

Whose Pain Matters: A Look through the Kaleidoscope

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Objectives

- ▶ Advocate a multidimensional lens that frames an ethical & clinical response to pain & maximizes safety of patients, family, medical practitioners & the public.
- ▶ Identify the ethical principles & the history & scope of inequities that inform the social justice mandate to reduce suffering & both assess & manage pain related to cancer & its treatment.
- ▶ Challenge the ethical solution to the “opioid crises” which risks the unintended consequence of either the abandoning of patients or an entire class of medications.

Ruby

African American single Mom of 10 year old son; pain from metastatic cancer managed at home with Patient Controlled Analgesia, comes to outpatient visit with home health aide; talking with 3 White clinicians - Escalating pain; does not want to increase her medication ... “My friend works in a hospital & she says this is the medicine the doctors are using to kill the patients.”



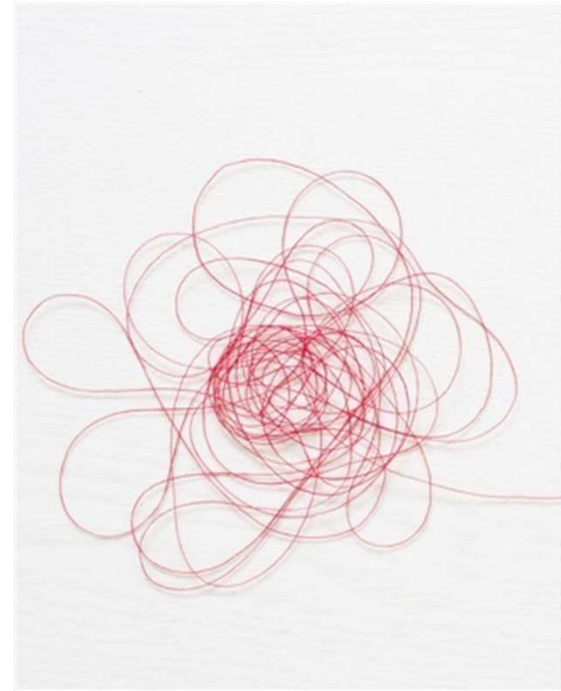
Revealing Disparities: Health Care Workers' Observations of Discrimination

Surveyed workers, across all races, ethnicities, ages, genders, & care settings, personally witnessed discrimination considering it to be a serious problem. Younger & health care workers of color more likely than their older or white counterparts to acknowledge witnessing this discrimination; under half of all workers indicated the discrimination causes them stress.”

~ Fernandez et al, 2024

Red Thread as Metaphor

The ancient Chinese proverb about a silken red thread signifies ongoing connections that are interwoven through our lived experiences &...

