


AOSW • APOS • ACCC
Joint Virtual Conference
10.07.21 12-4:30 PM EST
Achieving Health Equity in the Psychosocial Treatment of Cancer Pain


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 Achieving Health Equity in the Psychosocial Treatment of Cancer Pain




Cardinale Smith,
MD, PhD
Mount Sinai (Icahn)



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Palliative Social Worker



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The University of Texas at Austin



Phylicia Woods, JD, MSW
Cancer Support Community

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Dwain Fehon, PsyD
APOS Professional Education Committee
Associate Professor, Psychiatry
Yale School of Medicine

Moderator

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Achieving Health Equity in the Psychosocial Treatment of Cancer Pain



Krista Nelson,
MSW, LCSW, OSW-C, FAOSW
ACCC President



Bill McDermott,
MSW, LCSW
AOSW President



Joseph Greer,
PhD
APOS President

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ASSOCIATION OF
COMMUNITY
CANCER CENTERS

The leading education and
advocacy organization for the
cancer care community

ACCC-CANCER.ORG




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Dedicated to the enhancement of psychosocial services to people with cancer and their families.

AOSW is committed to initiatives designed to increase and strengthen policies promoting diversity and inclusion at all levels of the organization.

Join AOSW Today
www.aosw.org

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WE ADVOCATE FOR DIVERSITY, EQUITY, REPRESENTATION, AND INCLUSION in advancing the science and practice of psychosocial oncology care, recognizing the rights of all those affected by cancer to receive comprehensive person and family centered care.

Core Value 1 of 5

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WE'RE ON A QUICK BREAK AND WE'LL BE BACK SHORTLY!

AOSW • APOS • ACCC
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10.07.21 12-4:30 PM EST
**Achieving Health Equity in the Psychosocial
 Treatment of Cancer Pain**

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Thank you for attending the live webinar today, *Achieving Health Equity in the Psychosocial Treatment of Cancer Pain*.

Learners must complete an evaluation form to receive a certificate of completion. You must attend each chosen session in its entirety as partial credit is not available. If you are seeking continuing education credit for a specialty not listed, it is your responsibility to contact your licensing/certification board to determine course eligibility for your licensing/certification requirement.

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DISPARITIES IN CANCER PAIN MANAGEMENT

