

Decision Making in the Face of Ethical Dilemmas

Jonathan Weber, MA, PA-C, FAAPA
Assistant Professor, Dept of Internal Medicine,
Yale School of Medicine Physician Associate Program
Yale Medicine, Endocrine & Metabolism Division
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Disclosures

No relevant commercial relationships to disclose.



Pre-Session Questions

1. The Jonsen model is a clinical approach to ethical cases that involves addressing which 4 considerations:
 - A. Beneficence, Autonomy, Justice, Honesty
 - B. Medical Indications, Patient preference, Quality of life, Contextual features
 - C. Evidence based medicine, Hospital policy, Risk management, State law
 - D. Evidence based medicine, Patient preference, Ethics consult



Pre-Session Questions

2. Current evidence for the success of in-hospital CPR shows an “immediate survival rate” of _____ and “survival to discharge rate” of _____ respectively.
- A. 20% / 10%
 - B. 30% / 15%
 - C. 40% / 20%
 - D. 50% / 25%



Pre-Session Questions

3. **The primary role of an Ethics Committee consultation in complex ethics cases is to:**
 - A. Act as final decision maker through consultation
 - B. Provide support to institutions to reduce risk of medical liability
 - C. Provide policy and education support to medical teams
 - D. Provide support to patients, families and medical teams



Foray in Medical Bioethics...

One patient...

One pint of blood...

One conversation...



Case 1 - “Edward”

- **41 yo male admitted for recurrent aspiration PNA**
 - Severely brain damaged since birth
 - Seizure disorder
 - s/p PEG 6 mo ago due to progressive swallow dysfunction
 - 11 hospital re-admissions for recurrent PNA & dislodged PEG
- **Parents seeking change in care goals**
 - Concern that patient was “suffering”
 - Health care team supported parent’s concern
 - CT DDS (legal surrogate) was reluctant to change care goals



Case 1 – “Edward”

- 41 yo male admitted for recurrent aspiration PNA...
 - Was the “care” we were providing “good” for Edward?
 - Was all of this causing more harm than benefit for the patient?
 - What care was in his best interests?
 - Who should decide?



Objectives

At the conclusion of this session, participants should be able to:

- Identify & discuss the cardinal principles of health care ethics
- Describe & apply a practical approach to ethical dilemmas through case-based review
- Recognize contemporary cultural & public health issues in medical bioethics
- Formulate goals, considerations & approaches to ethical dilemmas & end-of-life decisions
- Describe & apply a COVID pandemic triage framework for decisions involving limited life supporting resources



What is an ethical dilemma?

- A situation where moral claims conflict
- A conflict of “goods”
- *“Are you sure?”* moments...*(Weber)*



Case 1 – “Edward”

- **41 yo male admitted for recurrent aspiration PNA**
 - Progressive swallow dysfunction s/p PEG
 - 11 hospital re-admits in 6 months for asp. PNA & PEG removal
 - Recurrent interventions
 - Patient fighting & crying more & withdrawing emotionally
- **Parents seeking change in care management goals**
 - Concern that patient was “suffering”
 - Health care team supported parent’s concern
- **Legal surrogate (DDS) reluctant to change care goals**



Framework of Ethical Principles

■ Autonomy

- To respect the decision-making of autonomous individuals

■ Beneficence

- To act to provide benefit – doing good

■ Non-maleficence

- To, first, do no harm

■ Justice

- To distribute health care fairly to those who need it or will need it



Framework of Ethical Principles

Table 1. Principles That Guide the ACP Ethics Manual Recommendations

Principle	Description
Beneficence	The duty to promote good and act in the best interest of the patient
Nonmaleficence	The duty to do no harm to the patient
Respect for patient autonomy	The duty to protect and foster a patient's free, uncoerced choices
Justice	The equitable distribution of the life-enhancing opportunities afforded by health care

Sulmasy LS, Bledsoe TA; ACP Ethics Manual 2019



Applied Clinical Ethics

- **Medical Indications** → **Beneficence & Nonmaleficence**
 - Do the treatments fulfill goals of medicine?
 - Do the treatments cause benefit & while NOT causing harm?
- **Patient Preferences** → **Autonomy**
 - What does the patient want?
 - If the patient does not have capacity, who will decide & what is their understanding of what the patient might want?
- **Quality of Life (QoL)** → **Autonomy, Beneficence & Nonmaleficence**
 - What is the QoL...from the patient's, family & provider perspectives?
 - What are the perceptions & definitions of QoL from each perspective?
- **Contextual Features** → **Justice**
 - What social, legal, cultural, institutional issues are influencing decisions?



Case 1 – “Edward”

■ Medical Indications for Intervention

- Recurrent aspiration pneumonia
- Seizure disorder w/ recurrent seizures during infections
- PEG due to failed swallow function
 - Data is weak for PEG use for prevention of aspiration PNA
- Severe brain damage
 - Studies for bedridden, post-CVA patients with & without PEG, no reduction in asp PNA

■ Artificial Nutrition & Hydration (ANH)

- Patients with PEG feeding at high risk for developing aspiration PNA
- Aspiration PNA - common cause of death after PEG
- 15-25% in-hospital mortality s/p PEG & 60% one-year mortality



Case 1 – “Edward”

■ Patient Preferences

- Patient preferences unknown
- Parent-surrogates feel patient/son is suffering

■ Quality of Life

- Withdraws, grimaces, cries from pain of invasive procedures
- Uncooperative & fearful behaviors in hospital
- Recurrently pulls out IVs & PEG tube prompting restraints

■ Contextual Features

- DDS is legal surrogate weighing legal & regulatory duties
- Patient is “ethically vulnerable”
- Parents highly interactive & involved



Case 1 – Summary

- **Medical Indications** - *Beneficence & Nonmaleficence*
 - Weak evidence for benefits outweighing risks for PEG
- **Patient Preferences** - *Autonomy*
 - Surrogates feel patient/son is suffering from repeat admissions & invasive interventions
- **Quality of Life** - *Autonomy, Beneficence & Nonmaleficence*
 - Objective & subjective perceptions of patient discomfort
 - High risk for iatrogenic self-injury
- **Contextual Features** - *Justice*
 - DDS is legal surrogate weighing legal & regulatory duties



Ethics Committee

■ Multi-disciplinary group

- Attorneys
- Community representatives
- Hospital Administration
- Nurses
- Nurse Practitioners
- Physician Assistants
- Physicians
- Religious ministries
- Social work
- Students



Common Ethical Conflict Themes

- Limitation of treatments
- Initiating & Withdrawing treatments
- Medical futility
- Artificial Nutrition & Hydration (ANH)
- Competency
- Surrogate decision making
- Utilization of finite resources



Purpose of Ethics Consultations?

- Clarify complex, often emotionally-laden issues
- Establish a framework for thinking about issues
- Identify ethically sound solutions
- Assist toward satisfactory resolutions



Clarifying Consultation Request

Consult Team Members Should Assist to:

- Characterize the type of request
- Obtain preliminary info
- Set realistic expectations about consult process
- Help formulate the ethical question...



