The Power of Language: Linking Word Choice to Inequity & Outcomes

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Objectives

Recognize that language & word choices integral to palliative care has the potential to create unintended consequences, creating distance when the goal is to build relationships.

Utilize constructs such as testimonial injustice & delegitimization to inform communication whether in documentation or conversation.

Develop confidence & emerging comfort in intervening when language & word choice used in patient care reflects potential bias & may foster inequities.

Foundational to Communication & Documentation in EMR of *Patient* across Professions & Settings with Potential to Harm & Heal

Intended to Invite Attention & Intention

– Rather than Agreement & to

Encourage Discovery whether Words

Are Used in the Present or Reported

from the Past

Changing Language Does Not Cost Anything, or Does It ??

Cultural norms & normalization of stigmatizing language suggests that this aspect of care be addressed at both individual & organizational level

~ Herron, 2021

The Meeting of Subjective Experience within Objective Landscapes

- Privileges numeracy - the ability to understand, use numerical information, & relate it to cognition, health behaviors, & medical outcomes
- Many (including us) lack numerical skills or do not view the world through numbers & interface with systems that understand & explain through data; "digital jungle"
- Low numeracy may impact outcomes, perceptions of risks & benefits, medication use, impede access to treatments etc.

~ Reyna, 2009

Confusing Medical Terminology

- Chest X ray was *negative*
- Biopsy was *positive*
- Blood cultures were *negative*
- Your white count is *increasing*
- *Progressing* through treatment

Considerations Across Age & Language

- I.C.U (I see you)
- *Shot*
- Stool collection
- Urine
- *CT scan (CAT Scan?)*
- Take your vitals ....
- The doctor will give you some dye (To make me die)

~ Gaynard et al. 1998

Considerations Across Populations

Adapting "Serious Illness Conversation Guide" for older adults experiencing homelessness based on interviews with service providers & recipients

Changing words & phrases; an example

How much does your family know about your wishes...to

Have you talked about your worries or what is important to you with other people...

~ Latimer et al., 2024

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
- Provider as transactional

& more…

- Pulling the plug
- Narcotics
- Hospice as "industry"
- Disposition
- Caregiver or Care partner
- Safety Net
- Burden, loved one

Attributed Meaning - Complicating Decision Making

- Withdrawing life-sustaining treatment
  - Brain death
- Withhold vs forego
- Ventilator descriptors
- Feeding tube; children & elders
- Suffering
- Challenges to personhood
  - Vegetative
  - Harvesting organs
- Comfort care - identify threads that infuse treatment choices; build specificity
  - Rxs continued, added or discontinued
  - "In Palliative Care"

Pain ~ Continues to Anchor Inequities & Bias & Invites Discovery

Drug seeking or relief seeking

Clock watcher

Addict, junkie, clean, dirty

Narcotics; diverting

They're asking for oxy

Likes the Percocet

Claims to be in pain

Does not look like they're in pain

They're dying anyway, who cares if they are addicted

Why is Pain Unique & Leads to Undertreatment

- Universal
- Culturally
- Spiritually
- Emotionally & socially infused - A subjective experience in settings that privilege objective knowledge

Delegitimizing...

A Narrative Review of the Impact of Disbelief in Chronic Pain

- Explore the social context in which individual's experience disbelief or discounted
- Key results integrate to form three main themes

~ 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

Testimonial Injustice

"that which occurs when a speaker receives unfair deficit of credibility due to prejudice on the part of the hearer"

... a hearer assigns lower credibility to a speaker due to "identity prejudice"

~ Fricker, 2007

Consider commonalities with epistemic micro aggressions; person's credibility as a knower is undermined

Testimonial Injustice

- Credibility Excess

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

- Credibility Deficit

  The prejudice results in them receiving less credibility

~ Fricker 2007

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

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

What Quotes May Signal

Scare Quotes may be used to convey an ironic, skeptical, or derisive stance toward the word or phrase; signals a nonstandard use which often requires a reader to read between the lines to intuit the particular sense intended by the author

~ Doose 2019

Medical Record: "a Mechanism for Transmitting Bias"

~ Goddu et al., 2018

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

Table 1 Text Employed in the Vignettes

Neutral language chart note	Stigmatizing language chart note
Section 1 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 breakthrough 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. 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. 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.	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. 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. 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.