Cardinale B. Smith, MD, PhD

Associate Professor

Division of Hematology/Oncology and Brookdale

Department of Geriatrics & Palliative Medicine

Icahn School of Medicine at Mount Sinai

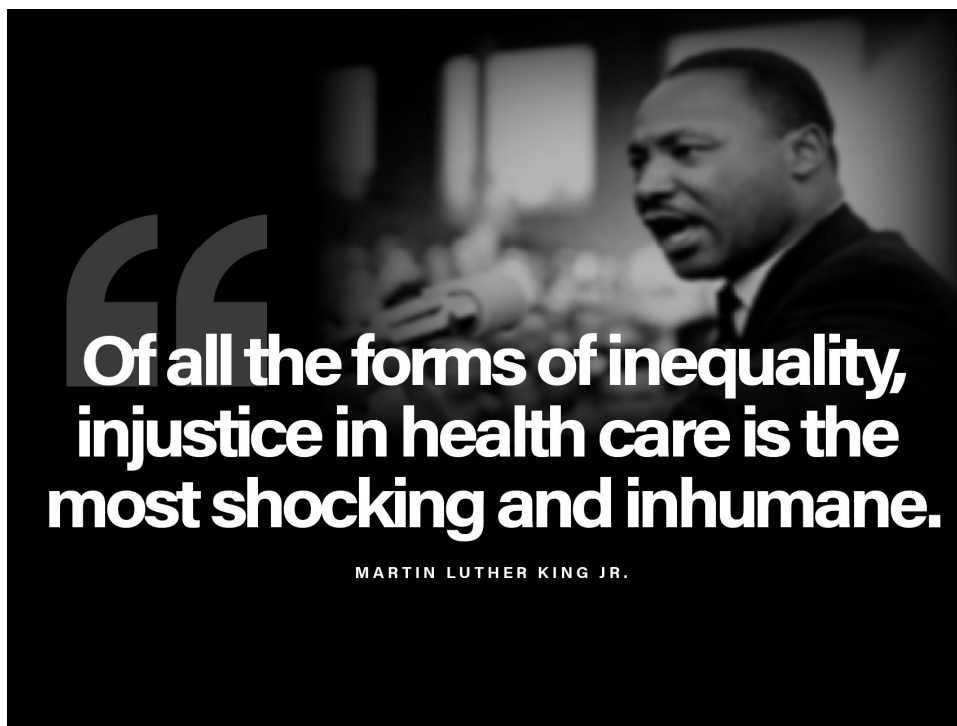


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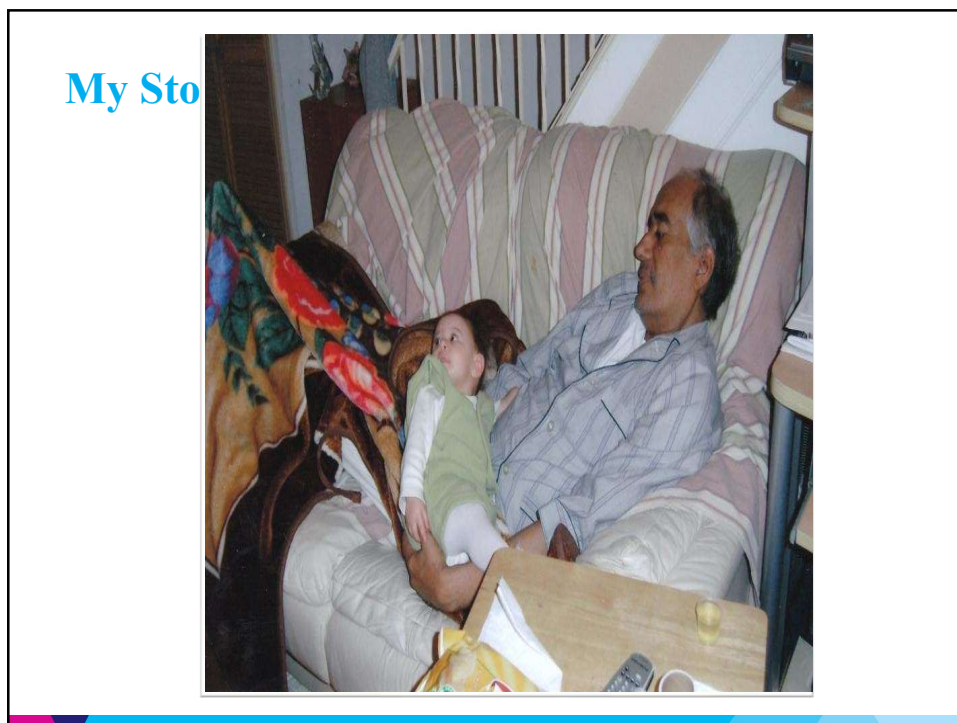
Objectives

- Discuss historical and contemporary health injustice towards minorities
- Identify patient, provider, system, and regulatory barriers to effective pain management

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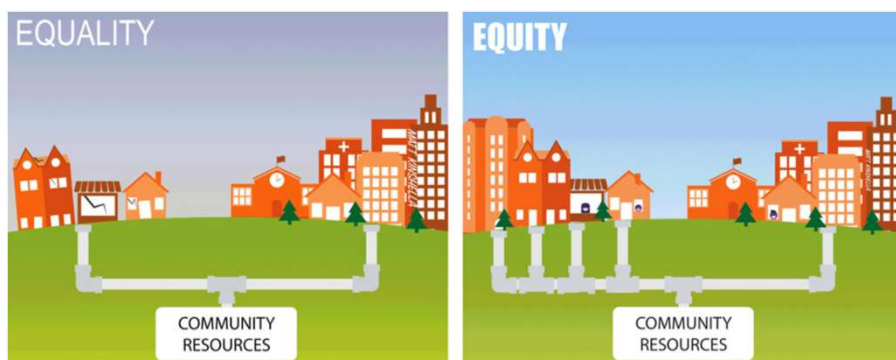
What is Health Equity?

