The Utility of Futility: What's the Point?

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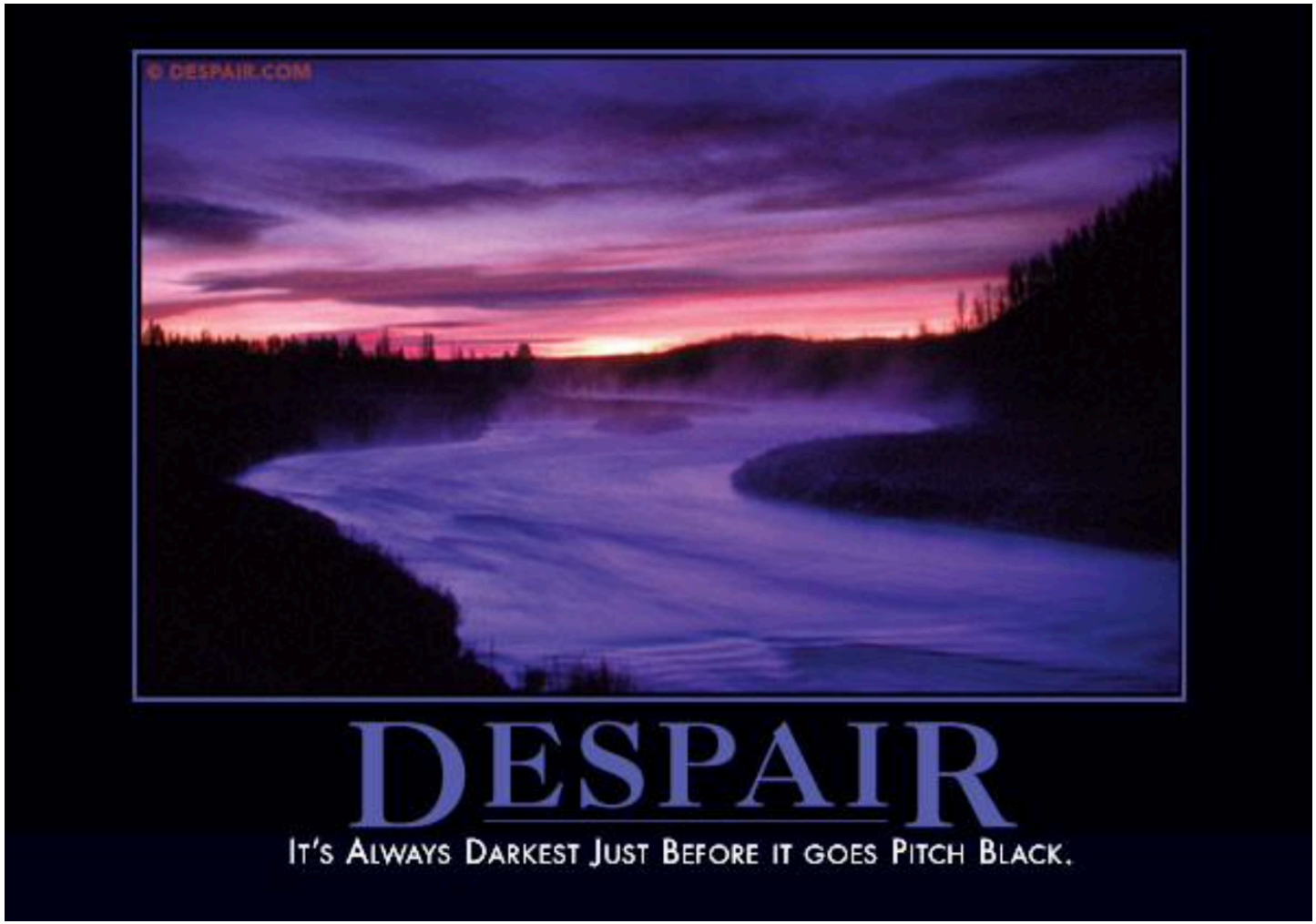
During This Webinar…

- Ask questions in the chat box
- Save your questions to ask during the discussion portion