Formulating Ethical Questions

- The initial formulation of the question should:
 - State the question in a way that is helpful to the consultants
 - Avoid emphasizing abstract ethics concepts

Use either of the following structures to formulate an ethics question:

Given _____, what decisions or actions are ethically justifiable?
uncertainty or conflict about values

Given _____, is it ethically justifiable to _____?
uncertainty or conflict about values decision or action



Formulating Ethical Questions – Case 1

Use either of the following structures to formulate an ethics question:

Given _____, what decisions or actions are ethically justifiable?
uncertainty or conflict about values

Given _____, is it ethically justifiable to _____?
uncertainty or conflict about values decision or action

- The ethical question can be stated as:
 - Given the conflict between the surrogate's right to make health care decisions on behalf of the patient & the health care providers' obligation to act in the best interests of the patient, is it ethically justifiable to not replace the PEG?



Case 1 – Ethics consult

- Bioethics committee supports family's request
 - To amend Advanced Directive & PEG feeding goals
- State DDS agreed to revisions in Advanced Directives & PEG feeding goals based on:
 - Recurrent rate of Aspiration PNA episodes
 - High risk of self-injury
 - Reduced QoL
- Care management goals changed to palliative measures
 - Including rectal diazepam to assist with seizure control



Approaching the Question of PEG

- Clinician colleagues:
 - Remain aware of current evidence
 - Weakest in advanced cancer - no improvement in survival is found
 - Strongest in patients with reversible illness (ie., sepsis)
- Patients & Families:
 - Inability to maintain po intake, in setting of a chronic life-limiting illness & declining function, is usually a marker of the dying process
 - Provide evidence-based info & clear recommendations for or against PEG
 - Provide options
 - Hand feeding
 - Comfort measures
 - If PEG is placed:
 - Establish clear goals (ie., improved function)
 - Establish a timeline for re-eval. Are goals being met? (typically 2-4 weeks)



Case 2 – “Abby”

- 21 yo female w/ traumatic multi-system injuries s/p MVA, cardiogenic shock, & anoxic brain injury.
- **Neuro exams:**
 - Initial diagnostic criteria of “minimally conscious” state
 - Subsequently meets criteria of persistent vegetative state (PVS)
 - Extremely poor prognosis for meaningful neurologic recovery
- Initial agreement to a “DNR/DNI” order by mother
- Family later rescinds “DNR/DNI” & urged aggressive care in any setting of cardiopulmonary failure



Case 2 – “Medical Indications”

- **Anoxic encephalopathy & PVS by criteria**
 - Decorticate posturing & bed bound
 - Reflex cycling of facial grimaces, crying & screaming
- **Severe multi-system traumatic injury**
 - Open & draining chest & abdominal wounds
 - Multiple thoracic & abdominal enterocutaneous fistulas
- **Nutrition & Hydration**
 - Unable to place PEG & received parenteral N&H
 - 58% survival in patients with 1st-time use at 1.5 yrs after initiation (Oterdoom et al 2014)
- **Recurrent intra-thoracic & abdominal infections w/ MDR organisms**
- **Tracheostomy tube & successfully weaned off ventilator**
- **CV**
 - Post-MVA cardiogenic shock requiring 3 CPR interventions
 - Does CPR fulfill goals of medicine?
 - Would CPR cause more harm than good?



In-hospital CPR

- **CPR survival to discharge rates**
 - Studies in 1990's – 13-14%
 - Study in 2003 of ~15,000 patients – 17%
 - Study in 2011 of 2262 patients
 - 32.8% survival after CPR
 - 12% survived to discharge

- **CPR survival to d/c rates remain: ~12-15%**
 - Despite rising prevalence of RR teams



CPR

- Today – CPR is only intervention we perform on patients that **DOES NOT** require an order
 - CPR requires an order NOT to provide
- CPR for hospitalized patients is associated with poor outcomes
- In 2013, the AHA recommended the completion of advance directives for all patients admitted to hospital
 - Include discussions on prognosis & CPR survival rates



Case 2 – “Patient Preferences”

- 21-year-old college senior
 - No existing Advanced Directives
 - Extemporaneous conversations suggested patient preference to “not be kept alive by machines”
 - Mother agreed with various caregivers that daughter “would not have wanted to live like this”



Case 2 – “Quality of Life”

■ PVS

- No consciousness, awareness, or cognitive function

■ Pain?

- Pain vs reflex facial grimacing & screaming

■ Functional status

- Bedbound & complete dependence on caregivers



Case 2 – “Contextual Features”

- **Supportive mother & uncle**
 - Mother visits daily
 - “Every day she is alive is a good day for me.”
 - Requests full range of intensive care services
 - Acknowledges poor prognosis
- **Initial agreement to “DNR/DNI” order**
 - Patient’s uncle persuades mother against it & order rescinded
- **Devoutly religious & prays daily for a “miracle”**



Formulating Ethical Questions – Case 2

Use either of the following structures to formulate an ethics question:

Given _____, what decisions or actions are ethically justifiable?
uncertainty or conflict about values

Given _____, is it ethically justifiable to _____?
uncertainty or conflict about values decision or action

- The ethical question can be stated as:
 - Given the conflict between the surrogate's right to make care decisions & the health care providers' obligation to act in the best interests of the patient, is it ethically justifiable to change the code status from FULL CODE to DNR/DNI?



Case 2 – Ethics consultation

■ Consult - Sept:

- Supported no change in care goals based on “relative” stability
- Supported reassessment of care goals if condition worsens

■ Consult - Nov:

- Worsening medical condition prompted Ethics reassessment
- Supported medical team’s decision to implement DNR/DNI

