# WORDS MATTER: IMPROVING WORD CHOICE WHEN TALKING WITH PATIENTS & FAMILIES

Terry Altilio, LCSW, APHSW-C; Anne Kelemen, LICSW, APHSW-C

# OBJECTIVES

- Review common language used in healthcare settings to raise consciousness about the influence of word choice on patients, families, staff & outcomes.

- Provide examples of words & phrases commonly used in both inpatient & outpatient settings such as ICU, hospice & oncology which have unintended consequences.

- Challenge silence or accommodation as a response to well-intended yet unhelpful communication suggesting alternatives.

# INTENDED TO INVITE ATTENTION & INTENTION – RATHER THAN AGREEMENT

Care imitates language; that is, we tend to relate to people the same way we write & talk about them

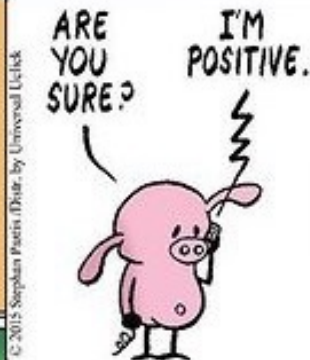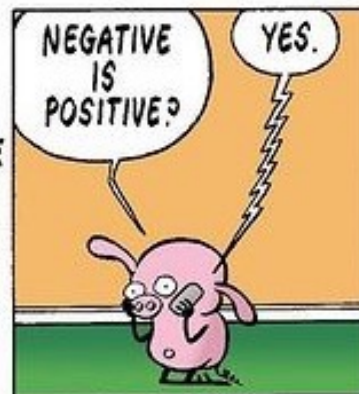~ Monroe, W., Holleman, W. & Holleman M.C. (1992)
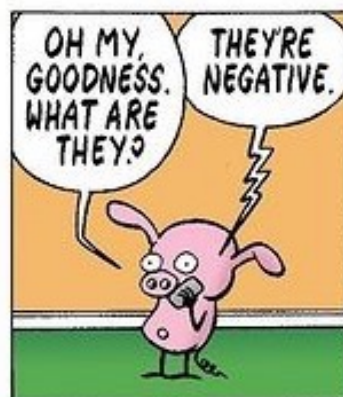
# CONFUSING MEDICAL TERMINOLOGY

- Chest X ray was *negative*

- Biopsy was *positive*

- Blood cultures were *negative*

- Your white count is *increasing*

- *Progressing* through treatment

# METAPHOR

- Congruity with self ?
- Sustainable over time ?
- Validates one as part of a group
  - Survivor
  - Warrior
  - Fighter
  - Victim
- Journey

# METAPHOR

In fact, metaphors may be as necessary to illness as they are to literature, as comforting to the patient as his own bathrobe & slippers. At the very least they are a relief from medical terminology. Perhaps only metaphor can express the bafflement, the panic combined with beatitude of the threatened person.

~ Broyard (1992)

# METAPHOR

My point is that illness is not a metaphor & that the most truthful way of regarding illness- & the healthiest way of being ill- is the one most purified of, most resistant to, metaphoric thinking. Yet it is hardly possible to take up one's residence in the kingdom of ill unprejudiced by the lurid metaphors with which it has been landscaped.

~ Sontag (1978)

# HOW WE SPEAK ABOUT OUR WORK HAS SOCIAL & POLITICAL RAMIFICATIONS

MESSAGING & ANCHORING

# ATTRIBUTED MEANING

- ## Political & Social Impacts
  - Physician aid /assisted death /suicide
    - Death with Dignity
  - Lethal medication…dose
  - "I did the morphine thing"
  - Terminal, Palliative extubation
  - Pulling the plug
  - Narcotics
  - Hospice as "industry"
  - Caregiver or Care partner

# ATTRIBUTED MEANING

- Complicating decision-making
  - Feeding tube; children & elders
  - Withdrawing life-sustaining treatment; forgoing
  - Brain death
  - Comfort care - build fluidity & specificity
    - Rxs continued, added or discontinued
- Challenges to personhood
  - Vegetative
  - Harvesting organs

# A Sampling of Labels

- In denial; doesn't get it
- Complains
- Addict /drug-seeking
- Clean / dirty
- Slow / simple
- Unrealistic
- Odd

- Dysfunctional
- Abusive
- Resistant, difficult
- Demented
- Unfortunate
- Cute, sweet, loved
- Entitled / VIP

# UNINTENDED CONSEQUENCES

Non-compliant or non-adherent

- Treatments not "offered"; not a "candidate"

- We can't *offer* a "finite resource to this patient"

  - Impacts length of life

- May limit options for post hospital plan

  - "Who will take this patient?"