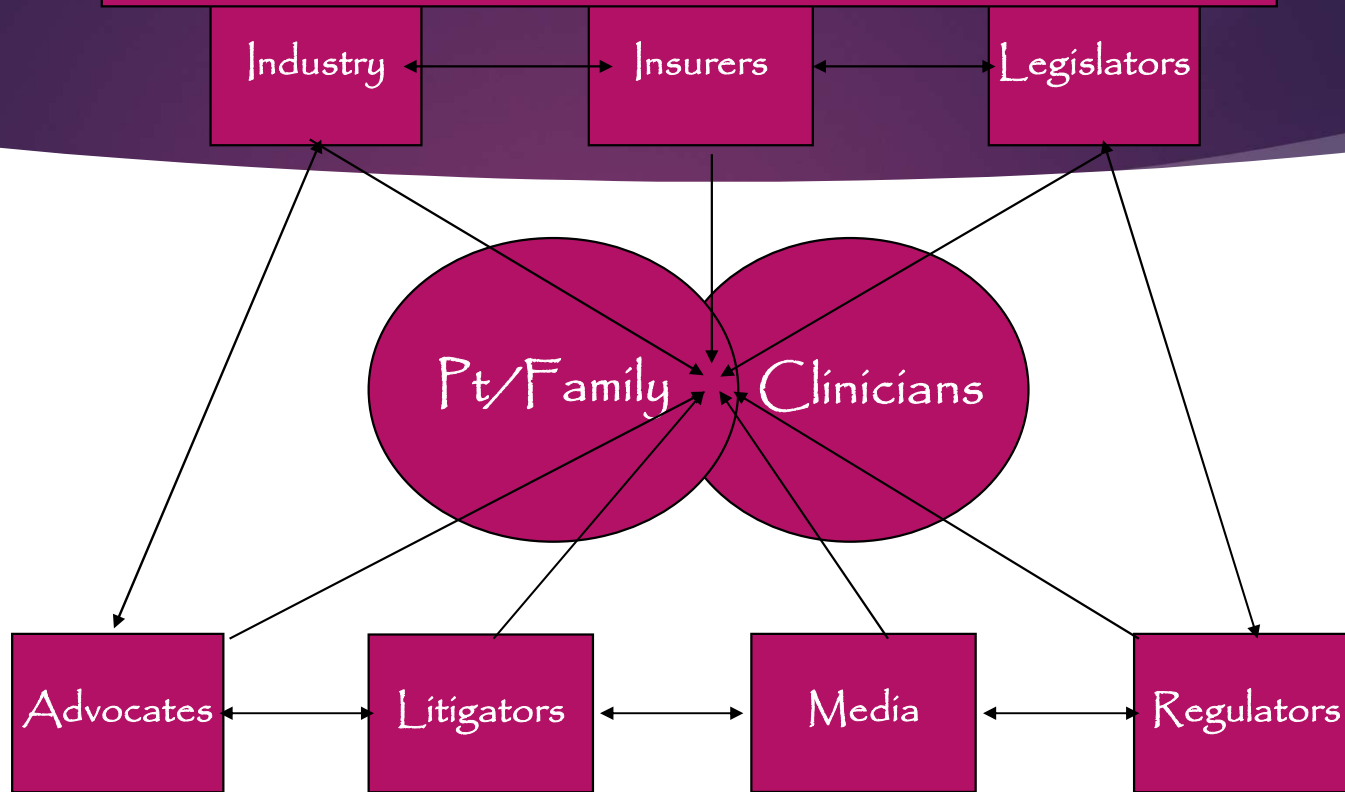




Silence Is Not an Option

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

CONVERGING CONTEXTS



Unintended Consequences

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

~ Issued 2016; revised 2022

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 end-of-life cancer pain management may be worsening.

~ Enzinger et al. 2021

Pain Definition 2020

“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 & the etymology of the word pain for further valuable context:

~ IASP, 1979; revised 2020

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. *

Bringing the Data Home

- ▶ Pain occurs in 20% to 50% of patients with cancer; roughly 80% with advanced-stage cancer having moderate to severe pain.
- ▶ A meta-analysis looking at pooled data from 52 studies found that more than half of patients had pain. With younger patients are more likely to experience cancer pain & pain flares than are older patients.
- ▶ A systematic review of the literature identified reports of pain occurring in 59% of patients receiving anticancer treatment & in 33% of patients after curative treatments.
- ▶ This data excludes pain from other conditions.

~ National Cancer Institute, 2024

Pain in End of Life across Diagnosis

~ Hedman et al., 2024

- ▶ The Swedish Register of Palliative Care was used to retrieve data on 315,000 pts from 2011 to 2022 about pain during the last week of life to examine if pain differed between patients with cancer, heart failure, COPD & dementia.
- ▶ Pain during the last week of life more commonly seen in cancer (81%) than in dementia (69%), heart failure (68%) or COPD (57%).
- ▶ Severe forms of pain were registered in 35% in patients with cancer & in 17-21% in non-cancer patients.
- ▶ At time of death, 97% of cancer patients, 90% of heart failure patients, 84% of COPD patients & 94% of dementia patients had an injectable opioid prescribed against pain as needed
- ▶ Complete pain relief was obtained in 86.8% of patients with dementia, followed by 77.6% in heart failure, 76.1% in cancer & 73.2% in COPD

