A Look Through the Kaleidoscope: The Intersection of Pain, Word Choice & Inequities.

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This presentation will focus on the intersection of pain, ethics, word choice & inequities - toward the goal of fostering attention & intention in our care of patients.

Objectives

- Identify spoken & written communication that infuse pain assessment & management, contributing to inequities.
- Reinforce the uniqueness of pain as both a shared & subjective experience, identifying populations at risk for undertreatment & the ethical principles that drive the concurring mandates to create benefit & protects from harm.
- Review research driven by federal mandates to enhance patient access to health information toward goal of intentional & effective communication &

Pain

- "An unpleasant sensory & emotional experience associated with, or resembling that associated with, actual or potential tissue damage," & is expanded upon by the addition of six key notes.

2020- IASP; Revised from 1979

IASP Revised Key Notes

- Pain is always a personal experience influenced to varying degrees by biological, psychological, & social factors.
- Pain & nociception (sensory nerve cells) are different phenomena. Pain cannot be inferred solely from activity in sensory neurons.
- Through their life experiences, individuals learn the concept of pain.
- *A person's report of an experience as pain should be respected.**
- Although pain usually serves an adaptive role, it may have adverse effects on function & social & psychological well-being.
- *Verbal description is only one of several behaviors to express pain; inability to communicate does not negate the possibility that a human or a nonhuman animal experiences pain.*

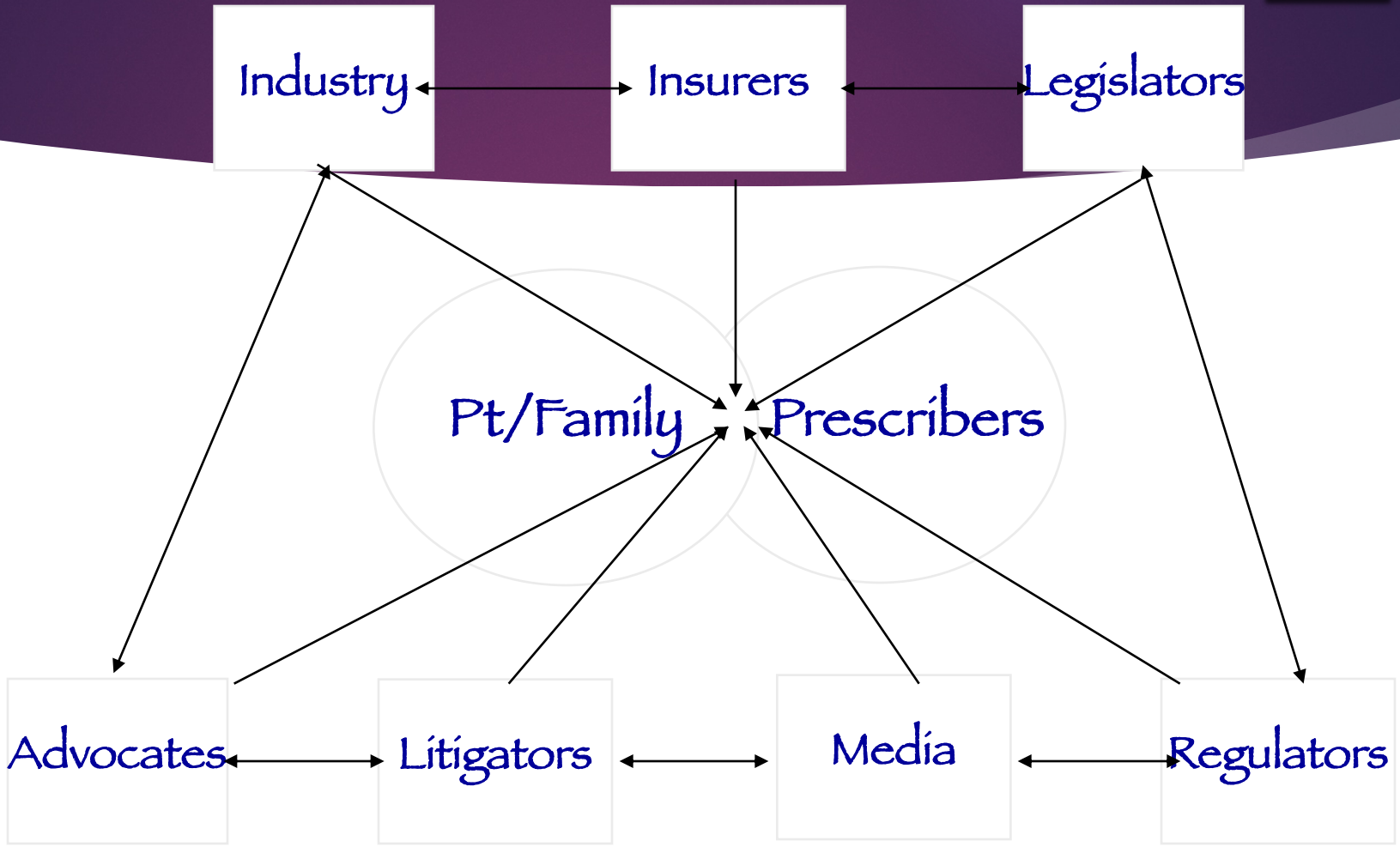
Why is Pain Unique & Lead to Under-treatment