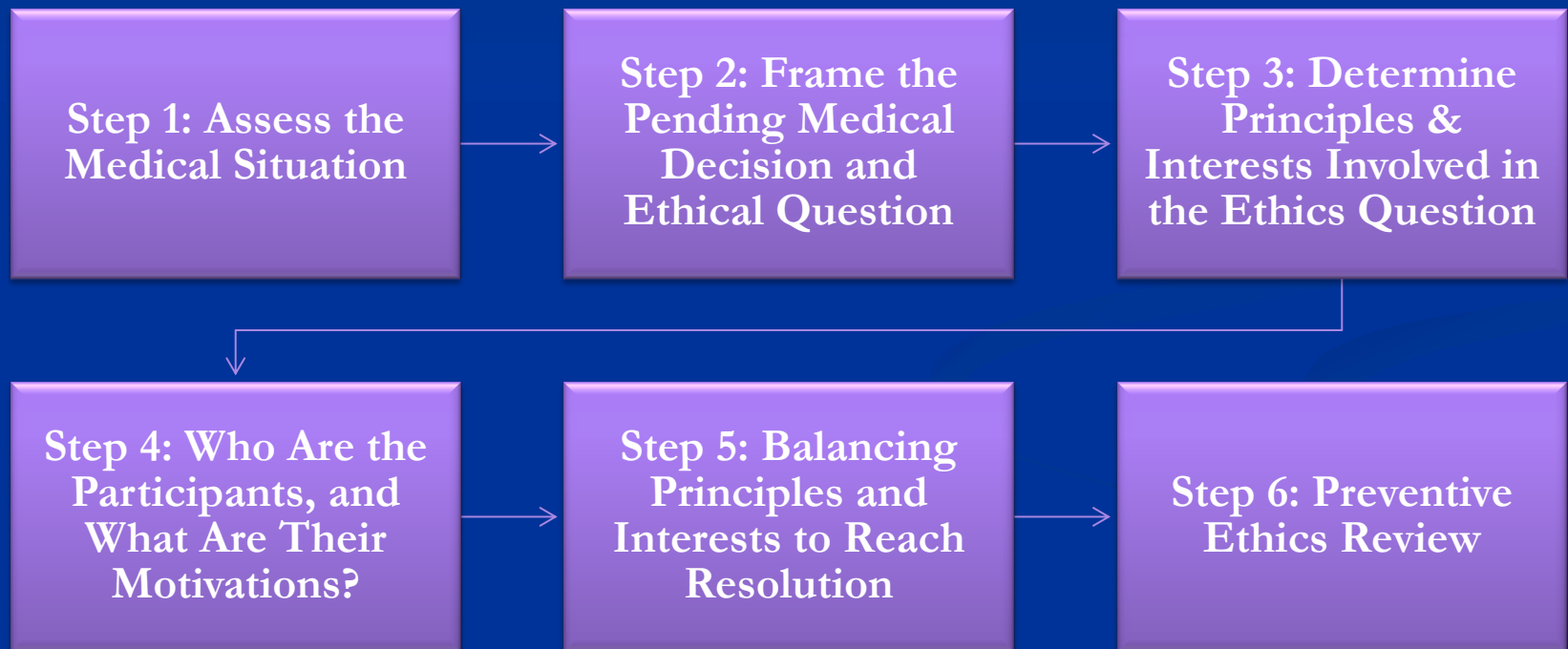


Jonsen Paradigm Key Points

- Jonsen Paradigm
 - Offers consistent & thoughtful approach to ethical conflict
 - Provides an effective method for reaching conclusions
 - Does not imply that resolving conflicts should be “simple”
- Seek Bioethics consultation for review & assistance
- Many dilemmas do not have clean & satisfying ends



ACP 6-Step Approach to Clinical Ethics Decision Making



Legacy of Theresa Schiavo

- Feb 25, 1990 - Anoxic brain injury due to cardiac arrest
- May 1998 - Diagnosis of PVS & petition by husband to remove PEG
- Feb 11, 2000 - Circuit court judge rules in favor of petition
- Apr 24, 2001 - **Feeding tube removed.** Parents file suit against spouse.
- Apr 26, 2001 - **Feeding tube reinserted** by court order
- Nov 22, 2002 - Judge rules: “No evidence for hope of recovery” & orders feeding tube removed
- Oct 14, 2003 - Appeals court refuses to block tube removal
- Oct 15, 2003 - **Feeding tube removed.**
- Oct 21, 2003 - FL legislature intervenes with “Terri’s Law” & FL governor signs it into law. **Feeding tube reinserted** by court order
- Sept 23, 2004 - FL Supreme Court strikes down “Terri’s Law” as unconstitutional encroachment on the judiciary
- Feb 25, 2005 - FL Circuit court judge gives permission for tube removal
- Mar 18, 2005 - **Feeding tube removed.**



Legacy of Theresa Schiavo

- Mar 20, 2005 - **US Congress** approves legislation allowing federal court jurisdiction to consider tube reinsertion
- Mar 21, 2005 - **US President** signs bill into law
- Mar 22, 2005 - Federal judge rules: “no due process rights violated” in FL court decision granting right to remove feeding tube
- Mar 23, 2005 - US Circuit Court of Appeals upholds decision; judge admonishes Congress & President for:
 - *“...acting in a manner demonstrably at odds with our founding fathers blueprint for the governance of a free people”.*
- Mar 24, 2005 - **US Supreme Court** denies parent’s application for stay of FL ruling
- Mar 30, 2005 - Federal Court denies US Congress petition for rehearing
- Mar 31, 2005 - Terri Schiavo dies at FL Hospice
- June 2005 - NGO devoted to supporting end-of-life wishes reports:
 - >800,000 requests for “Five Wishes” : Do-it-Yourself Living Will & Medical Proxy kit



Advance Directives

- **Living Wills**
 - Specifies wishes regarding certain health care decisions
- **Durable Power of Attorney for Health Care (DPAHC)**
 - Designates surrogate power to make decisions IF patient lacks decisional capacity
- **Combination Forms**



5 Wishes

“Five Wishes” lets your family & care providers know:

- Who you want to make health care decisions for you when you can't make them?
- What kind of medical treatment you want or don't want?
- How comfortable you want to be?
- How you want people to treat you?
- What you want your loved ones to know?

5 WISHES: <https://fivewishes.org/>



Use of Advance Directives

- **Systematic Review 2011-2016 of 150 studies**
 - 37% of adults in US completed Advance Directives
 - 38.2% patients with chronic illnesses
 - 32.7% healthy adults

- **Retrospective cohort study in 2014**
 - 72% of older Americans completed ADs prior to death
 - Increased from 47% in 2000 to 72% in 2010



Physician Orders for Life Sustaining Treatment (POLST)

Organizational Objectives

- To help develop, implement & evaluate state POLST Paradigm Programs
- To educate the public & health care professionals about the POLST Paradigm
- To improve the quality of end-of-life care



POLST – Patient Site

Honoring the wishes of those with serious illness and frailty.

POLST is a process and a form

POLST has **different names in different states**. At the national level, it is simply called **POLST: Portable Medical Orders**, or POLST for short.

POLST communicates your wishes as medical orders

A POLST form tells **all** health care providers during a medical emergency what you want:

- “Take me to the hospital” or “I want to stay here”
- “Yes, attempt CPR” or “No, don’t attempt CPR”
- “These are the medical treatments I want”
- “This is the care plan I want followed”

POLST is many things, including:

- **A process** Part of advance care planning, which helps you live the best life possible.
- **Conversation** A good talk with your provider about your medical condition, treatment options, and what you want.
- **A medical order form** that travels with you (called a POLST form).

