put tube down
 your throat and into your lungs and attach you to life support,
 we know that people who need that generally haven't done
 very well in terms of survival.
- In fact, very few have survived, and many have been younger or without medical problems
- So if it's okay, I'd like to talk with you about what your preferences are
- This will let you have more control over what happens to you

Goals of care, defined

- Aims for a patient's care, as agreed upon between the patient, POA/family members, caregivers, and healthcare team
- Sometimes narrowly defined
- Covers many steps in healthcare decision-making, including decisions about specific treatments, code status, the intensity of care, and planning for future care needs (advanced care planning)



Background

- For the first time in recent history, hospital systems and states scrambling to develop protocols to allocate scare resources and ration ventilators
- Scare resources
 - Ventilators/hospital beds
 - ICU and medicine staff, RN's, RT's
- Once intubated and in ICU, often "full court press"
- Luckily most regions have not had to enact these protocols, though as states reopen the effect on health care systems is difficult to predict



But first, ask!

- We should be asking patients what they want well before we make rationing decisions that effect life and death
- Allow patients and family members to make informed decisions about their care
- Win-win-win:
 - Provide goal-concordant care
 - Decrease hospital resource utilization
 - Decrease decision-making burden on family
 - Maintain resources for patients who want and would benefit from them



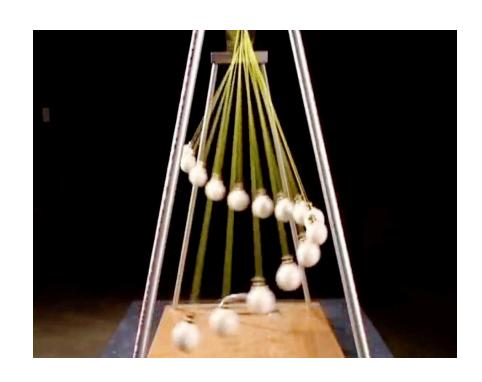
Why now?

- Ventilators and end of life care are being discussed much more in the popular media and at home
- Patients more open to discussions
- Eliciting patient values before intubation decreased family-member guilt and allows them to follow wishes
- For most, there are many existences worse than death
 - E.g., permanent ventilator dependence with poor mental status in an LTAC



The Intubation Pendulum

Intubate early and often



Awake proning

Happy hypoxemics



COVID Patient Outcomes

- Patients 64 and older with COVID-19 in Italy had double the mortality of younger patients (36% vs. 15%)
- In Seattle, 50%+ of intubated patients died, though researchers noted this was likely an underestimate (Bhatraju, 2020)
- In Wuhan, 66% of ventilated patients died (Wu, 2020)
- Of 388 patients in London who received advanced respiratory support, 84% died (ICNARC)



Risk factors for death

- Age: Death from ARDS was more likely to occur in those of older age ≥64 years (hazard ratio [HR] 6.17; 95% 3.26-11.67)
- Need for intubation
- Comorbidities (e.g., cardiac and pulmonary conditions, HTN, diabetes, CKD)
- Markers of inflammation or coagulation (e.g., D-dimer, INR)
- Select laboratory studies (e.g., worsening lymphopenia, neutrophilia)



There's a lot more to life than death

- Death is a small piece of the picture
- Long-term outcomes are unclear
- PTSD
- Critical care neuromyopathy
 - Higher in COVID due to prolonged intubation, higher use of paralysis and sedatives
- latrogenic opioid dependence > Rush methadone protocol
- Post-intensive care syndrome (PICS): impairment in cognition, mental health, and physical function
- PICS-F: adverse effects on mental health of family members
- Trach/PEG/LTAC



Visitor Restrictions

- To protect patients and staff
- Family members making life and death decisions without being able to see or talk with their loved ones
- The ultimate fear: dying alone
- A view through the window
- Without full information, decisions might be different and more aggressive
- Videochat/Webex family conferences



Who to ask about code status?

- Everyone!
- Especially if above the age of 65 with medical comorbidities
- They can occur anytime
 - At home
 - With family members
 - Video visits/telemedicine
 - PCP
 - Specialists
 - ED
 - Long before infected with COVID
- These conversations simply do not seem to be happening

A weird world

- You can't insist on getting Tylenol, but you can insist on CPR?
- Unilateral DNR policies



BACK TO ROSE



Case Continued

- Unfortunately an informed goals of care conversation did not occur (or was not documented) with Rose
- On hospital day 3, she starts decompensate, loses capacity and is transferred to the ICU



A SCRIPT FOR FAMILIES



ED CODE STATUS CONVERSATION GUIDE

Goal: Identify patients who **PREFER** symptom/comfort-oriented treatments **AND** consider the best possible outcome of mechanical ventilation/CPR "worse than death."

Is this patient at high risk for poor outcome?

- ❖ Serious illness (ESRD, Home O₂, etc.) **OR**
- ❖ Frail elder OR
- Patient resides in a nursing home or LTAC
- ❖ Suspected COVID in age > 70



Does the patient have a DNR/DNI?