Disclosures

- Drs. Oei, Mohr, and Namm have no relevant financial disclosures
- Ethical disclosures
  - There is no “one size fits all” answer



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Objectives

- Identify the historical context of "medical futility" and its limitations
- Recognize the importance of goals of care discussions
- Apply a practical approach to these situations

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treatises will give elearer instruction. I will now turn to medicine, the subject of the present treatise, and set forth the exposition of it. First I will define what I conceive medicine to be. In general terms, it is to do away with the sufferings of the sick, to lessen the violenee of their diseases, and to reruse to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless. That medicine fulfils these conditions,

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Jones WHS, trans-ed. *Hippocrates Vol. II: Prognostic.* Cambridge, MA: Harvard University Press; 1981:193

Language of Futility

- Language differs, concept is the same
  - Futility
  - Medically ineffective therapy
  - Potentially ineffective therapy
  - Treatment that is not medically indicated
- Lack of consensus on appropriate treatments for a patient or what treatments are “worth it”
  - Often centers around intensive care level or invasive interventions
  - Patient suffering and quality of life
  - Distribution or use of scarce resources

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PROBATE CODE - PROB

DIVISION 4.7. HEALTH CARE DECISIONS [4600 - 4806] *(Division 4.7 added by Stats. 1999, Ch. 658, Sec. 39.)*

PART 2. UNIFORM HEALTH CARE DECISIONS ACT [4670 - 4743] *(Part 2 added by Stats. 1999, Ch. 658, Sec. 39.)*

CHAPTER 4. Duties of Health Care Providers [4730 - 4736] *(Chapter 4 added by Stats. 1999, Ch. 658, Sec. 39.)*

4735. A health care provider or health care institution may decline to comply with an individual health care instruction or health care decision that requires medically ineffective health care or health care contrary to generally accepted health care standards applicable to the health care provider or institution.

(Added by Stats. 1999, Ch. 658, Sec. 39. Effective January 1, 2000. Operative July 1, 2000, by Sec. 43 of Ch. 658.)

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https://leginfo.legislature.ca.gov/faces/codes_displaySection.xhtml?sectionNum=4735.&lawCode=PROB

Medically ineffective healthcare is:

Treatment that would not offer significant benefit to the patient

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The California Law Revision Commission recommendation on
Health Care Decisions for Adults Without Decision Making Capacity, 1998

Medically Ineffective Treatment

- Terminology
  - Medically ineffective
  - Not medically indicated
  - Potentially inappropriate therapy

Recommendation 2

The term "potentially inappropriate" should be used, rather than "futile," to describe treatments that have at least some chance of accomplishing the effect sought by the patient, but clinicians believe that competing ethical considerations justify not providing them. Clinicians should communicate and advocate for the treatment plan they believe is appropriate.

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Bosslet, *AJRCCM*, 2015

Patient AB

- 60-year-old female diagnosed endometrial cancer 2 months ago is brought to the ED by her family for altered mentation. She has not had a bowel movement in 6 days and has had poor oral intake and vomiting for the past 3 days.
  - Family is concerned about dehydration and hypoglycemia
  - At time of diagnosis AB was not a candidate for surgical resection or palliative chemotherapy or radiation due to the extent of the disease and her functional status
- ED course:
  - Abdominal / pelvis CT → large bowel obstruction from tumor burden
  - Acute care surgery consult → not a candidate for surgical resection
  - Gyn-onc consult → not a candidate for surgical resection

Patient AB

- Family desires aggressive treatment → admitted to the MICU
- TPN started for nutrition and hydration
- AB was intubated on ICU day 2 for acute hypoxic respiratory failure
- AB went into cardiopulmonary arrest in the evening of ICU day 2 → return of spontaneous circulation after 2 rounds of CPR
- AB went into cardiopulmonary arrest on ICU day 3 with return of spontaneous circulation after 3 rounds of CPR
- Currently on high dose vasopressor and inotropic support with progressively worsening acidosis and organ failure

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Defining Medically Indicated Therapy