# UNINTENDED CONSEQUENCES

## Bereavement & Legacy of Illness

### Documentation

"Family decided to go with minimal care & comfort medications only"

### Memory of Words

The neurologist- "99% sure there's nothing we can do."

Wondering about the 01% keeps the mother up at night

~ Goldstein, (2015)

# DELEGITIMIZING…

- Context in which one's experience is disbelieved or discounted
  - Claims to be in pain
  - Refuses
  - Doesn't get it
  - Poor historian

# DELEGITIMIZING…

A Narrative Review of the Impact of Disbelief in Chronic Pain

- Explore the social context in which individuals experience disbelief
- Key results integrate to form three main themes

~ B.J. Newton et al, (2013)

# THEMES CAPTURED

- *Stigma* – through actual or perceived encounters

  - Psychological explanation of pain
  - Perceived challenge to integrity & thereby affect identity
  - May be influenced by negative female stereotypes

- The experience of *isolation* consequent to loss of relationships & being disbelieved – may be self-initiated

- Disbelief can lead to *emotional distress* – guilt, anger depression

# SUFFERING

# RESILIENCE & SELF CARE

- Heard differently at times when discontinuity has evolved between the values we may have *thought* were shared & we find that they are not.
  - Ethics related to individual or situated in relationships
  - Relational autonomy – what might we owe each other ?

- Can messages about resilience & self care imply individual responsibility when systems level concerns are ignored, seem insurmountable or profound threats to values & competence are not acknowledged.

# RESILIENCE & SELF-CARE

- Empathic curiosity seeks to discover the unique meaning of events over the past two years - listening to understand – not respond or solve.

  Halpern, (2007)

- Bouncing forward; do not return to normal as one knew it; rather change to navigate new terrain & react to reorganization.

  Walsh, (2003)

# WHAT MAY BE USEFUL TO DECONSTRUCT – SPOKEN OR WRITTEN

# LISTEN FOR COGNITIVE DISTORTIONS

# ALL OR NOTHING
## (BINARY)
# OVERGENERALIZATION (BROAD
## ASSUMPTION FROM LIMITED EXPERIENCE)

- Always
- Never
- All
- Every

There is nothing I can do for you.

No-one has ever recovered...

- None
- Everyone / No one
- Nobody
- All the time

Do you want everything done?

If your heart stops do you want us to bring you back?

# WHAT CATASTROPHIZING MIGHT SOUND LIKE

Imagine the worst possible outcome & react as if it will surely come true

- Resuscitation (DNR vs DNAR)
  - Pound on the chest
  - Break ribs
  - Shock you…
    - Informed consent ~ coercion ?
- Torture, inhumane
  - What does this say about "us"

# PERSONALIZATION

- Taking responsibility beyond our control
  - Death ~ Letting go, giving up, stop fighting
    - Simplify the mysterious
    - Unfinished business
    - Cause & effect vs uncertainty
      - True, true, unrelated
    - Dying as a matter of will
    - Allow Natural Death

# PERSONALIZATION

"If she did not fail the chemotherapy, then I failed"

~ Oncology MD Fellow, a Hallway Conversation

# DEPERSONALIZING

- Identifying person with….
  - Disease ~ Addict, sickler
  - Status ~ DNR, Room 3
  - Medical constructs ~ Case
    - Instance of disease
  - Body part …..

# I HAVE OTHER PATIENTS

## "If you have other patients to see, then why is no one seeing me?"

*~ Patient at MedStar Washington Hospital Center; & former RN*

# SILENCE GIVES CONSENT

# HELP ME UNDERSTAND WHAT YOU ARE SEEING, HEARING…

# MITIGATING UNINTENDED HARMS

- Shared inquiry: consider information as data to be explored
- Use preferred phrases & words
- Identify patient & or family responses & frame as invitations for further clarification & discovery
- Direct exploration, discussion with colleagues always assuming best of intentions
- Journal clubs; shared learning

# 100% CONTROL OF WHAT WE SPEAK & WRITE

~ Amy Herman, 2015

# TESTIMONIAL INJUSTICE

- 3 linguistic features suggesting disbelief

  - Quotes (had a "reaction" to the medication)
  - Judgement words ("claims" "insists")
  - Evidentials – (sentence construction in which patients' symptoms or experience is reported as hearsay)
    - Complains, denies, says, reports .....