~ Goddu et al., 2018

Non-Compliant / Non-Adherent

Take Away....

- Adherence is a cluster of behaviors not as simple as "they did not want to take medications today" or "they do not respect my guidance"
- We cannot assume to know the meaning of what we see...the task is to discover context & meaning
- Behaviors are informed & impacted by structural forces that sustain inequities & contribute to poor health outcomes

Unintended Consequences Do Harm

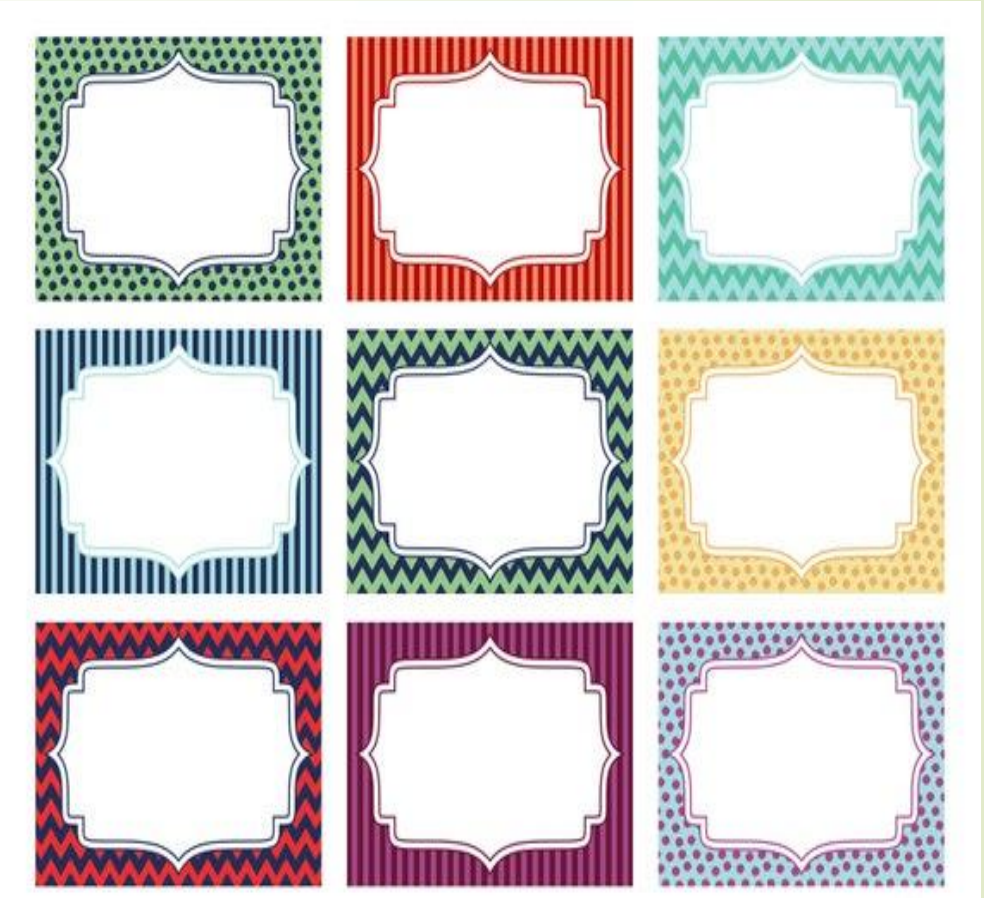
Non-compliant or non-adherent

- Treatments not "offered"; not a "candidate"
- We can't *offer* "finite resource to this patient" – impacting length of life
- May limit options for post hospital plan ~ "Who will "take" this patient?"