“Attainment of the **highest level of health for all people**. Requires valuing everyone equally with focused and ongoing societal efforts to **address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities.**”

Healthy People, 2020

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What is Health Equity?



Health equity is multifaceted:
Equity of access, equity of treatments, and equity of outcomes

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WHAT FACTORS CONTRIBUTE?

7

The New York Times

***Syphilis Victims in U.S. Study
Went Untreated for 40 Years***

By **JEAN HELLER**
The Associated Press

WASHINGTON, July 25—For 40 years the United States Public Health Service has conducted a study in which human beings with syphilis, who were induced to serve as guinea pigs, have gone without medical treatment for the disease and a few have died of its late effects, even though an effective therapy was eventually discovered.

The study was conducted to determine from autopsies what the disease does to the human body.

Officials of the health service who initiated the experiment have long since retired. Current officials, who say they

have serious doubts about the morality of the study, also say that it is too late to treat the syphilis in any surviving participants.

Doctors in the service say they are now rendering whatever other medical services they can give to the survivors while the study of the disease's effects continues.

Dr. Merlin K. DuVal, Assistant Secretary of Health, Education and Welfare for Health and Scientific Affairs, expressed shock on learning of the study. He said that he was making an immediate investigation.

The experiment, called the Tuskegee Study, began in 1932 with about 600 black men,

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Barriers: Biological Differences

Item	Study 1 (n = 92) %	Study 2, %			
		1 st yr (n= 63)	2 nd yr (n= 72)	3 rd yr (n= 59)	Residents (n = 28)
Blacks age more slowly than whites	23	21	28	12	14
Blacks' nerve endings are less sensitive	20	8	14	0	4
Black people's blood coagulates more quickly	39	29	17	3	4
Whites have larger brains than blacks	12	2	1	0	0
Whites are less susceptible to heart disease*	43	63	83	66	50
Blacks are less likely to contract spinal cord diseases*	42	46	67	56	57
Blacks' skin is thicker than whites'	58	40	42	22	25
Whites are less likely to have a stroke than blacks*	29	49	63	44	46
Blacks have stronger immune systems than whites	14	21	15	3	4
False beliefs composite (11 items), mean (SD)	22 (23)	15 (19)	16 (19)	5 (10)	7 (15)

Hoffman, KM. Proc Natl Acad Sci U S A. 2016 Apr 19;113(16):4296-301

9

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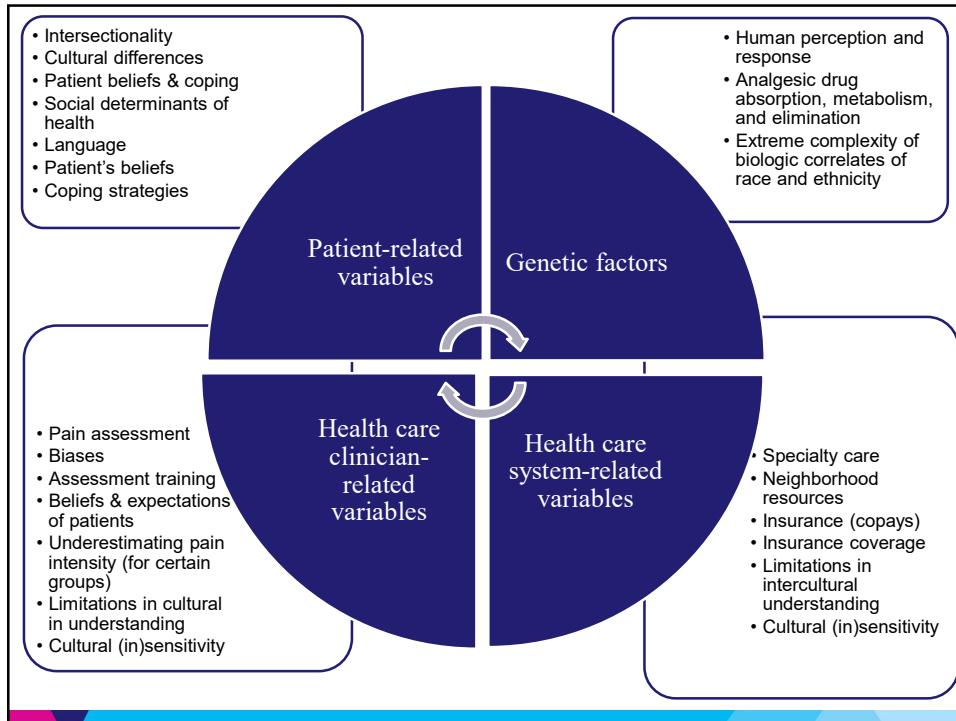
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Barriers: Biological Differences