~ Beach et al., 2021

# TESTIMONIAL INJUSTICE

- Credibility Excess

     The prejudice results in the speaker receiving more credibility than they otherwise would have.

- Credibility Deficit

     The prejudice results in the speaker receiving less credibility.

Fricker, 2007

# CONSEQUENTIAL HARMS

- Acted out in law enforcement's response in Black communities

- In healthcare
  - Delayed diagnosis, inappropriate treatment, unnecessary pain & suffering & possible death

- Links to substantive harms similar to harms of microaggressions & experience of being disbelieved

- When discredited we are dishonored as human- a symbolic, consequential, "core epistemic insult."

# EVIDENTIALS

- Grammatical element indicating the source of knowledge.
- It will rain later; I heard it will rain later.
- Evidentials are used often: "the patient reports that the headache started yesterday."
- While not necessarily casting explicit doubt on veracity of the information, the choice to use evidentials allows the speaker to be agnostic about the statement's truthfulness.

# CAUTIONARY NOTES

- Linguistic features may not be precise markers of testimonial injustice.
- Use of evidentials is not inherently disparaging & may be helpful for clinical reasoning.
- Need for further work to explore racial differences in use of evidentials represent true testimonial injustice.

## Table 1 Text Employed in the Vignettes

| Neutral language chart note | Stigmatizing language chart note |
| --- | --- |
| **Section 1**<br>Mr. R is a 28-year old man with sickle cell disease and chronic left hip osteomyelitis who comes to the ED with 10/10 pain in his arms and legs. He has about 8–10 pain crises per year, for which he typically requires opioid pain medication in the ED. At home, he takes 100 mg OxyContin BID and oxycodone 5 mg for break-through pain. Over the past few days, he has taken 2 tabs every 4–6 hours. About 3 months ago, he moved to a new apartment and now has to wheel himself in a manual wheelchair up 3 blocks from the bus stop.<br><br>He spent yesterday afternoon with friends and wheeled himself around more than usual, which caused dehydration due to the heat. He believes that this, along with recent stress, precipitated his current crisis. The pain is aching in quality, severe (10/10), and not alleviated by his home pain medication regimen.<br><br>On physical exam, he is in obvious distress. He has no fever and his pulse ox is 96% on RA. The rest of the physical exam is normal other than tenderness to palpation on the left hip.<br><br>~Goddu et al; 2018 | Mr. R is a 28-year old sickle cell patient with chronic left hip osteomyelitis who comes to the ED stating he has 10/10 pain "all up in my arms and legs." He is narcotic dependent and in our ED frequently. At home he reportedly takes 100 mg OxyContin BID and oxycodone 5 mg for breakthrough pain. Over the past few days, he says that he has taken 2 tabs every 4–6 hours. About 3 months ago, patient states that the housing authority moved him to a new neighborhood and he now has to wheel himself in a manual wheelchair up 3 blocks from the bus stop.<br><br>Yesterday afternoon, he was hanging out with friends outside McDonald's where he wheeled himself around more than usual and got dehydrated due to the heat. He believes that this, along with some "stressful situations," has precipitated his current crisis. Pain is aching in quality, severe (10/10), and has not been helped by any of the narcotic medications he says he has already taken.<br><br>On physical exam, he appears to be in distress. He has no fever and his pulse ox is 96% on RA. The rest of the physical exam is normal although he reports tenderness to palpation on the left hip. |

# WHY DOES STIGMATIZING LANGUAGE MATTER?

- Exposure to stigmatizing language associated with more negative attitudes toward patient

- Reading stigmatizing language was associated with less aggressive management of pain

~ Goddu et al.

2018

# RACIAL BIAS IN EHR

- Black patients had 2.54 times the odds of having at least one negative descriptor in the history & physical notes

- Most commonly used descriptors in any contexts were:
  - Refused
  - Not compliant
  - Agitated

~ Sun et al., 2022

# STRUCTURAL COMPETENCE

Moves understanding & documentation from the level of the individual to institutions, communities & policy.