- Physiologic benefits of the treatment outweigh the physiologic burdens
  - Benefits include known medical effectiveness of the treatment
  - Burdens include medical side effects of the treatment
- Treatment advances the patient towards their goal for their healthcare
  - Determined by their lived and states preferences and values

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Continuum of Medically Indicated Therapy

Medically Indicated

Not Medically Indicated

Physiologic Benefit > Physiologic Burden
Treatment advances patient towards goal

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Continuum of Medically Indicated Therapy

- Physiologic benefits equivocal or are less than the physiologic burdens
  - As burdens accumulate, the patient determines the acceptable ratio of burden / benefit
  - Is this still worth it?
- Treatment advances the patient towards their goal for their healthcare
  - Determined by their lived and states preferences and values

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Continuum of Medically Indicated Therapy

Medically Indicated

Not Medically Indicated

Physiologic Benefit = / < Physiologic Burden
Treatment advances patient towards goal

Physiological Benefit > Physiological Burden
Treatment advances patient towards goal

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Continuum of Medically Indicated Therapy – Gray Area

- Potential physiologic benefits of the treatment are much smaller than the known physiologic burdens
  - Treatment has no reasonable chance of producing the physiological or functional effect desired or expected of the treatment
  - Treatment causes disproportionate harm to the intended benefit
  - Treatment has no realistic chance of returning the patient to a level of health that permits survival outside of an acute care hospital
  - Treatment is contrary to generally accepted medical standards or established clinical guidelines

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Continuum of Medically Indicated Therapy – Gray Area

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Defining Futile and Potentially Inappropriate Interventions: A Policy Statement From the Society of Critical Care Medicine Ethics Committee

Alexander A. Kon, MD, FCCM[1]; Eric K. Shepard, MD, FCCM[2]; Nneka O. Sederstrom, PhD, MPH, FCCM[3]; Sandra M. Swoboda, RN, MS, FCCM[4]; Mary Faith Marshall, PhD, FCCM[5]; Barbara Birriel, MSN, ACNP-BC, FCCM[6]; Fred Rincon, MD, MSc, MBE, FCCM[7]

2. ICU interventions should generally be considered inappropriate when there is no reasonable expectation that the patient will improve sufficiently to survive outside the acute care setting, or when there is no reasonable expectation that the patient's neurologic function will improve sufficiently to allow the patient to perceive the benefits of treatment.
3. The above definition should not be considered exhaustive. There will be cases in which life-prolonging interventions may reasonably be considered inappropriate even when the above definition is not met.
4. Decisions regarding whether specific interventions are inappropriate should be made on a case-by-case basis (1).

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Kon, *CCM*, 2015

Continuum of Medically Indicated Therapy – Gray Area

- Patient’s goal for their healthcare
  - Treatment will not reasonably produce effects that will further the patient’s stated goals
  - Will only serve to maintain the patient's life in a quality of life that is unacceptable to the patient

Continuum of Medically Indicated Therapy

Medically Indicated

Physiologic Benefit = / < Physiologic Burden
Treatment advances patient towards goal

Not Medically Indicated

Physiological Benefit > Physiological Burden
Treatment advances patient towards goal

Desired physiologic benefit cannot be achieved
Treatment does not advance the patient towards goal

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Continuum of Medically Indicated Therapy – Problems in the Gray Area

- Patient and/or patient's surrogate may change the goal
- Can clinicians unilaterally refuse to provide treatment in the gray area?

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Ethics of Providing Potentially Inappropriate Therapy

- Social Contract
  - Society has empowered physicians with a monopoly to provide certain life saving activities
  - Physicians should provide these services to society, even if an individual believes these services to be inappropriate, under certain conditions
- Federal Regulations
  - Affordable Care Act "[prohibits] discrimination on the basis of race, color, national origin, disability, sex, and exercise of conscience and religion in HHS-funded programs."
  - "Persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities."