POLST: <https://polst.org/>



POLST – Professional Site

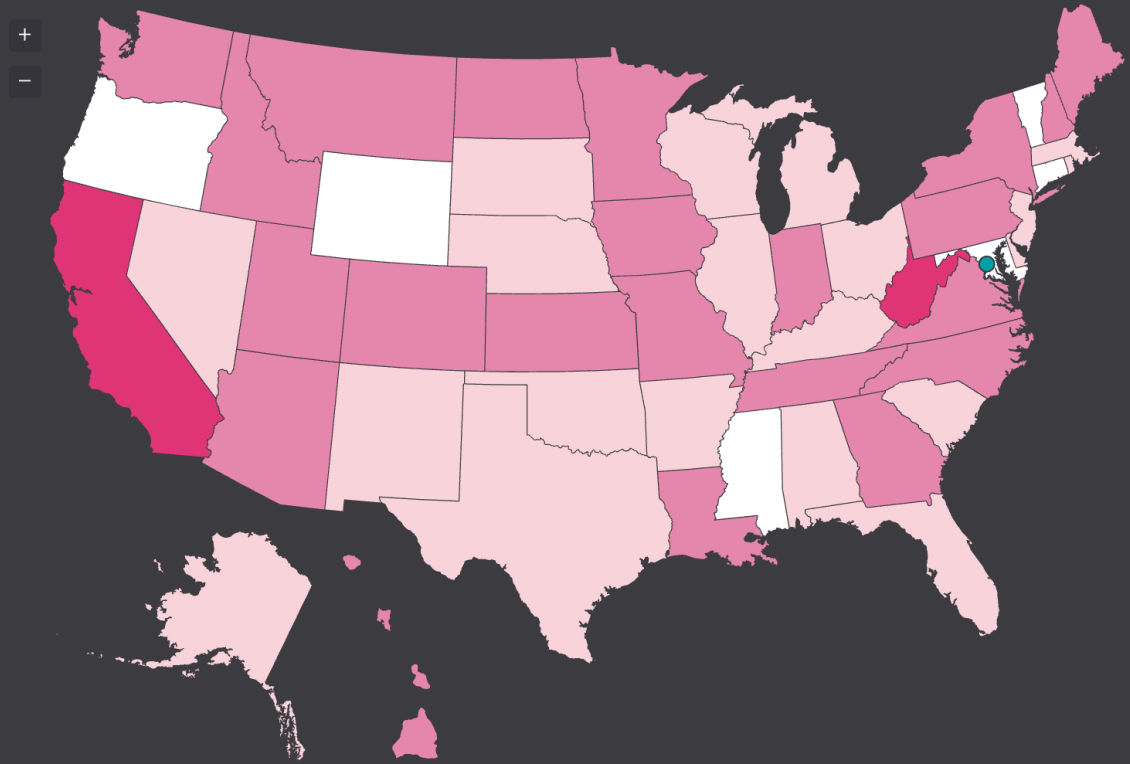
National POLST Program Designations

Click a state for more information

- 2 mature
- 24 endorsed
- 21 active
- 6 unaffiliated

Only active programs are eligible for endorsed status; unaffiliated status does not reflect program development. Mature programs also endorsed and counted in both the mature and endorsed program totals. Totals include Washington DC.

[LEARN MORE](#) in the text below the map.



POLST: <https://polst.org/professionals-page/?pro=1>



CT MOLST

Certificate of Completion
**THE CONNECTICUT
DEPARTMENT OF PUBLIC HEALTH**
CONFIRMS THAT

Jonathan Weber

**Has successfully completed the Medical Orders
for Life Sustaining Treatment Training Course
for Clinicians**

On

02/27/2019



Keeping Connecticut Healthy



CT MOLST: <https://portal.ct.gov/DPH/Medical-Orders-for-Life-Sustaining-Treatment-MOLST/MOLST>



Conversation into...

Advance Care Planning

- Who should I call if something were to happen to you?
- Is that person your Health Care Agent?
- Do they know your wishes?
- What are your wishes?



Systematic Review of ACP



ELSEVIER

JAMDA

journal homepage: www.jamda.com

Review

Efficacy of Advance Care Planning: A Systematic Review and Meta-Analysis

Carmen H.M. Houben MSc^{a,*}, Martijn A. Spruit PhD^a, Miriam T.J. Groenen MSc^a,
Emiel F.M. Wouters PhD, MD^{a,b}, Daisy J.A. Janssen PhD, MD^{a,c}

^a Program Development Center, Center of Expertise for Chronic Organ Failure (CIRO+), Horn, The Netherlands

^b Respiratory Medicine, Maastricht UMC+, Maastricht, The Netherlands

^c Center of Expertise for Palliative Care, Maastricht UMC+, Maastricht, The Netherlands

Advance Care Planning Conversations:

- Increased completion of advance directives
- Increased concordance between patient preferences & care delivered



Goal Concordant Care in Serious Illness Communication

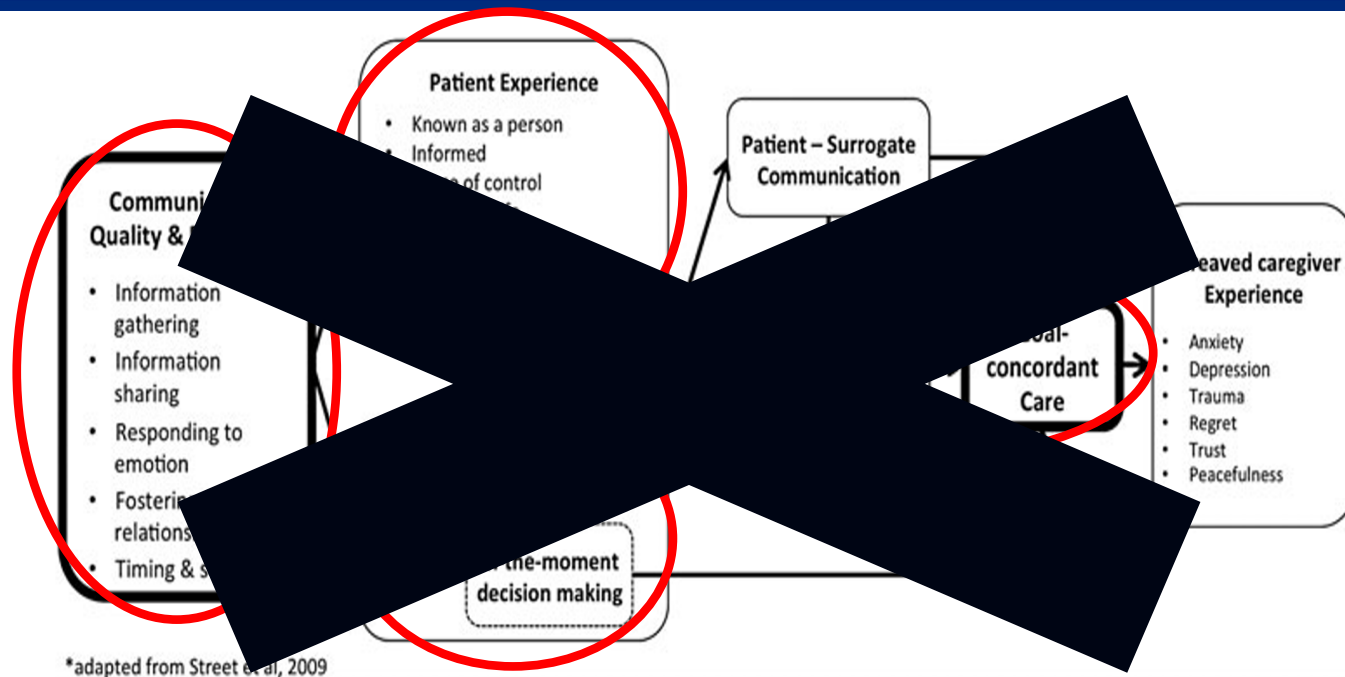


FIG. 2. Clinician–patient communication improves patient and caregiver experience enables shared decision making, and mediates goal-concordant care. Adapted from Street et al.²⁷