~Hansen 2022

# Medical record: "a mechanism for transmitting bias"

~ Goddu et al. 2018

# ADDITIONAL EVIDENCE

- Objective: How many patients feel judged or offended due to something they read in an outpatient note & why?

- Methods: Analyzed responses from at least 1 note at 2 large academic medical systems

- Results: One in 10 respondents reported feeling judged & / or offended by something read in their note.

~ Fernandez et al., 2021

# WHAT WAS JUDGMENTAL OR OFFENSIVE?

Errors or Surprises:

• How much personal information was in the note

Labeling:

• "elderly" "anxious" "well groomed"

• "pleasant" or "delightful"

Disrespect:

• "patient claims" or "patient denies"

• former smoker as "blaming"

# CHANGING LANGUAGE DOES NOT COST ANYTHING

# "PERSON" OR "THERAPY" FIRST

- Person-first language (PFL)
  - Avoids marginalizing or dehumanizing by categorizing a person by a condition or a trait such as disease, age, disability rather than as a person who *has* that condition or trait. *(individuals may chose to self-identify – as a blind person/deaf person – so ask "how do you self identify?")*

- Therapy-first language
  - Avoids blame & focuses on treatments that are no longer effective or haven't had the intended outcome.
    - "The chemotherapy is no longer working."

~ Kelemen & Groninger, 2017

# "AND" RATHER THAN "BUT"

But – Negates what came before
- Stops a thought; often heard as rejection.
  - "I hear that you believe your mom is responding to you but the doctors indicate that this is not purposeful"

And – Builds & joins; connects words & thoughts.
- Invites shared consideration; creates an atmosphere of acceptance & possibility
  - "I hear that you believe your mom is responding to you & we wish her responses were purposeful"

http://nlp-now.co.uk/be-careful-with-but/
http://petermargaritis.com

# "REQUIRES" RATHER THAN "USES"

Requires – Has need of

- 49 yr. old female with stage IV lung cancer requires 60 mg oxycontin to manage her pain

Uses – Habit, routine, custom

- 49 yr. old female with stage IV lung cancer uses 60 mg oxycontin to manage her pain

# AN EXAMPLE - REFRAMING

- There is nothing I can do for you
  - I wish there was something more to do to contain the disease.
  - I wish we had more effective treatment for your condition.

- Wishes express empathy;
  - Joining to wish circumstances were different & simultaneously acknowledges the emotional impact of the loss.

- By expressing wishes, clinicians join as human beings faced with circumstances that are, most of the time ~ not of their own choosing.

- Wish statements imply the desired outcome is unlikely to occur; very different then saying something hopeful that may not be connected to reality

- I wish statements are only the beginning of a conversation…

# CONSIDERATIONS IN WORD CHOICE

- Use descriptors rather than labels
  - Homeless male
  - Person experiencing homelessness (put in social hx not HPI)
- More objective; less judgment
  - Drug abuser (reports history of substance use)
- Empower; support
  - Instead of "former smoker" ~ *"Patient reports they stopped smoking 10 years ago"*
- Describe accomplishments
  - Stopped smoking
  - Patient describes a 30 year recovery

~ Fernandez et al., 2021

# COVID LANGUAGE

| Common Questions/Concerns | Suggested Response |
|---|---|
| I am dying and my family can't come to be with me. | We hear that this is not what you had imagined at the end of this life. Let's see how we can create sharing time, memories or legacy through phone or skype. Suggestions: record messages on a smart phone to give to family; have the patient dictate a note that can be given to family, assist staff when time allows to share thoughts about the patient. |

~ Kelemen, A., Leff, V. Altilio, T.
~

# PHRASES THAT PROVIDERS USE

| Phrases that May Alarm You | Consider Using Instead | Rationale |
| --- | --- | --- |
| You are failing the inotrope | The inotrope (or other therapy) is no longer working | Removes blame from patient & focuses on the progressing disease or therapy that has become ineffective |
| You are not a candidate for the LVAD | The LVAD or medication, or procedure, etc.) will not help achieve your goals; create our hoped for outcome | Focuses conversation on intervention best fit for patient's condition, rather than on patient. Aligns clinician with patient in shared decisions & hopes |
| Nothing more we can do for you | No effective therapy to cure (or mitigate, slow, temporize etc..) the disease | There is always something that can be done to help. |

# PHRASES
## PATIENTS & FAMILIES USE

| Phrase that May Alarm You | Consider Using Instead | Rationale |
|---|---|---|
| They want to live | What goals are important for you to live the best life?<br>We can promise you effort, not outcome | Focuses discussion on what is specifically important to the patient & may be possible. |
| Do everything | We will continue to do everything that may help achieve your goals, if possible. | Clarifies an otherwise unhelpful general statement & focuses on patient's specific goals |
| | | |

# REFERENCES

Altilio, T. (2011) . The power and potential of language. In: T. Altilio T & S. Otis-Green (Eds). *Oxford textbook of palliative social wor*k (pp. 689-695). Oxford University Press.