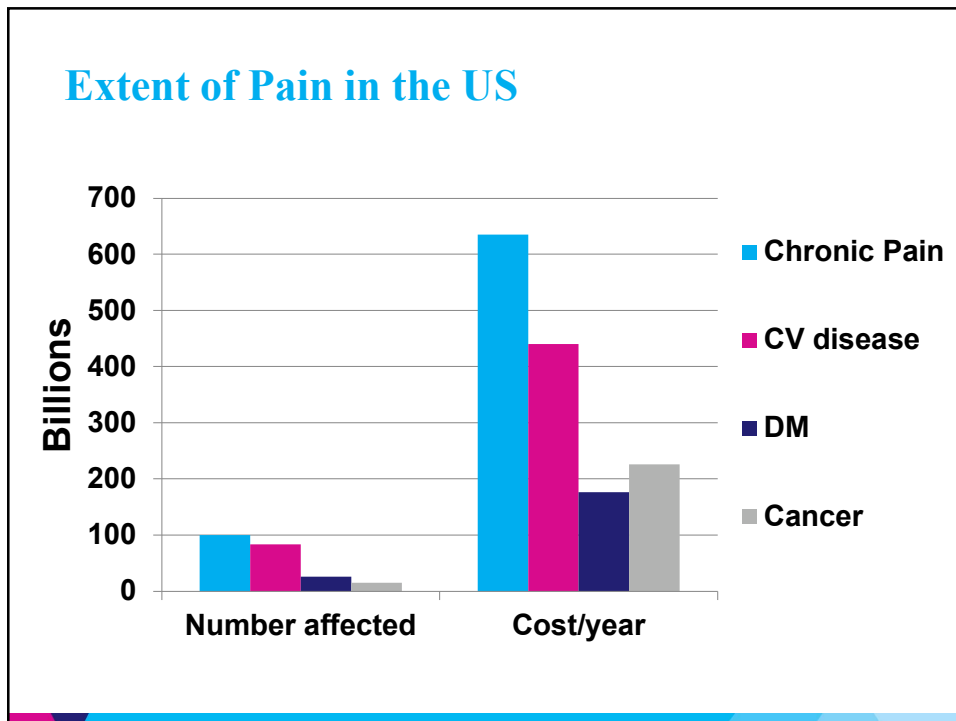
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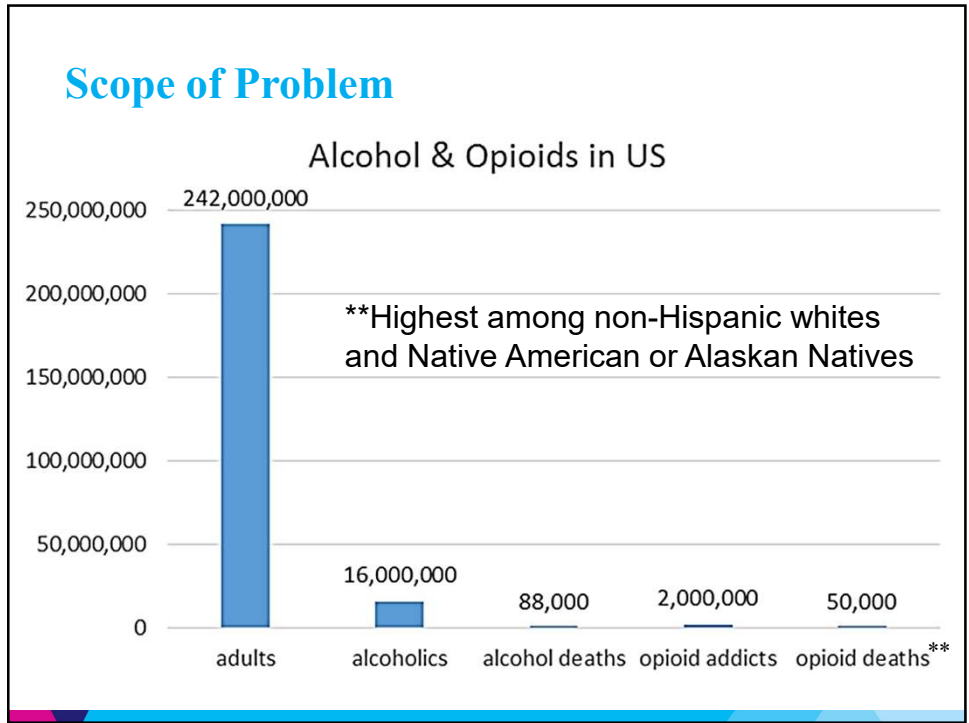
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Unequal Burden of Pain