MEDICAL ERROR IF NOT ACHIEVED



Goals at End of Life

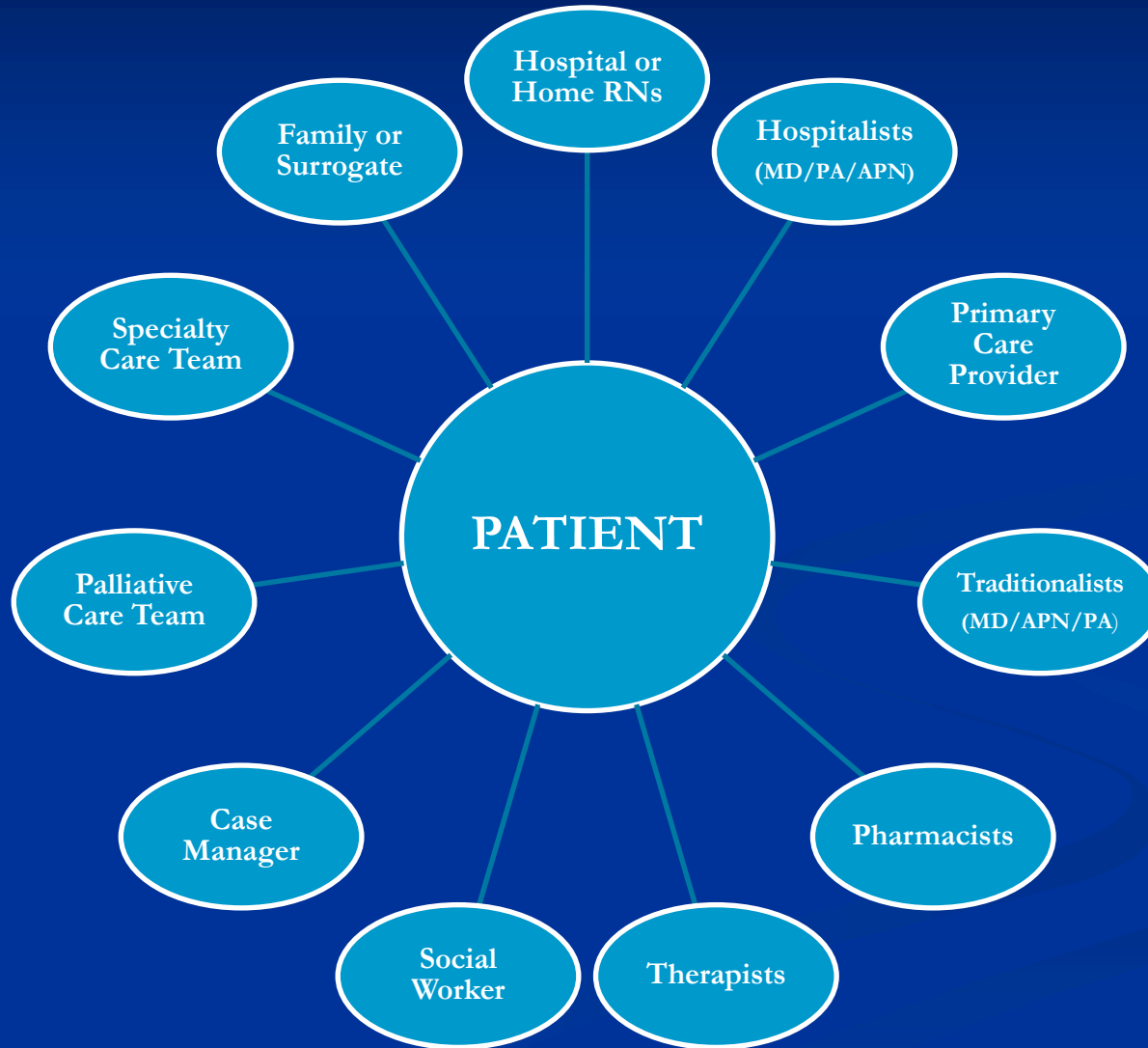
- Information sharing
- Advance directives
- Control of symptoms
- Psychosocial & Spiritual care
- Prognosis