- Universal,
- Culturally, Spiritually, Emotionally & Socially Infused - A Subjective Experience in Settings that Privilege Objective Knowledge

Persons with Pain are Treated within Converging Contexts

Within relationships & in environments which are impacted by individual, team, institutional & societal values, culture, history, beliefs & influences which invite, at the very least, inquiry, curiosity, attention & action ~ yet risk is not equitable

WHOSE PAIN IS IT ?



A Sampling of Data

- Pain occurs in 20% to 50% of patients with cancer.
- Roughly 80% of patients with advanced-stage cancer have moderate to severe pain.
- One meta-analysis of pooled data from 52 studies found that more than half of patients had pain.
- Younger patients are more likely to experience cancer pain & pain flares than are older patients.

National Cancer Institute, 2020

Persons at Special Risk for Under-Treatment Paice, 2010

- Those who are
  - Older; Cognitive impairment increases vulnerability
  - Younger
  - Female
  - English as a second language
  - Low literacy, innumeracy
  - Persons of color
    - Unintended consequence- lower % increase in deaths
    - until 2020.

Silence Is Not an Option

Care of patients who suffer, whether with or without pain is a Shared Responsibility & yet the risk for each discipline is not equal

Pain: Multidimensional Phenomenon

- Integrates
  - Knowledge of symptoms & treatments
  - Individualized illness experience - patient & family
- Impacts
  - Mood – depression, anxiety, demoralization etc.
  - Function
  - Quality of life
  - Grief & bereavement

Pain

- Assessed & treated in context of
  - Goals of care
    - Palliative Care &/or EOL
    - Chronic conditions
  - Progression of disease
  - Patient & family values
  - Political & social structures

Assessment of Pain

- Self report: no tool to objectively measure
  - Assessment tools, scales, numbers, words, colors etc.
- Extends from physical & sensory (bio) to more global construct – "cultural & social factors; the foundation for the expression & treatment"

(Roselyne Rey, *Histoire de la Douleur*, Editions La Decouverte, Paris 1993)

- Self report may be incongruous with observations or appraisal of family, caregiver or healthcare professionals
- Pain does not equal suffering & / or distress: Hurt may not equal harm.

Overdose Deaths

DATA & ITS IMPACTS

Overdose Mortality – Race & Ethnicity

CDC: 2020 - 93,655 + 30% CDC: 2021- 107,622 + 15%

Evaluation of data per 100,000 persons of 4 groups

Deaths among Black persons increased from 24.7 in 2019 to 36.8; Black mortality higher than White for the 1st time since 1999; In 2020, Black persons had largest % increase in opioid mortality (48.8%) compared with White (26.3%); American Indian or Alaska Native persons experienced highest rate of mortality (41.4%); Hispanic or Latino persons had the lowest rate (17.3 %) but experienced a large percentage increase (40.1%).

Friedman et al. 2022

Impacts + & -

As deaths increased in White communities

- Impacts stigma; obituaries
- "public health crises" rather than "criminal response"
  - CDC Guidelines, 2016
- Precipitous de-prescribing
- Emphasis on treatment resources & education of clinicians
- Organizations have disappeared & revised advocacy
  - Joint Commission, WHO, American Pain Society etc

Unintended Consequences

"It is clear that the CDC guideline has harmed many patients."