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https://www.dhcs.ca.gov/Documents/COVID-19/Joint-Bullletin-Medical-Treatment-for-COVID-19-033020.pdf

Suggested Conditions for Providing Potentially Inappropriate Therapy within the Social Contract

1. There is an ongoing physician-institution / patient relationship
2. The physician and/or institution can provide the desired skill or service
3. There is no other physician and/or institution who can or is willing to provide the skill / service
4. There is equitable funding for the service – i.e. cost of the service is not borne by the institution but rather by a readily available funding mechanism such as insurance
5. The treatment preserves a known fundamental interest such as preservation of life or appropriate relief of pain

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Veatch, *Perspectives in Biology and Medicine*, 2017

Continuum of Medically Indicated Therapy – Problems in the Gray Area

- Patient and/or patient's surrogate may change the goal
  - Treatment may subsequently meet criteria for medical indication
- Can clinicians unilaterally refuse to provide treatment in the gray area?
  - It depends…

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Defining Medically Indicated Therapy

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Goals of care

- Important to discuss prior to talking about treatments
- Once goals are known recommendations can be made
- Goals are based on personal values
- Values are not medically determined

Be careful with assumptions

- “What would you do if this were your Mom?”
- Not everyone wants all available interventions to prolong life (but many do)

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True physiologic futility

- Relatively rare

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Example

- 65 y/o woman with DM, HTN, stroke who develops respiratory failure due to COVID – on bipap but DNAR
- Indicates wants bipap off
- Husband and son understand she is not improving and don't want to prolong suffering

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What “futility” tries to explain

- There are limits to medicine
- Humans are mortal

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Example

- 36 y/o woman with metastatic cancer admitted multiple times for acute GI bleeds – recommended to go home on hospice each time
- Survives 14 months until develops liver failure

When families ask for a “miracle”

- Is this a legitimate request?
- We don’t perform miracles
- But we can give more time

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Example

- 26 y/o man with cardiac arrest due to drug overdose
- Now with hypoxic brain injury – no significant improvement expected
- Peg/trach/vent can extend life in this state (but won't improve brain function)

Tradeoff's

- "What are you willing to go through to get more time?"
- Individual values determine this, not medical prognosis alone

Society's goals for medicine

- What do we want collective funds used for?
- Is prolonging death an acceptable goal?

Endings Matter

- "In stories, endings matter. Endings are not entirely controllable, but, we are not helpless either. The chance to shape one's story is essential to sustaining the meaning in life."
  - Atul Gawande, "Being Mortal"

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Four Box Model

Clinical judgment

Surrogate's substituted judgment

Medical Indications	Patient Preferences
Beneficence Nonmaleficence	Respect for Autonomy Decisional Capacity Informed Consent
Quality of Life	**Contextual Features**
Beneficence Nonmaleficence Respect for Autonomy Goals of Care Withdrawal of Life Support	Justice Financial Toxicity Religion and Culture Conflict of Interest

Shared decision making
Societal norms

Policy and law

AR Jonsen, M Siegler, W Winslade, *Clinical Ethics*, 7th edition. McGraw-Hill, 2010.

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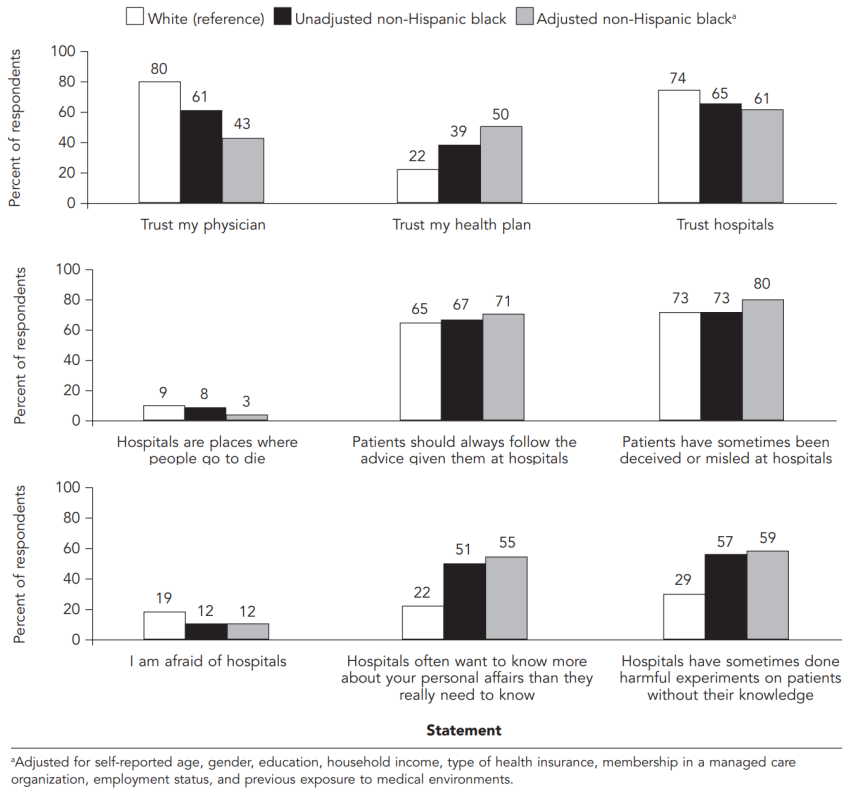
Therapeutic relationship in medicine