Variable	White	Hispanic	Black
Rates of “illicit” drug use ^{1,2}	8.8%	9.6%	7.9%
Drug induced deaths ²	12.6%	9.5%	8.9%

¹National Survey on Drug Use and Health, 2010 survey.
²CDC, 2011

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Consequences of Pain



- Physical Function
- Family/Social Role
- Economic
- Psychological function

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The New York Times

Finding Good Pain Treatment Is Hard. If You're Not White, It's Even Harder.

August 9, 2016

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Factors Responsible for Disparities

- Health systems-level factors
- Clinician-level factors
- Patient-level factors
- Disparities arising from clinical encounters



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Race/Ethnicity and Pain

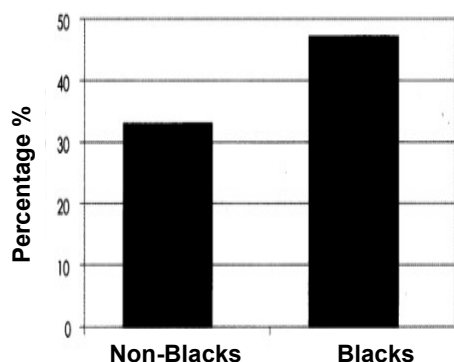
Minority patients with pain:

- Have less access to pain management
- Less likely to have pain recorded/assessed
- Receive less pain medications
- Are at risk for under-treatment



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Clinician Barriers: Underestimation



❖ Patient and physician perception of pain (chronic non-cancer pain) in 12 academic medical centers

❖ Physicians underestimated pain in 33% of non-blacks as compared to 47% of blacks ($p < 0.005$)

Staton, LJ, et al. JNMA. May;99(5):532-8.

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Clinician Barriers: Prescribing