LABELS

Avoid descriptors that imply singular identity, generalize or message victimization, or helplessness

~ Herron, 2021



A Sampling of Labels

- In denial; doesn't get it
- Complains
- Slow / simple / odd
- Unrealistic
- Poor historian
- No show; missed treatment opportunity …
- Dysfunctional
- Abusive, difficult
- Resistant, refuses
- Demented
- Unfortunate
- Cute, sweet, lovely
- Entitled / VIP

Designed an Algorithm to Search

- Close to 1 million notes 2010-2023
- 2700 patients' w/ substance / opioid use disorder
- Looking for stigmatizing language ~ terms such as addict, abuse, dirty, junkie & alcoholic

- 85 % had stigmatizing language terms
- Female healthcare providers & social workers used stigmatizing language at a relatively high rate
- Demeaning language was used more often in medical records of Hispanic & Black patients, reaffirming previous research

~ Anderson, 2024

Labels & Messages May Be Useful to Deconstruct - Spoken or Written

Listen for Cognitive *Distortions*

- All or nothing thinking
- Overgeneralization
- Catastrophizing
- Depersonalizing

Patients during COVID; They did not die alone

~ Rabbi – panel member

All or Nothing
(Binary)
Overgeneralization
(Broad assumptions often 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?

Examples of 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; a joining to wish circumstances were different & simultaneously acknowledges the emotional impact of the loss
- Wishes join clinicians as human beings faced with circumstances that are, most of the time, not of their own choosing
- Wish statements are the beginning of a conversation; implying the desired outcome is unlikely to occur; different then hopeful words that may not be connected to reality

~ Quill et al. 2001

Catastrophizing Might Sound Like

Imagining the worst possible outcome & react as if it will surely come true: often driven by mora; distress

- 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
  - Medical constructs ~ Case
  - 3rd person referencing
  - "Salvage' chemo
  - Body part .....

Silence Gives Consent to Language which May Do Harm ~ 100% Control of What We Speak & Write

~ Herman, 2015

Consider the Purpose

- Notes –
  - Support diagnoses; are necessary for billing
  - Communicate across disciplines, settings & specialties
  - Written for multiple audiences including patients & families
  - What else ? Protect from litigation
- Our notes & words may impact how one enters the room

~ Klein et al., 2016

Power in Communication ~

"Good luck in there"
"Difficult to work with..."

~ Rusch, 2023

Help Me Understand What You Are Seeing, Hearing; Joining ...

We Listen from Our Training

- MD training may lead to a working hypothesis before they walk in the room; listening & valuing information to cohere & support; confounded by biases we all carry
  - May devalue other data ~ confirmation bias
  - Can we count on each other to enrich listening – to respond to clues others may have missed?
- Assist colleagues with unique listening to create shared vision of patient & family, assist in clarifying terminology, missed emotional, cultural & spiritual cues

Mitigating Unintended Harms

- Shared inquiry: information as data to be explored
- Use preferred phrases & words
- Identify patient & or family responses as invitations for further clarification & discovery
- Share writing of notes with patient & or family when sensitive information needs to be documented
- Hold sacred details of intimate conversations

~ Werder et al., 2022

- Exploration, discussion with colleagues always assuming best of intentions; shared learning

"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
- People may self-identify differently ~ as a blind person/deaf person ~ ask "how do you self identify?"

Therapy-first language

- Avoids blaming by focusing on treatment or intervention which has not had intended effect; the chemotherapy is no longer working

~ Kelemen & Groninger, 2017

They Will "Need"

- "If her breathing gets any worse, she will need to be intubated"
- What do families "hear" when clinicians use the word "need" – defined as "require because it is essential or very important; expressing necessity or obligation"
- Consider: "Your mother's condition is getting worse; can we talk about what this means & what to do next"?

Create space & invitation in a relationship to review & deliberate, express & respond to emotion

~ Kruser et al., 2023

"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 inviting shared consideration, creating an atmosphere of acceptance & possibility;

> I hear that you believe your mom is responding to you & we wish her responses were purposeful

https://petermargaritis.com/the-difference-between-but-and/

Breaking "Bad News"

- *Breaking Bad* News vs. Sharing Serious Information
- Interchange instead of unilateralism
- Health information is often "serious"; "bad" is based in an assumption made by clinicians

~ Berger & Ribeiro Miller, 2022

Considerations in Word Choice

- Use descriptors rather than labels ~ Homeless male becomes a person without stable housing (social Hx)
- Objectivity & less judgment ~ Drug abuser becomes reports a history of substance use
- Empower & support ~ Former smoker becomes a patient who reports they stopped smoking 10 years ago
- Describe accomplishments ~ Stopped smoking becomes patient describes a 30-year recovery

~ Fernandez et al; 2021

Care Imitates Language; That Is, We Tend to Relate to People the Same Way We Write & Talk about Them

Monroe, W. et al. 1992

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Q & A

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