MS PowerPoint Stock image V 16.46

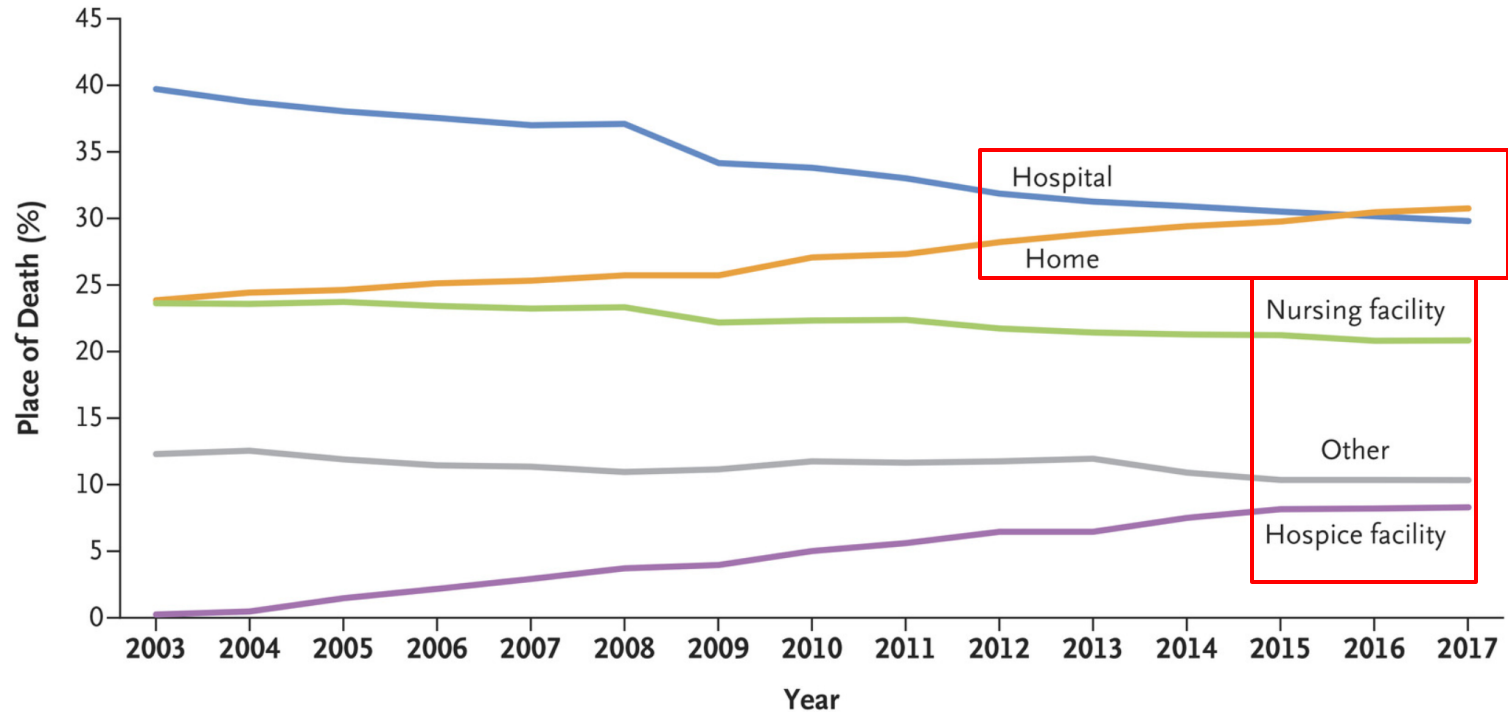


Multi-disciplinary Care

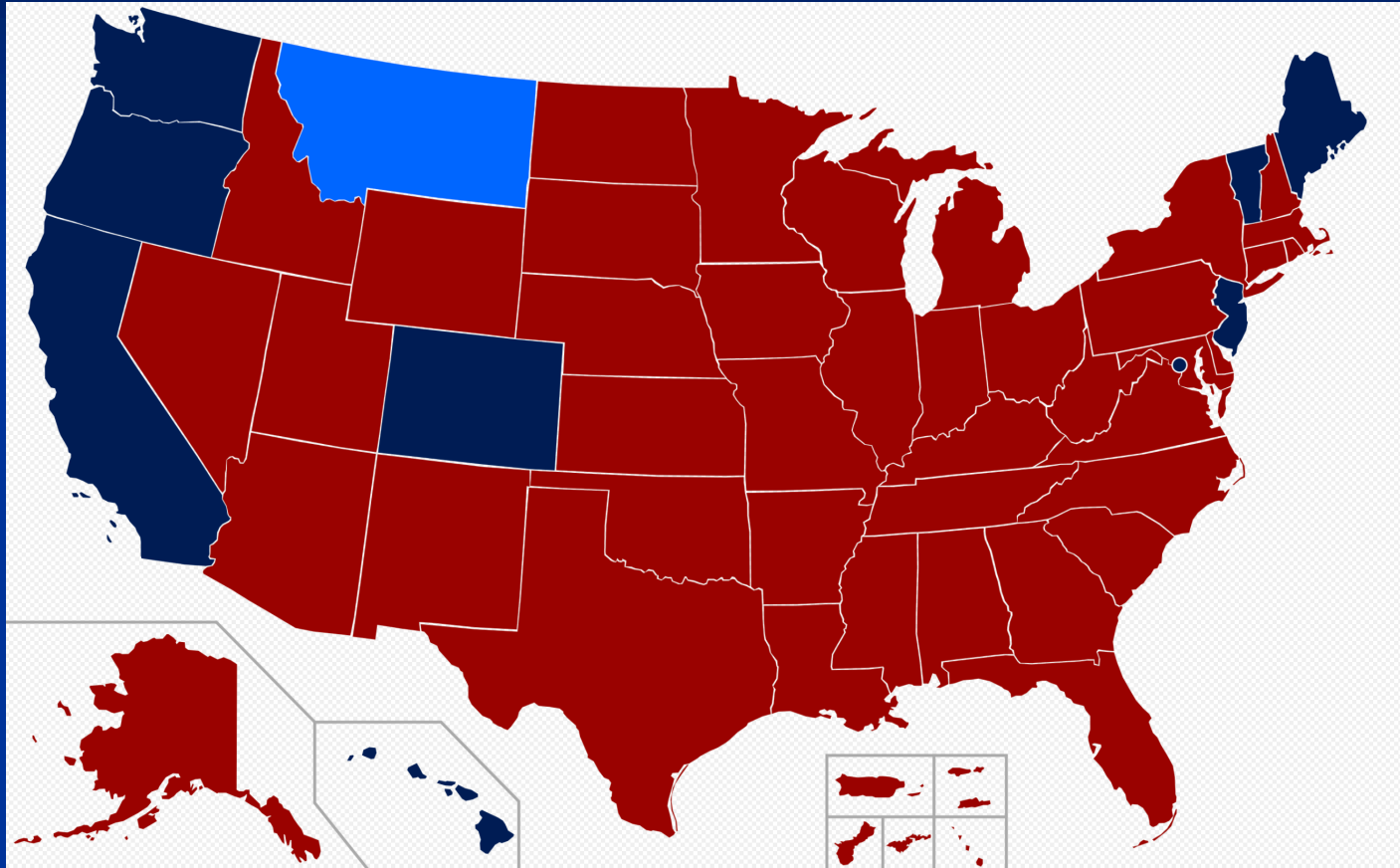


Death in the USA

A Changes in the Place of Death in the United States



Assisted Suicide or Medical Aid in Dying



State laws regarding assisted suicide in the United States

- Legal
- Legal under court ruling¹
- Illegal

¹ In some states assisted suicide is protected through court ruling even though specific legislation allowing it does not exist.

V · T · E

Compassion & Choices: <https://compassionandchoices.org/end-of-life-planning/learn/understanding-medical-aid-dying/>



Assisted Suicide or Medical Aid in Dying

- Brittany Maynard (1984-2014) was a terminally ill 29-year-old woman who fought for medical aid-in-dying legislation for California after moving to Oregon to access the option.
- *"Having this choice at the end of my life has become incredibly important. It has given me a sense of peace during a tumultuous time that otherwise would be dominated by fear, uncertainty and pain."*



Pros & Cons of AID

YALE JOURNAL OF BIOLOGY AND MEDICINE 92 (2019), pp.747-750.

YALE JOURNAL OF BIOLOGY AND MEDICINE

YJBM

CELEBRATING 90 YEARS 1928-2018

PERSPECTIVES

Pros and Cons of Physician Aid in Dying

Lydia S. Dugdale^{a,*}, Barron H. Lerner^b, and Daniel Callahan^c

^aDepartment of Internal Medicine, Columbia University, New York, NY; ^bDepartment of Medicine and Population Health, New York University, New York, NY; ^cformerly of the Hastings Center, Garrison, NY

The question of a physician's involvement in aid in dying (or "assisted suicide") is being debated across the country. This article adopts no one position because its authors hold contrasting views. It aims instead to articulate the strongest arguments in favor of aid in dying and the strongest arguments opposed. It also addresses relevant terminology and reviews the history of its legalization in the United States.

Dugdale et al 2019



COVID-19 Pandemic Ethics

- Rationing of COVID-19 testing
- Allocation of scarce resources
- Withdrawal of life supporting care
- Family visit limitations
- Quality of end-of-life support
- Vaccine distribution & rationing
- Vaccine mandates



YNHHS COVID-19 Planning

- Formation of the *Ethics Advisory Taskforce*
 - What if we run out of ICU beds?
 - What if we run out of ventilators?
- Aimed to develop “Critical Care Triage Protocol”
 - To be used IF patient demand exceeded resources
 - To save as many lives as possible
 - To assist frontline provider decision-making