Meta-analysis 1989-2011

Group	Outcome [†]	Number of Studies	Odds Ratio (95% Confidence Interval)	P Value	I ² (P Value)
Hispanics vs Whites	Prescription of "any" analgesia	15	0.90 (0.77–1.06)	0.251	32.4 (0.109)
	Prescription of "opioids"	11	0.78 (0.65–0.93)	0.006*	49.4 (0.031)
	Prescription of "non-opioids"	7	0.89 (0.55–1.43)	0.640	65.5 (0.008)
	Prescription of "COX-2 inhibitors"	1	0.47 (0.30–0.72)	0.001*	N/A
Blacks vs Whites	Prescription of "any" analgesia	17	0.77 (0.68–0.88)	0.000*	61.3 (0.000)
	Prescription of opioids [†]	15	0.70 (0.62–0.80)	0.000*	52.5 (0.009)
	Prescription of "non-opioids"	10	1.07 (0.80–1.43)	0.618	84.4 (0.000)
	Prescription of "COX-2 inhibitors"	5	0.68 (0.61–0.75)	0.000*	13.2 (0.329)
Asians vs Whites	Prescription of "any" analgesia	6	0.91 (0.66–1.25)	0.576	0.00 (0.737)
	Prescription of "opioids"	4	0.76 (0.53–1.07)	0.124	27.8 (0.245)
Native Americans vs Whites	Prescription of "any" analgesia	3	1.05 (0.75–1.46)	0.759	0.00 (0.709)
	Prescription of "opioids"	1	1.88 (0.41–8.53)	0.413	N/A
Minorities [‡] vs Whites	Prescription of "any" analgesia	7	0.80 (0.54–1.17)	0.251	80.1 (0.000)
	Prescription of "opioids"	1	0.70 (0.42–1.23)	0.219	N/A

Meghani, et. Al. Pain Medicine 2012; 13: 150–174

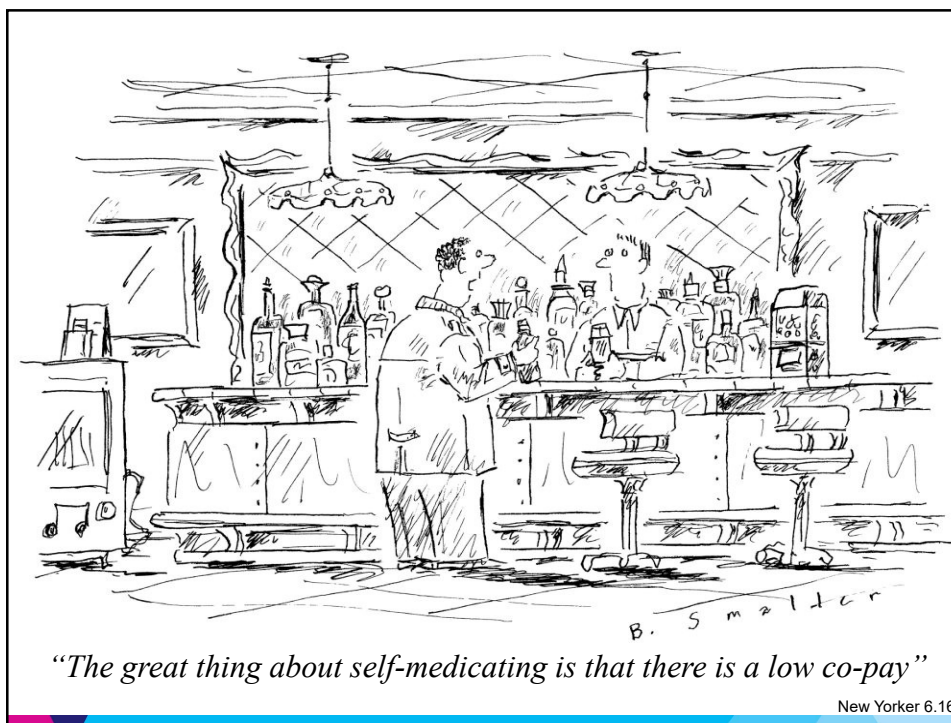
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Clinician Barriers: Prescribing