- ❖ YES → Confirm these choices
- NO → Proceed to ED Code Status Conversation



STEPS	WHAT TO ASK
Ask what they know	Hello. I am Dr I am sorry to meet you this way. What have you heard about what has happened today to your [loved one]?
Break bad news	Warning shot: I am afraid I have serious news. Would it be OK if I share? Headline: Your [mother] is not breathing well from [pneumonia/COVID]. with her other health issues, I am worried she could become/is very sick and may even die.
Establish urgency. Align	We need to work together quickly to make the best decisions for her care.
Baseline function	To decide which treatments might help your (mother) the most, I need to know more about her. What type of activities was she doing day-to-day before this illness?
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Source: ACEP

Patient's Values (Select appropriate questions)	Has she previously expressed wishes about the kinds of medical care she would or would not want? If time is short, what is most important to her? How much would she be willing to go through for possibility of more time? What abilities are so crucial to her that she would consider life not worth living if she lost them? Are there states she would consider worse than dying?
Summarize	What I heard is Did I get that right?
Make recommendations	We will use all available medical treatments that we think will help your loved one recover from this illness. For her, this means care focused on We will do and not do
Forecast [If the they elect ICU care]	I hope these treatments will help your [mother]. We are still worried about how sick she is – ICU team will discuss with you how (your mother) is responding to treatment in the next 24 to 48 hours.

Source: ACEP

Case Continued

- Rose does not improve in the ICU
- It is now hospital day 12
- She is receiving maximal ventilator support and on multiple pressors
- She is not waking up or responding despite being off all sedation for several days
- You are able to get a visitor exception so her daughter can see her through the ICU window
- You would like to readdress goals of care with her family



R.E.M.A.P.

An Adaptable Framework for Discussing Goals of Care



REMAP: A Framework for Goals of Care

- R: Reframe why the status quo isn't working
 - "We're in a different place"
- E: Expect emotion and empathize
 - "I can see you are really concerned about [x]."
- M: Map out patient goals
 - "Given this situation, if Rose were in this room, what would she say is important to her?"
- A: Align with goals
 - "As I listen, it sounds the most important things are [x,y,z].
- P: Propose a plan
 - "Here's what I propose now to help us achieve that. Does this sound right to you?"

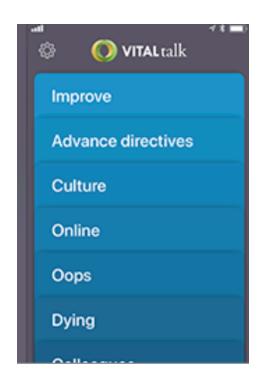
Source: VitalTalk 2

Other tips

- Just start the conversation. You don't have to finish it.
- Only need a few minutes
- You may be the last person who can elicit their wishes
- Agree on a time limited trial: reduce family burden later on
- Work backwards: figure out what their values are and the type of life that would or wouldn't be acceptable to them
- Be comfortable making recommendations based on elicited values
- Focus on what the team WILL do first



Suggested apps





- VitalTalk Tips: https://www.vitaltalk.org/vitaltalk-apps/
- Fast Facts: https://www.mypcnow.org/fast-facts/



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Summary

- Discussing goals of care and code status is everyone's responsibility and more important now than ever before
- Target all high risk patients (e.g, >65 years old with comorbidities) before they develop COVID/are ill
- Conversations don't need to be long or difficult
- Use an adaptable script/framework that works for you
- R.E.M.A.P.: a framework for many discussions
 - Reframe, Expect Emotion, Map out goals, Align, Propose Plan
- Ensure comfort and control



Sources

- ICNARC. "ICNARC report on COVID-19 in critical care." 2020 Apr 4. Accessed: https://www.icnarc.org/About/Latest-News/2020/04/04/Report-On-2249-Patients-Critically-III-With-Covid-19
- https://www.rtmagazine.com/disorders-diseases/critical-care/icuventilation/early-data-on-ventilated-covid-19-patients-reveals-severemortality/
- Xiaobo Yang, et al. "Clinical course and outcomes of critically ill patients with SARS-CoV-2 pneumonia in Wuhan, China: a single-centered, retrospective, observational study." Lancet Resp Med. 2020 Feb 24. Accessed https://doi.org/10.1016/S2213-2600(20)30079-5
- Bhatraju P, et al. "Covid-19 in Critically III Patients in the Seattle Region— Case Series." N Eng J Med. 2020 Mar 30. Accessed <u>DOI:10.1056/NEJMoa2004500</u>
- ACEP American College of Emergency Physicians https://www.acep.org/
- VitalTalk <u>https://www.vitaltalk.org</u>
- Wu C, Chen X, Cai Y, et al. Risk Factors Associated With Acute Respiratory Distress Syndrome and Death in Patients With Coronavirus Disease 2019 Pneumonia in Wuhan, China. JAMA Intern Med. Published online March 13, 2020. doi:10.1001/jamainternmed.2020.0994



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