Racial & Ethnic Disparities: Opioid Access & Urine Drug Screening

~Enzinger et al, 2023

- ▶ Purpose: To characterize racial & ethnic disparities & trends in opioid access & urine drug screening (UDS) among patients dying of cancer, & to explore potential mechanisms.
- ▶ Among 318,549 non-Hispanic White (White), Black, & Hispanic Medicare decedents older than 65 years with poor-prognosis cancers, we examined 2007-2019 trends in opioid prescription fills & potency per day near the end of life (EOL) & disparities in UDS.
- ▶ Estimating the effects of race & ethnicity on opioid access, controlling for demographic & clinical factors, adjusting models for socioeconomic factors including dual-eligibility status, community-level deprivation, & rurality.
- ▶ Between 2007 & 2019, White, Black, & Hispanic decedents experienced steady declines in EOL opioid access & rapid expansion of UDS.

Racial & Ethnic Disparities: Opioid Access & Urine Drug Screening

~Enzinger et al, 2023

- ▶ Compared with White patients, Black & Hispanic patients were less likely to receive any opioid; long-acting opioids; received lower daily doses & lower total doses
- ▶ Black patients were more likely to undergo UDS
- ▶ Disparities in EOL opioid access & UDS disproportionately affected Black men. Adjustment for socioeconomic factors did not attenuate the EOL opioid access disparities.
- ▶ Conclusion; There are substantial & persistent racial & ethnic inequities in opioid access among older patients dying of cancer, which are not mediated by socioeconomic variables.



Persons with Pain are Treated within Converging Contexts

Within relationships & in environments which are impacted by individual, team, institutional & societal values, history, beliefs & influences which invite, at the very least, inquiry, curiosity, attention & action -

Why is Pain Unique & Why Does it Lead to Under-treatment

- ▶ Universal,
- ▶ Culturally, Spiritually, Emotionally & Socially Infused -
A Subjective Experience in settings that privilege
objective knowledge & value data



Multidimensional Exploration of Pain

Multidimensional exploration of pain is not a denial of physical pain - rather it is expression of interest, caring & concern for the total person. Medical management needs to accompany efforts to understand beliefs, thoughts, behaviors & feelings & the environmental context of their lives that may contribute to pain, suffering & distress

Pain as a Multidimensional Experience

▶ Integrates

- ▶ Knowledge of symptoms & treatments
- ▶ Individualized illness experience – mediated by patient, family, & HCP interpretation

▶ Impacts

- ▶ Mood
- ▶ Function
- ▶ Quality of life
- ▶ Grief & bereavement & more

Persons at Special Risk for Under-Treatment

Those who are

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

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, Cassity, Schechter, 1994

A Sampling of Mandates

- Ethical principles
 - Justice, beneficence, non-maleficence
 - Do these principles ethically both permit & require care?
 - 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
- Litigation & emphasis on end-of-life care



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 ?

~ Rich, 2000

Principle of Balance

- ▶ Opioids may be 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 as a public health concerns should not interfere with legitimate medical practice
- ▶ Pain & symptom control ethically defensible in end of life even if treatment may impact life expectancy
- ▶ Use of palliative sedation may be engaged more often as a consequence of lack of expertise

Data 2019; 2022

- 2019 - In US, 70,630 drug overdose deaths; Opioid deaths 49,860
 - White non-Hispanic - 35,997; Black non-Hispanic - 7,464; Hispanic - 5,264
 - Male - 34,635; female - 15,225
- 2022 - In US, 107,699 drug overdose deaths; Opioid deaths 81,051
 - White - 53,022; Black - 14,537; Hispanic - 9,921; Asian - 533; American Indian or Alaskan Native - 932
 - Male - 56,757; Female - 23,654

~ www.kff.org/state-category/health-status/opioids

Impacts + & -

As deaths increased in White communities

- ▶ Impact on stigma; obituaries
- ▶ “public health crises” rather than “criminal response”
- ▶ Precipitous de-prescribing; litigation
- ▶ Emphasis on treatment resources & education of professionals
- ▶ Organizations have disappeared &/or revised advocacy
 - ▶ Joint Commission, WHO, American Pain Society, Academy of Integrative Pain Management...