Characteristic	Racial or Ethnic Group	Number of Studies	Odds Ratio (95% Confidence Interval)	P Value	I ² (P Value)
Subgroup Hispanics/Latinos vs Whites					
Outcome	Opioids (prescription of)	11	0.78 (0.65–0.93)	0.006*	49.4 (0.031)
Study quality†	High (≥76% criteria)	6	0.76 (0.60–0.97)	0.028*	44.8 (0.107)
	Medium (51%–75% criteria)	5	0.80 (0.57–1.10)	0.176	61.0 (0.067)
Study period‡	Prior to TJC pain guidelines	5	0.64 (0.41–1.01)	0.059	65.3 (0.021)
	After 2001§	4	0.85 (0.69–1.05)	0.136	15.1 (0.316)
Setting	ED	8	0.80 (0.68–0.94)	0.008*	23.3 (0.243)
	Non-ED	3	0.60 (0.22–1.59)	0.307	76.9 (0.013)
Subgroup Blacks/African Americans vs Whites					
Outcome	Opioids (prescription of)	15	0.70 (0.62–0.80)	0.000*	52.5 (0.009)
Study quality†	High (≥76% criteria)	9	0.66 (0.56–0.79)	0.003*	50.5 (0.040)
	Medium (51%–75% criteria)	6	0.76 (0.63–0.90)	0.001*	50.8 (0.070)
Study period‡	Prior to TJC pain guidelines	5	0.74 (0.57–0.94)	0.029*	62.9 (0.029)
	After 2001§	8	0.67 (0.56–0.81)	0.000*	55.3 (0.028)
Setting	ED	10	0.68 (0.58–0.78)	0.000*	44.5 (0.060)
	Non-ED	5	0.76 (0.60–0.96)	0.024*	57.9 (0.050)

Meghani, et. Al. Pain Medicine 2012; 13: 150–174

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System Barriers: Access

TABLE 2. ADEQUACY OF OPIOID SUPPLIES AT 347 PHARMACIES, ACCORDING TO THE RACIAL AND ETHNIC COMPOSITION OF THE NEIGHBORHOOD.

RACIAL AND ETHNIC COMPOSITION OF NEIGHBORHOOD	TOTAL PHARMACIES	PHARMACIES WITH ADEQUATE OPIOIDS	P VALUE FOR TREND
	no.	%	
White			<0.001
0-39%	110	25	
40-69%	72	56	
70-79%	72	50	
≥80%	93	72	<0.001
Black			
<10%	173	61	
10-19%	53	45	
20-39%	57	42	0.002
≥40%	64	30	
Hispanic			
<10%	89	56	
10-19%	108	54	0.01
20-39%	70	50	
≥40%	80	34	
Asian			
<10%	241	54	
10-19%	74	42	
20-39%	16	44	
≥40%	16	25	



Morrison, RS, et al. N Engl J Med. 2000 Apr 6;342(14):1023-6.

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System Barriers: Access

- 54% reported little demand
- 44% concern about disposal
- 20% fear of DEA investigations
- 19% fear of robbery
- 7% problems with reimbursement

Morrison, RS, et al. N Engl J Med. 2000 Apr 6;342(14):1023-6.

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System Barriers: Pharmacies

INCOME GROUP*

≥ MEAN ZIP CODE INCOME < MEAN ZIP CODE INCOME



Perspective: Michigan pharmacies in minority zip codes were 52 times less likely to carry sufficient opioid analgesics than pharmacies in white zip codes regardless of income. Lower income areas and corporate pharmacies were less likely to carry sufficient opioid analgesics. This study illustrates barriers to pain care and has public health implications.

© 2005 by the American Pain Society

Abbreviation: CI, confidence interval.