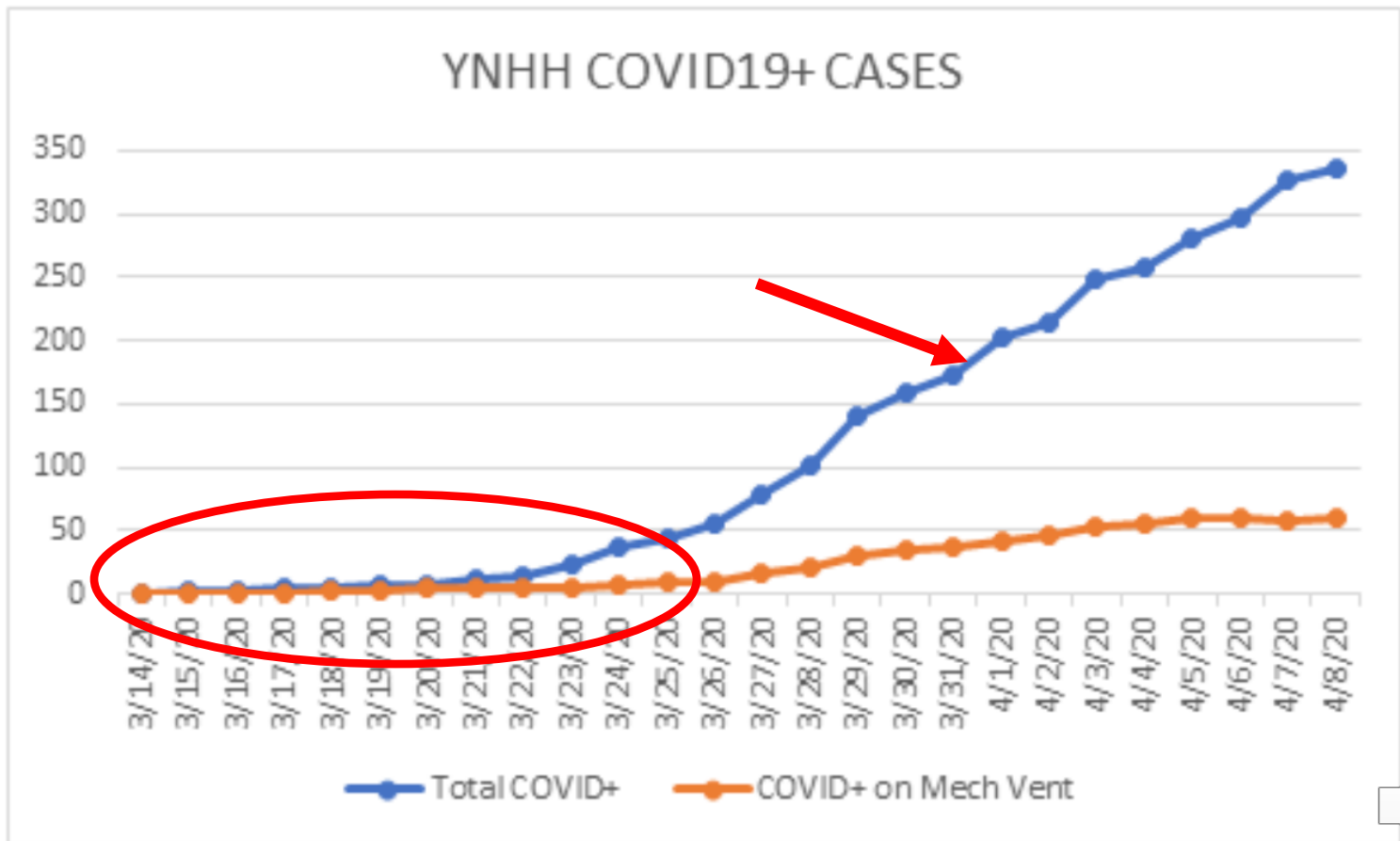
YNHHS Triage Protocol

- Patients who arrive at hospital close to death
- Triage rules for allocation of resources
- Re-evaluation of inpatients for triage
- Non-discrimination rules
- Triage teams & advisors
- Cardio-pulmonary resuscitation (CPR)
- How patients & families can help

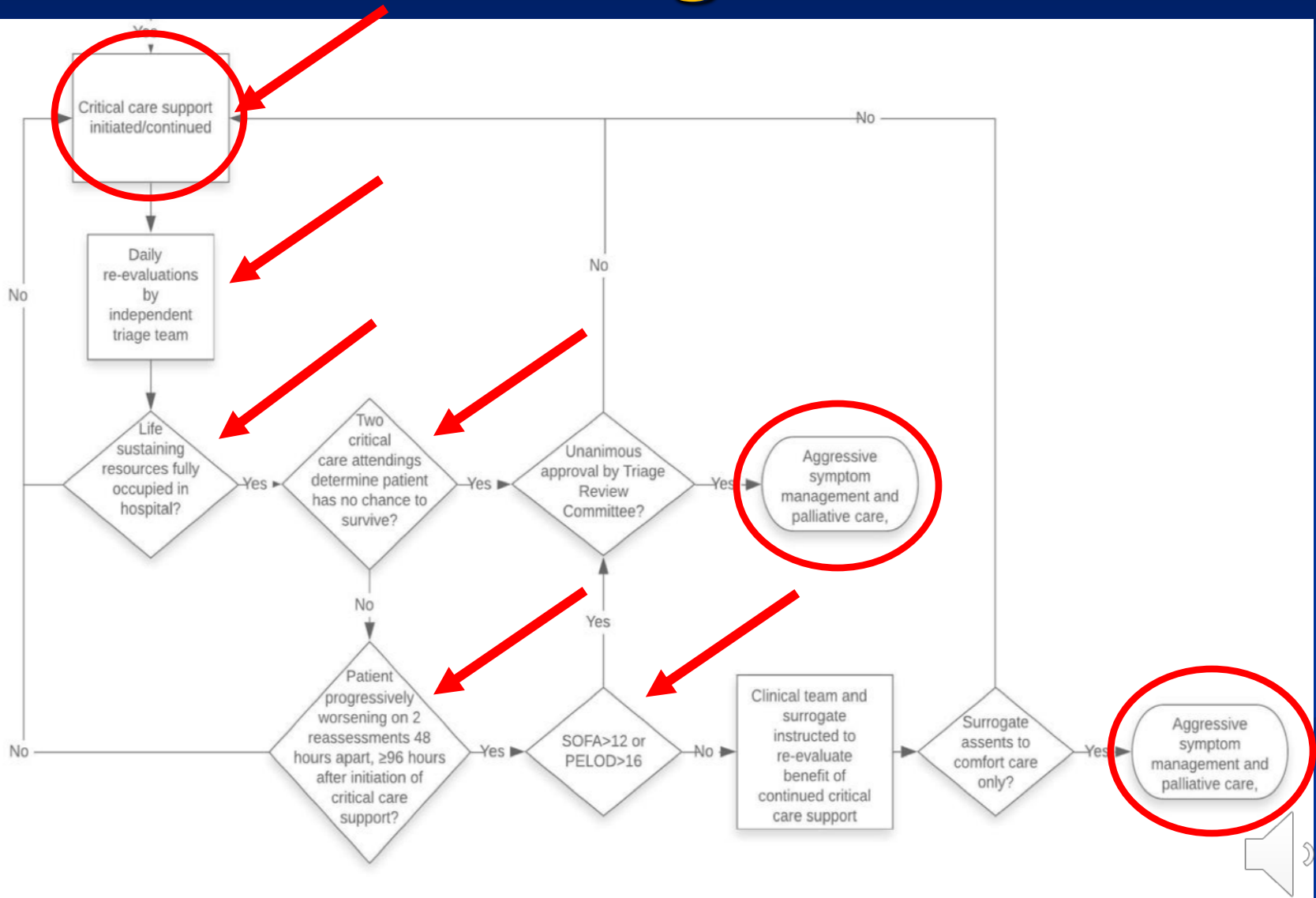


Triage Protocol Work & Approval

The Daily Snapshot - **COVID-19** Cases at Yale New Haven Hospital (4/8/20 at 8 a.m.):