Deprescribing Amongst a Veterans Population

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

~ Gaither et al., 2018




The Answer Does not Rest
in Abandoning the Use of a
Class of Medications



Nor Does It Rest in Treating
Those Already at Risk of
Undertreatment through the Lens
of White Distress - Fairness.

~ WAILOO 2020



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

Trust & Trustworthiness

- ▶ Consider the history of your institution & practice
~ Callahan 2021
- ▶ Imagine what needs to happen to become trustworthy; reframe mistrust & what might be seen as “barriers” as situational & protective
~ Laws, 2020
- ▶ Transition from pain management by “substituted judgment” of clinicians to “intersubjective understanding” & respect for “situatedness” of persons.
~ Wailoo, 2020

Delegitimization

... 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

Delegitimization

A Narrative Review of the Impact of Disbelief in Chronic Pain

~ Newton et al, 2013

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

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

Delegitimization & Language

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

Listen & Read - Data

- ▶ Likes the Percocet
- ▶ Claims to be in pain
- ▶ Doesn't 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

& 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

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 micro-aggressions & experience of being disbelieved
- ▶ When discredited we are dishonored as human- a symbolic, consequential & "core epistemic insult."

~ Fricker, 2009; Beach et al 2021

Interventions

- ▶ Data to be explored & understood; joining
- ▶ 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



A Sampling of Research Related to Inequities

An Essential Place that Captures the
Impact of Bias & the Relevance of
Language & Word Choice

Racial Bias Grounded in False Beliefs

~Hoffman et al., 2016

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?”



The Impact of False Beliefs Within Medical Training

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.”

~ Hoffman et al., 2016



A Sprinkling of *Barriers* ~ Protective

Perhaps ?

to be Understood & / or Overcome ?

Invitations ~

Barriers - Patient & Family

- Emotional Factors - a sampling
 - Distress, denial &/or depression impact
 - Ability to assess & report pain
 - Willingness to acknowledge pain
 - Acceptance of need for treatment

Barriers - Patient & Family

- Beliefs & Values

- Pain / suffering inevitable, necessary
- Requires stoic response
- Represents sacrifice, redemption
- Intent of clinicians & medical system is suspect
- Situational mistrust

- Fears

- Bothering / distracting clinician from "cure"
- Side effects, handling meds, hastening death
- Addiction / tolerance
- Symbolic significance
- Upsetting family