Issued 2016; update in process

Concerns about possible legal or professional jeopardy have been a significant factor in drastically reducing opioid prescribing by physicians. Liability for failing to prescribe opioids when medically indicated, especially if it results in a patient's suicide, may now be emerging as a countervailing force against the heedless tapering of patients with chronic pain.

American Medical Association, 2020

Unintended Consequences

Opioid use among patients dying of cancer has declined substantially from 2007 to 2017. Rising pain-related ED visits suggests that EOL cancer pain management may be worsening.

Enzinger et al. 2021

Deprescribing Among a Veterans Population

Among patients testing positive for illicit drug use while receiving long term opioid therapy, clinicians are substantially more likely to discontinue opioids when the patient is Black

Gaither et al., 2018

A Sampling of Mandates

PERMIT & REQUIRE CARE

Ethics, Standards & Litigation

- Ethical principles –
  - Justice, beneficence, non-maleficence
  - Fidelity, competence, non-abandonment
- Standards & guidelines; science & regulation
  - Usual & customary yet applied to unique circumstances
  - Fiduciary moral responsibility for technical competence – *Trust* we are doing our best & keeping pace with science; situational mistrust
  - Palliative sedation; relationship to knowledge
- Litigation
- Emphasis on end-of-life care; Legacy

Ethical Mandate: "Do No Harm"

Harm occurs when the amount of hurt or suffering is greater than necessary to achieve the intended benefit. Here lies the basic ethical challenge to caregivers; since pain seems harmful to patients & caregivers are categorically committed to preventing harm…not using all the available means of relieving pain must be justified."

Walco et al.1994

Respect for Persons

Human dignity requires & demands that unnecessary, treatable pain be relieved. Severe or chronic pain blocks or seriously impedes the realization of almost all other human values. Relief of unrelenting pain is required to allow the human being to reflect, enjoy human relationships & even to think & function on a most basic level.

Johnson, JLME 2001

Justice

- Fairness in access to care; persons will receive care equal to others
- Justice is violated when subgroups of patients receive less adequate pain management & as racial, socioeconomic & ethnic disparities continue
- Do we have an ethical duty to challenge conditions that create hostile environments including interventions suggestive of law enforcement or risk aversion rather than patient care ?

Principle of Balance

Opioids, often indispensable to managing pain, may also be abused

- Happenings in the world do not obviate ethical duty to patient
- Continued suffering must be result of inherent limits of science rather than lack of expertise

- Efforts to address abuse & public health concerns should not interfere with legitimate medical practice
- Pain & symptom control is ethically defensible in end of life even if treatment may impact life expectancy

The Answer Does Not Rest in Abandoning a Class of Medications

Nor Does It Rest in Treating Those Already at Risk of Undertreatment through the Lens of White Distress – Equity

WAILOO, 2020

But Rather Learning How to Assess & Treat & Advocate & Build

Trust & Trustworthiness

- Consider the history of your institution & practice

J. Callahan 2021

- Imagine what needs to happen to become trustworthy; reframe mistrust & what might be seen as "barriers" as situational & protective.

T.Laws, 2020

- Work to move from pain management by "substituted judgment" of clinicians to "intersubjective understanding" & respect for "situatedness" of persons.

K. Wailoo, 2020

A Sampling of Research Related to Inequities

CONSIDER USING TO ADVOCATE

Racial Bias Grounded in False Beliefs

- Black Americans are systematically undertreated for pain relative to White Americans.
- Is this racial bias related to false beliefs about biological differences between Blacks & Whites such as
  - "Black people's skin is thicker than White people's skin."
  - "Blacks' nerve endings are less sensitive than Whites."

Hoffman et al., 2016

The Impact of False Beliefs

- Study 1 documented false beliefs among White laypersons; those who more strongly endorsed false beliefs reported lower pain ratings for a Black *target*.
- Study 2 extended to the medical context to find, on average, the White medical students & residents endorsed 11.55% of the false beliefs
  - About 50% reported that at least one of the false belief items was possibly, probably, or definitely true.
  - Those who endorsed false beliefs rated the Black patient's pain as lower & made less accurate treatment recommendations.
- Those who did not endorse false beliefs rated the Black patient's pain as higher, but showed no bias in treatment recommendations

The Impact of False Beliefs

Findings suggest that individuals with at least some medical training hold & may use false beliefs about biological differences between Blacks & Whites to inform medical judgments, which may contribute to racial disparities in pain assessment & treatment.