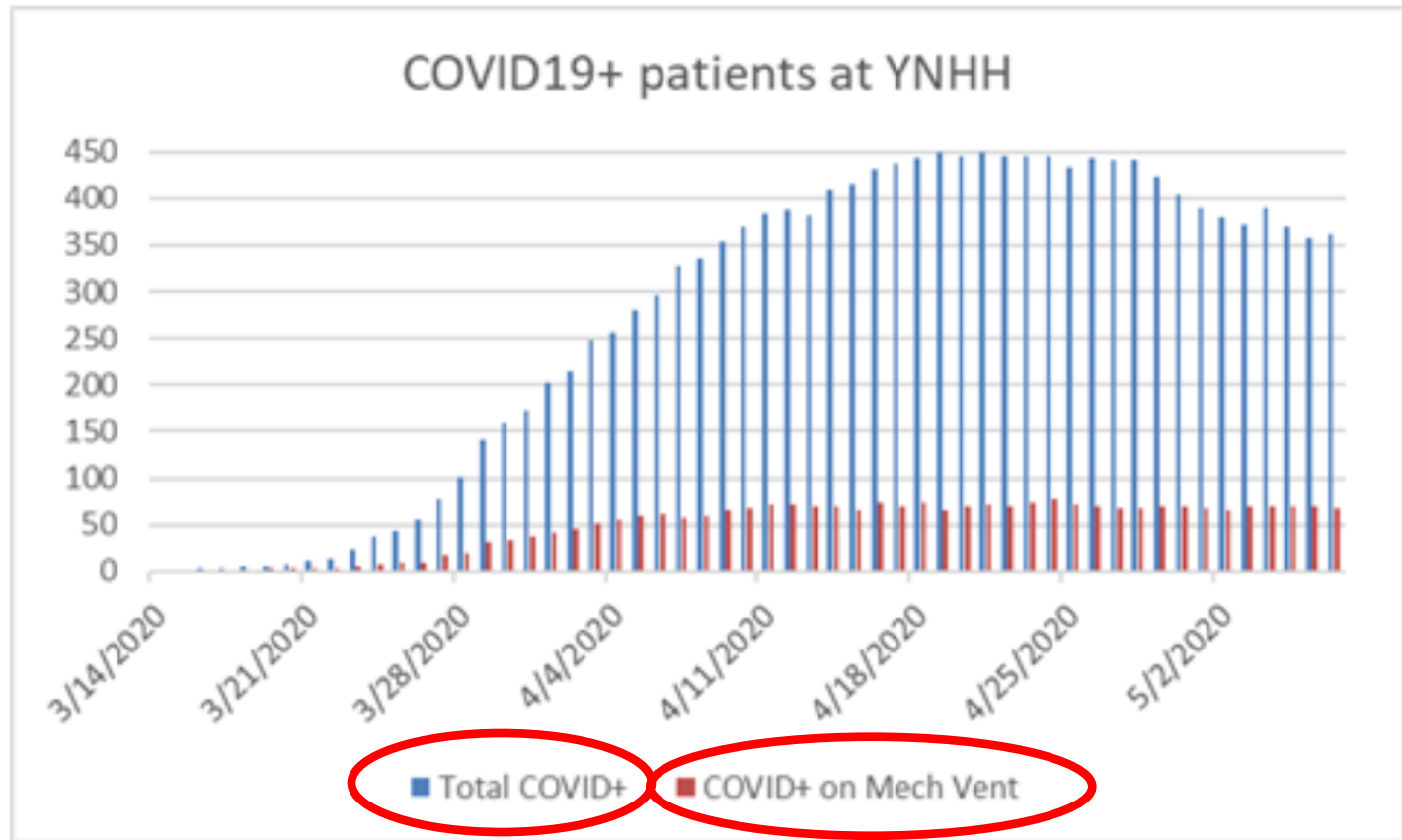


Portion of Triage Flowchart



COVID-19 Snapshot – May 2020

The **COVID-19** at Yale New Haven Hospital Snapshot:



AMA Resource Guide

- AMA online resources to help guide ethical decision making by clinicians during COVID-19
- AMA Code of Medical Ethics
- AMA Code of Medical Ethics: Guidance in a pandemic
- COVID-19 Ethics Resource Center



Return to Case 2 – Contextual Features

- Devoutly religious & pray daily for a “miracle”
- Acknowledged poor prognosis but belief in miracles drove many of her decisions
- How best to approach “Miracle Language”?



Approach to Miracles

Addressing a Patient's Hope for a Miracle

Myrick C. Shinall Jr., MD, PhD, MDiv, Devan Stahl, PhD, MDiv, and Trevor M. Bibler, PhD, MTS

Vol. 55 No. 2 February 2018

Journal of Pain and Symptom Management

- Focus on “RAPPORT BUILDING”...
 - Affirm feelings of helplessness, anger & sadness as normal grieving process
 - Affirm hope for the outcome
 - Set expectations (ie., time trials) & Probe prognostic awareness
 - “Meaning making” → What would that look like? Tell me more about that...
- Engage pastoral care assistance & leaders of religious community



Return to Case 2 – Contextual Features

- Devoutly religious & pray daily for a “miracle”

What does that miracle look like?

- “Well, maybe not 100% recovery, but even if it was 25%. I think that would be a miracle. But my main hope is just for her to be happy.”

What do you think would make her happy?

- “For me to give her what she needs, to be with & to take care of her.”
- “She would just want to go home...even if she does not get any better.”
- “I know, she would just want to be home...”
- “Maybe that’s the miracle to pray for...”



Take Home Points

- Communication, communication, communication...
 - "Lean in" to the "Are you sure?" moments
 - Evidence must drive end of life care
 - Don't start something without discussions about when to stop it
 - All involved should be "on board" with plan
 - Avoid offers of false hope
- Use a systematic approach to identify & manage ethical issues
- Practice goal concordant & end of life care
- Seek assistance from Ethics Committees & multi-disciplinary teams
- Discuss ethical challenges with colleagues
 - The NYT Ethicist: <https://www.nytimes.com/column/the-ethicist>
 - Kwame Anthony Appiah considers readers' ethical quandaries



“Best Jobs in America - 2021”

Rank	Job Title	Job Growth
1	<u>Physician Assistant</u>	31%
2	<u>Software Developer</u>	22%
3	<u>Nurse Practitioner</u>	45%
4	<u>Medical & Health Services Manager</u>	32%
5	<u>Physician</u>	4%



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Inquiries

Jonathan Weber, MA, PA-C
jonathan.weber@yale.edu



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