Aspects of Patient Experience

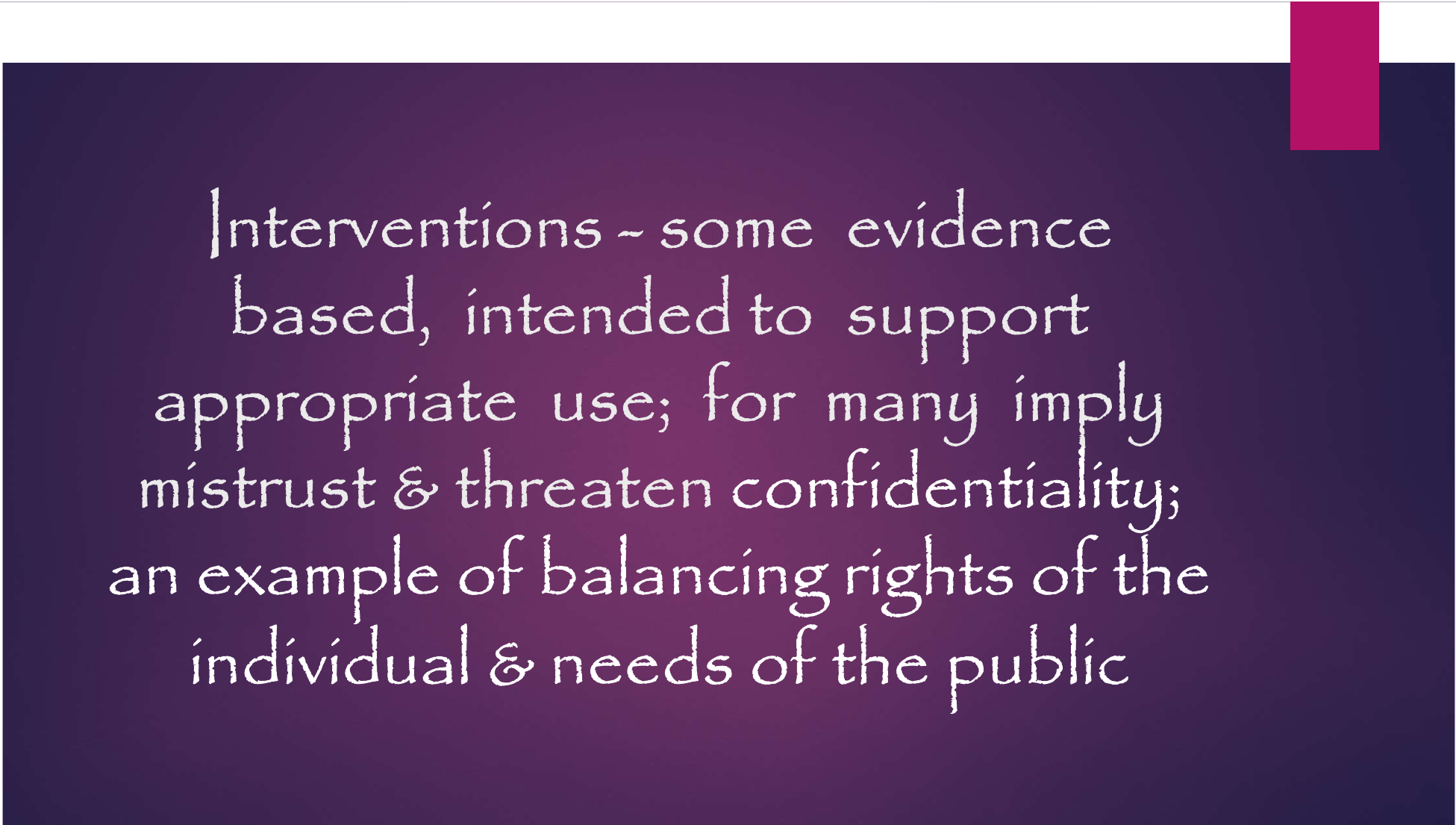
- Signals status of disease, life – “pain better”
- Family, work & financial pressures
- Literacy, innumeracy, language difference
- Stigma attached to opioids & pain
- Compensation claims, litigation

Structure & Stewardship

- Professional & ethical mandates lead to practices that structure & build safety
 - Policies – send message to all patients & staff
 - Assessment – extension of good medical practice; pain, drug & trauma hx, directed physical exam, review of prior interventions, co-existing diseases or conditions, 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 as all seem to have risk
 - Shared review of outcomes – function, pain relief, side effects informs continued planning
 - Ongoing evidence-based risk assessment
 - Continuing therapy relates to benefit
 - Education re: withdrawal



Interventions - some evidence based, intended to support appropriate use; for many imply mistrust & threaten confidentiality; an example of balancing rights of the individual & needs of the public