Delegitimation

... the withdrawal of legitimacy, usually from some institution such as a state, cultural practice, etc. which may have acquired it explicitly or implicitly, by statute or accepted practice.

...to diminish or destroy the legitimacy, prestige or authority of

Delegitimation

A Narrative Review of the Impact of Disbelief in Chronic Pain

- Explore the social context in which individuals experience disbelief or feel discredited
  - 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 stereotypes of women
- The experience of *isolation* consequent to loss of relationships & being disbelieved – may be self-initiated
- Disbelief can lead to *emotional distress* – guilt, depression, anger

Delegitimation & Language

What accusations, discrediting, innuendo & misinformation may sound & read like

The Power of Language

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

Listen & Read - Data

- Likes the Percocet
- Claims to be in pain
- Do not look like they're in pain
- They're asking for oxy
- They're dying anyway, who cares if they are addicted
- Non compliant / non adherent
- Dysfunctional
- Drug seeking
- Clock watcher
- Addict, junkie, clean, dirty
- Narcotics
- Diverting

Interventions

- Data to be explored & understood
- Redefine, reinforce & reframe
- Repeat using preferred phrases or words
- Ask questions – eschew assumptions
- Explore issues of trust
- "Columbo" approach; I am confused
- "I need *your* help"
- Affirm shared mandate to assess & provide best care

& When it is Written

Testimonial Injustice

Beach et al., 2021

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

Fricker, 2009

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

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

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."

Fricker, 2009; Beach et al., 2021

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

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.	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.
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.	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 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.	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

Pain & Substance Use

SOME CONSIDERATIONS

The Landscape: A Sampling of Influences

- Media attention adding to the fears of patients & families & clinicians
- Clinicians refusing or reluctant to prescribe
- Greater scrutiny of patients through treatment agreements, pill counts etc.
  - Lack evidence base for effectiveness & may enhance the atmosphere of mistrust.
- Prescriptions monitoring programs
- Undertreatment of pain in groups economically & socially marginalized may account for the previous slower rate of related deaths

Pain Management does not = opioids – it is evidence-based integrated, interdisciplinary care accessible to some & not to others - as is addiction treatment

Structure & Stewardship

- Professional & ethical mandates lead to practices that structure & build safety
  - Policies – send message for patients & staff
  - Assessment – extension of good medical practice
    - Pain, drug & trauma hx, directed physical exam, review of previous interventions, co-existing diseases or conditions, range of rx options, integrative, pharmacologic, needed consultations.
  - CAGE - Cut down, Annoyed, Guilt, Eye opener; ORT Opioid Risk Tool
  - SOAPP-R – Screener & Opioid Assessment for Persons in Pain –Revised

Structure & Stewardship

- Trial of opioids –
  - *Informed consent agreement*, as we do with other medications where there is risk
  - Shared review of outcomes - function, pain relief, side effects informs adaptation of treatment plan
  - Ongoing evidence based risk assessment
  - Anticipatory guidance
  - Continuing therapy relates to benefit
  - Education re: withdrawal

Interventions - some evidence based, intended to support appropriate use; for many imply mistrust & threaten confidentiality

Structure for Safety

- Team approach
- Family involvement
- Frequent visits
- Honest, open communication
- Diaries & journals

- Agreements, *contracts*, Patient Provider Agreements (PPAs) , Informed consent etc.
- Urine toxicology - expert
- Pill counts, PMP programs
- Appropriate referrals
- Mediate access barriers

& What of Those Who Fear our Intentions & Medications

- Psycho-education
- If in recovery, integrate sponsors, counselors
- Anticipatory guidance
- Reframing: addiction harms; appropriate medication improves life
- Structure for safety
- Negotiate & trial ....

Persons with Pain are Treated within Converging Contexts

Within relationships & in environments which are impacted by individual, team, institutional & societal values, culture, history, beliefs & influences which invite, at the very least, inquiry, curiosity, attention & action ~ yet risk is not equitable

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