Altilio, T., Leimena, M. & Li, Y. (2014). Attention and Intention. An invitation to reflect on language. *AAPHM Quarte*rly, 14-18.

Beach, M.C., et al. (2021). Testimonial injustice: Linguistic bias in the medical records of Black patients and women. *Journal of General Internal Medicine,* 36**,** 1708-1714. doi.org/10.1007/s11606-021-06682-z

Bedell, S.E., et al. (2004). Words that harm, words that heal. *Archives of Internal Medicine*, *164* (13), 1365-1368.

Bosslet, G.T., et al. (2015). An official ATS/AACN/ACCP/ESICM/SCCM policy statement: Responding to requests for inappropriate treatments in intensive care units. *American Journal of Respiratory and Critical Care Medicine*, *191*(11), 1318-1330.

Broyard, A. (1992). *Intoxicated by my illness and other writings on life and death.* New York: Balantine Books.

Buechner, F. (1991). *The sacred journey: A memoir of early days* (p.68). Harper Collins.

Charon, R. (2001). Narrative medicine: A model for empathy, reflection, profession and trust. *Journal of the American Medical Association*, *286*(15), 1897-1902.

# REFERENCES

Charon R. (2006). *Narrative medicine: Honoring the stories of illness*. Oxford University Press. NY.

Ciriello, A., Dizon, Z. & October, T. (2017). Speaking a different language: A qualitative analysis comparing language of palliative care and pediatric intensive care unit physicians. *American Journal of Hospice and Palliative Medicine*, DOI:10.1177/1049909117700101.

Curtis, JR, et al. (2005). Missed opportunities during family conferences about end-of-Life care in the intensive care unit, *American Journal of Respiratory and Critical Care Medicine*, *171*(8), 844-849.

Fernández, L., et al. (2021). Words matter: What do patients find judgmental or offensive in outpatient notes? *Journal of General Internal Medicine, 36*, 2571-2578.

Fricker, M. (2007). *Epistemic injustice - Power and the ethics of knowing*. Oxford University Press.

Fine, R.L. (2007). Language Matters: "Sometimes we withdraw treatment but we never withdraw care". *Journal of Palliative Medicine,10*(6), 1239-1240.

Gaynard, L. (1998). *Psychosocial care of children in hospital: A clinical practice manual from the ACCH child life research project*.

# REFERENCES

Goddu, P.A., et al. (2018). Do words matter? Stigmatizing language and the transmission of bias in the medical record. *Journal of General Internal Medicine*, *33*(5), 685-691. doi.org/10.1007/s11606-017-4289-2.

Goldstein, R. (2015). What conversations do bereavement parents remember? *Journal of Palliative Care Medicine, 5*(1).

Groninger, H., Kelemen, A., & Ruiz, G. (2016). "Vote For Me." *JAMA, 316*(1), 31-2.

Halpern, J. Empathy and Patient–Physician Conflicts. *Journal of General Internal Medicine,* 22, 696–700 (2007). https://doi.org/10.1007/s11606-006-0102-3

Hartzband, P. & Groopman, J. (2011). The new language of medicine. *New England Journal of Medicine, 365*(15), 1372-1373.

Herman, A. (2016). Visual Intelligence. https://www.youtube.com/watch?v=4v_tn4nyjwE

Holm, S. (1993). "What is wrong with compliance?" *Journal of Medical Ethics*, (19),108-110.

Hutchison, L. (2014, May 12) "Battle cancer? Yes. But lose? No way. Fredersickburg.com Via The Free Lance-Star.

Hitchens,C. *Mortality*. (2012). New York, NY.

# REFERENCES

Kearney, M.K., et al. (2009). Self-care of physicians caring for patients at end of life. *Journal of American Medical Association*, *301*(11),1155-1164.