Structure for Safety

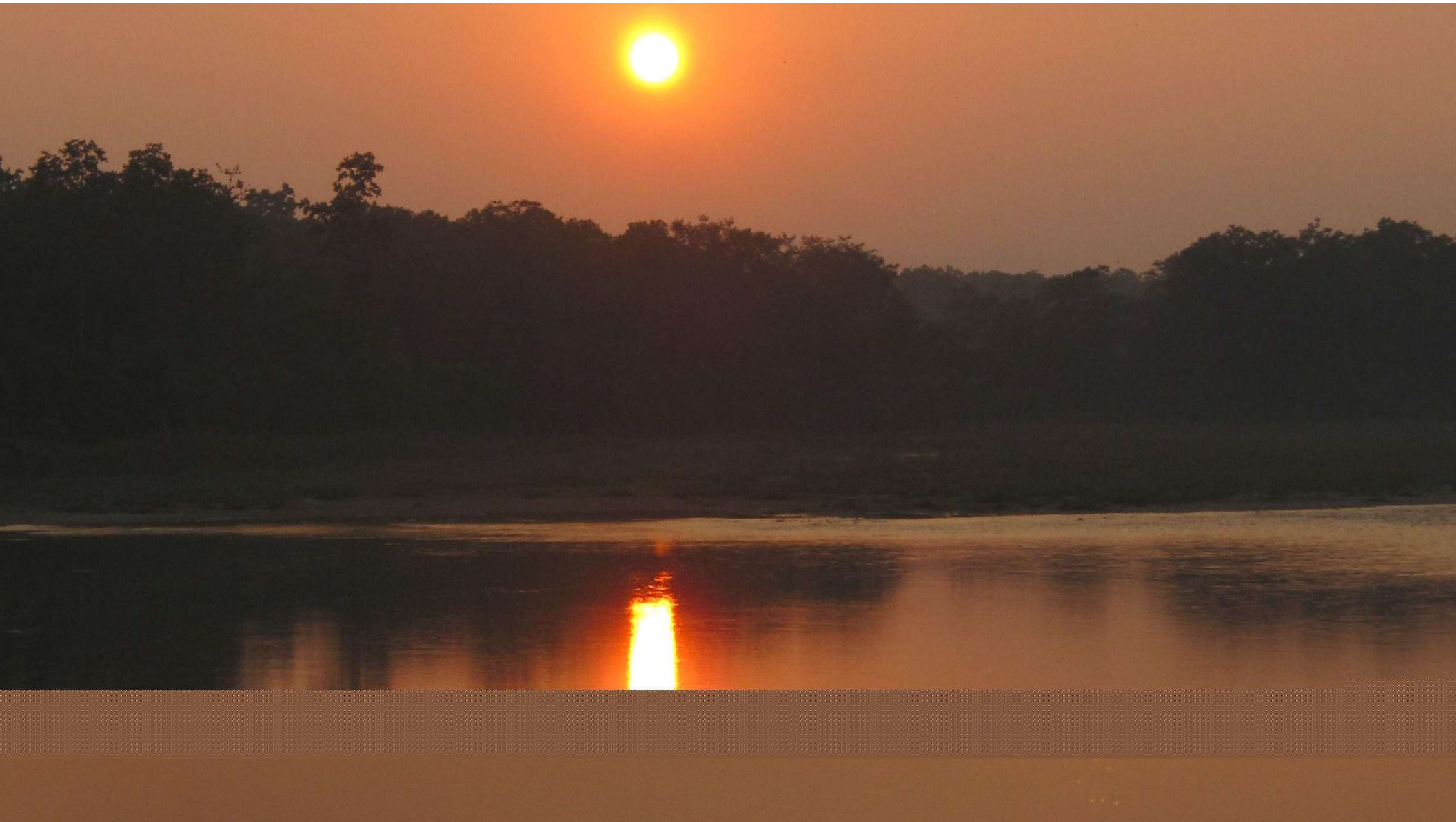
- Team approach
- Family involvement
- Frequent visits
- Honest, open communication
- Diaries & journals
- Agreements, contracts, Patient Provider Agreements (PPAs), Informed consent etc
- Urine toxicology - expert
- Pill counts, PMP programs
- Appropriate referrals
- Mediate access barriers

& 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



An Invitation... & the End of
Ruby's Narrative ...



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