Trust

- Society has entrusted the medical profession
- The medical field has eroded that trust
- We must rebuild and nurture that trust

BUILDING TRUST
An initiative of the ABIM Foundation



Boulware LE et al. Public Health Rep. 2003 Jul-Aug;118(4):358-65.

Therapeutic relationship in medicine

Physician-patient relationship

- **Communication style** is equally important as the actual information that is being communicated
  - Verbal
  - Non-verbal (eye contact, folded arms or legs, phone)
- **Effective communication** has been shown to influence emotional health, symptoms resolution, function, pain control, and physiologic measures such as blood pressure levels
- **Miscommunication** can have severe negative implications such as impeding patient understanding, expectations of treatment, treatment planning, decreasing patient satisfaction of medical care, and reducing levels of patient hopefulness
- **Collaborative communication** and decision making have been correlated with greater patient satisfaction and loyalty

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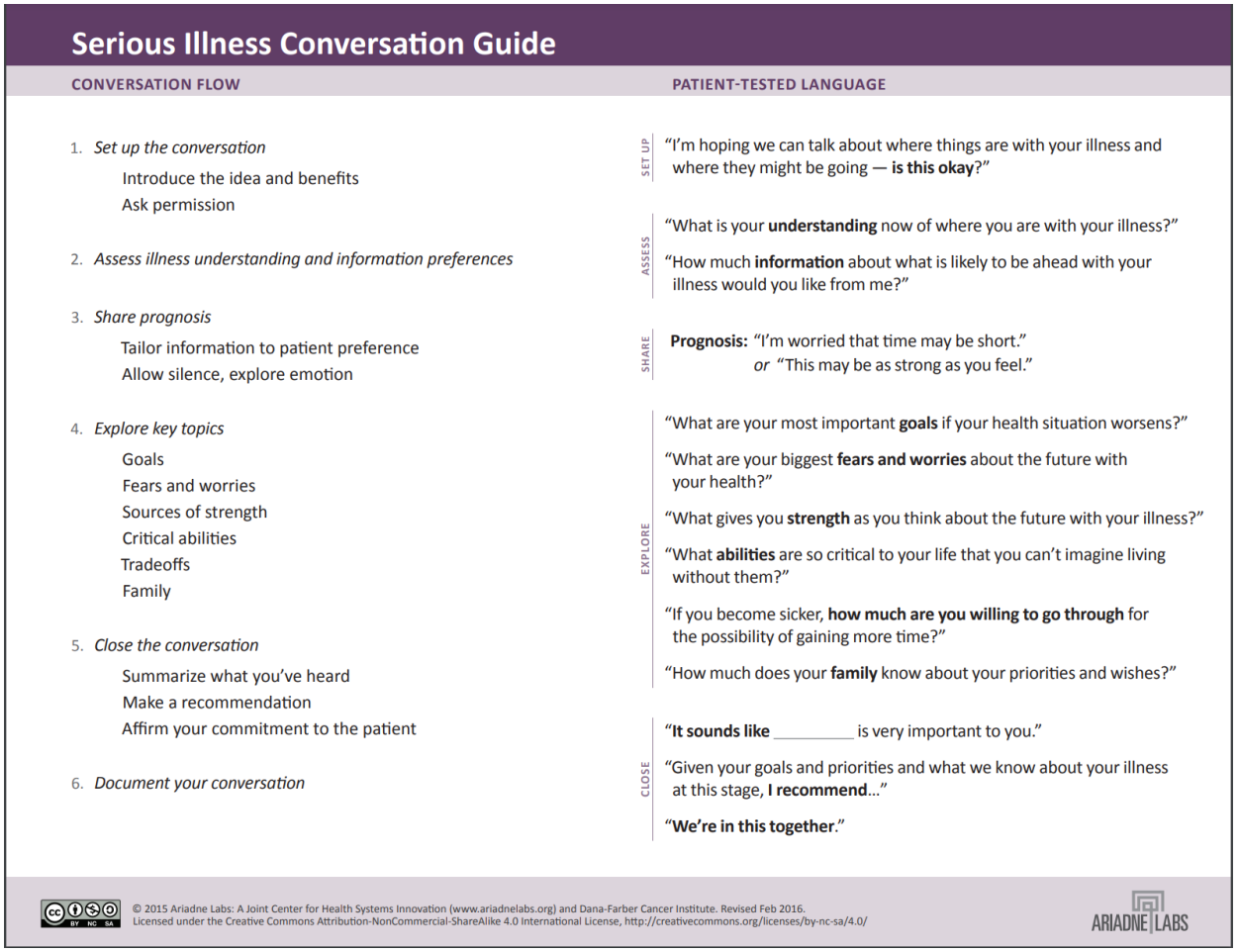
Lee SJ et al. Hematology Am Soc Hematol Educ Program. 2002;464-83.
Stewart MA et al. CMAJ. 1995;152(9):1423-33.
Ha JF et al. The Ochsner journal 2010;10(1):38-43.