Kelemen, A., Ruiz, G., & Groninger, H. (2016). Choosing words wisely in communication with patients with heart failure and families. *American Journal of Cardiology*, *117*(11), 1779-82.

Kelemen, A., Groninger, H. (2017). Therapy first, Not the patient? *Journal of Social Work in End-of-Life & Palliative Care,* Published Online Feb. 10th.

Liben, S. (2011) "Words Matter: The importance of the language we use." *Journal of Palliative Medicine, 14*(2).

Luks, Andrew M. (2021). Watch your language! – Misusage and neolgisms in clinical communication. *JAMA Internal Medicine, 181*(1), 5-6.

Lutfey, L. & Wishner, W. (1999). Beyond compliance is adherence. Improving the prospect of diabetes care. *Diabetes Care, 22*, 635-639.

Lundebjerg, N.E. et al.(2017). When it comes to older adults, language matters: Journal of the American Geriatrics Society adopts modified American Medical Association Style. *Journal of the American Geriatric Society* (JAGS), *65*, 1386-1388.

Margaritis, P. (2016) The difference between "But" & "And".
http://petermargaritis.com/the-difference-between-but-and/

# REFERENCES

McDonough, J.R., et al. (2004). Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction. *Critical Care Medicine*, *32*(7),1484-1488.

McKee M. (2003). Excavating our frames of mind: the key to dialogue and collaboration. *Social Work, 48*(3), 401-8.

Monroe, W.F., Holleman, W.L. & Holleman M.C. (1992). "Is there a person in this case?" *Literature and Medicine, 11*(1), 45-63.

Newton B.J., et al. (2013), A narrative review of the impact of disbelief in chronic pain. *Pain Manag Nurs, 14*(3):161-71. doi: 10.1016/j.pmn.2010.09.001. Epub 2010 Nov 26. PMID: 23972867.

Pantilat, S.Z. (2009). Communicating with seriously ill patients: Better words to say. *JAMA, 301* (12),1279-1281.

Park, J. et al. (2021). Physician use of stigmatizing language in patient medical records. *JAMA Netw Open, 4*(7):e2117052. doi: 10.1001/jamanetworkopen.2021.17052. PMID: 34259849; PMCID: PMC8281008

Parles, K. (2004) . "The patient failed chemotherapy". *The Oncologist,* 9, 719.

Pegasus NLP. The word 'but' Use it with caution. https://nlp-now.co.uk/be-careful-with-but/

# REFERENCES

Quill, T.E. et al. (2001). "I wish things were different": expressing wishes in response to loss, futility, and unrealistic hopes. *Ann Intern Med.(7)*:551-5.doi: 10.7326/0003-4819-135-7-200110020-00022. PMID 11578166.

Reyna, V.F. et al. (2009). How numeracy influences risk comprehension and medical decision making. *Psychogical Bulletin, 135*(6), 943-973.

Sasser, C.G. (1999). The interdisciplinary team. In S.K Joishy (Ed.), *Palliative medicine secrets* (pp*. 21-27).* Philadelphia, Hanley & Belfus  Ins.

Semino, E. et al. (2017). *The online use of Violence and Journey metaphors by patients with cancer, as compared with health professionals: a mixed methods study. BMJ Supportive & Palliative Care, 7*:60-66.

Sinclair,  S. (2011).  Impact of death and dying on the personal lives and practices of palliative and hospice care professionals. *Canadian Medical Association Journal*, *183*(2), 180-187.

Sontag, S. (1978).  Illness as a metaphor. Farrar Straus Giroux. NY.

Sun, M., et al. (2022). Negative patient descriptors: Documenting racial bias In the electronic health record. *Health Affairs, 41*(2), 203-211.

Walsh, F. (2003). Family resilience- A framework for clinical practice. *Family Process*, 42:1-18.

# RESOURCES

American Medical Association and Association of American Medical Colleges. (2021) Advancing Health Equity: Guide on Language, Narrative and Concepts. Available at ama-assn.org/equity-guide

COVID handout: https://seriousillnessconversations.org/resources%2C-downloads#5cd8f366-b0f0-4c22-86f5-05d3668b8cfe

Hansen, H. (2022). Structural Competency: Medicine for the Inequalities that are Making Us Sick.
https://www.youtube.com/watch?v=x-fIvBmb_hU

Open Notes Learning Collaborative: https://www.opennotes.org/learning-collaboratives/