Scripts

1. Ask permission
2. Seek to understand
3. Explore
   - ***"I worry…"***
   - ***"I wonder…"***
   - ***"I wish…"***
4. Support a shared decision



Serious Illness Conversation Guide

CONVERSATION FLOW		PATIENT-TESTED LANGUAGE
1. *Set up the conversation* Introduce the idea and benefits Ask permission	SET UP	"I'm hoping we can talk about where things are with your illness and where they might be going — **is this okay**?"
2. *Assess illness understanding and information preferences*	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?"
3. *Share prognosis* Tailor information to patient preference Allow silence, explore emotion	SHARE	**Prognosis:** "I'm worried that time may be short." *or* "This may be as strong as you feel."
4. *Explore key topics* Goals Fears and worries Sources of strength Critical abilities Tradeoffs Family	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?"
5. *Close the conversation* Summarize what you've heard Make a recommendation Affirm your commitment to the patient	CLOSE	"**It sounds like** _____ is very important to you." "Given your goals and priorities and what we know about your illness at this stage, **I recommend**…" "**We're in this together**."
6. *Document your conversation*		

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Moral Distress

Moral distress

- Occurs in situations in which a person recognizes a moral problem but is constrained from acting on it or resolving it

Moral residue

- Lingering feelings which each of us carries from those times when in the face of moral distress we have seriously compromised ourselves or allowed ourselves to be compromised

> *"Every surgeon carries within themselves a small cemetery, where from time to time they go to pray—a place of bitterness and regret, where they must look for an explanation for their failures."*
>
> *René Leriche*

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Moral Distress

Causes	Best Practices
Delayed end of life discussions (ECMO) Delayed or poor decision making (unrepresented patient) Medically inaccessible care (COVID) Medically inappropriate care (code status) Miscommunication (death by neurologic criteria, cultural assumptions, bias) Grieving family members	Debriefing (**recognize**) Ethics consultation service *24/7* (**ask for help**) Reflection and Community Resiliency Model (**resilience**) Schwartz Rounds (**community**)

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MS Rosenthal et al. AMA J Ethics. 2017;19(6):585-594.

Legal Perspective

Questions?