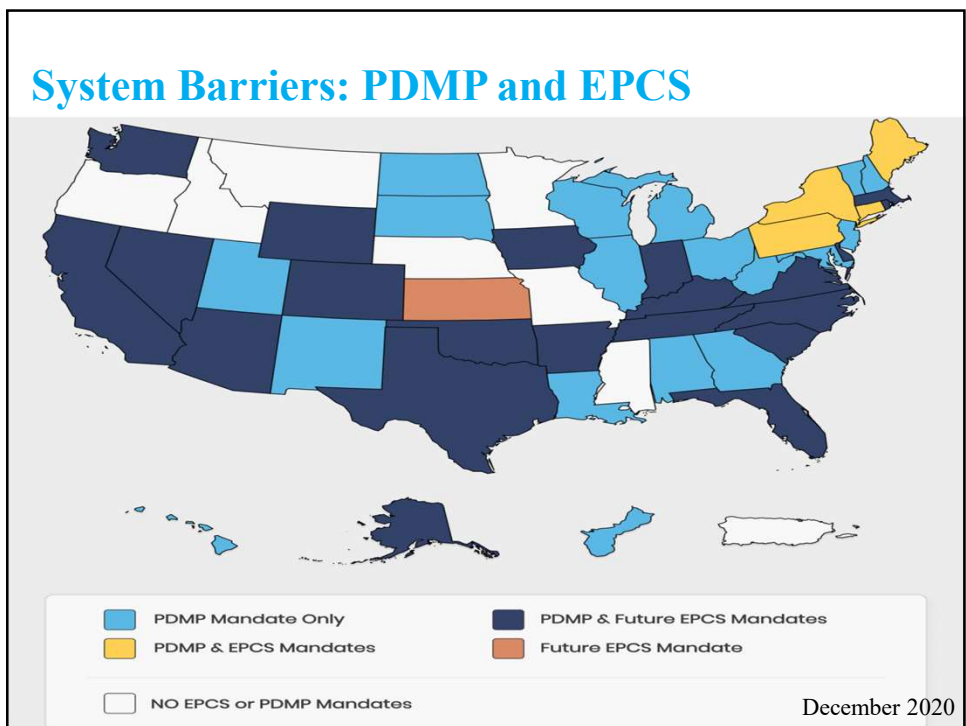
- * Pharmacies are divided into 2 income groups: those in zip codes with a median income that is greater than or equal to the average median zip code income and those with a median income that is less than the average median zip code income.

Green, CR, et al. J Pain. 2005 Oct;6(10):689-99

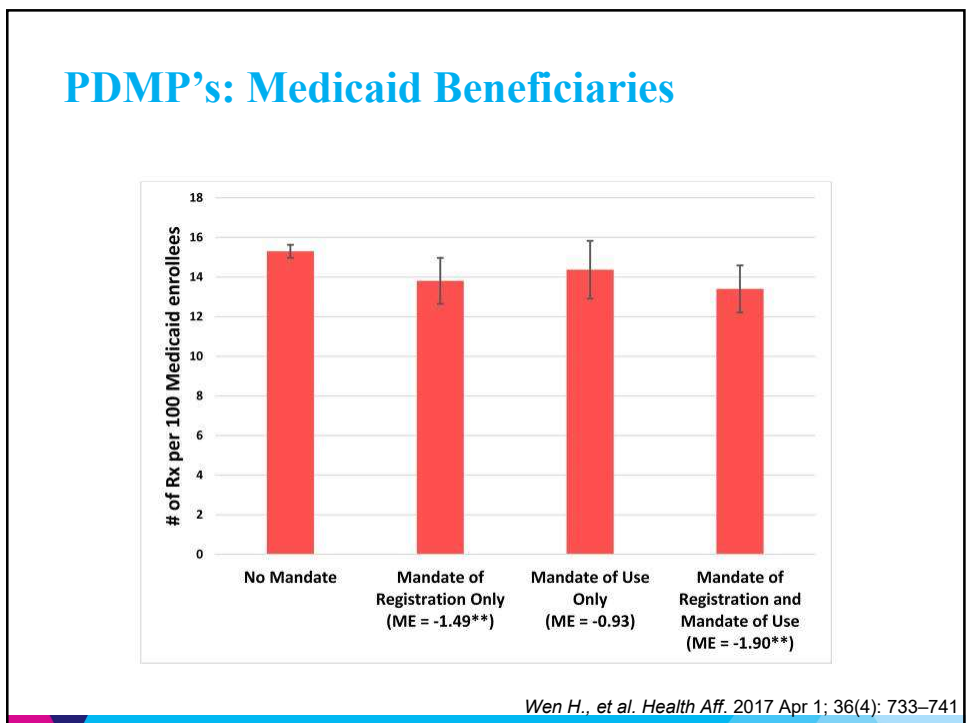
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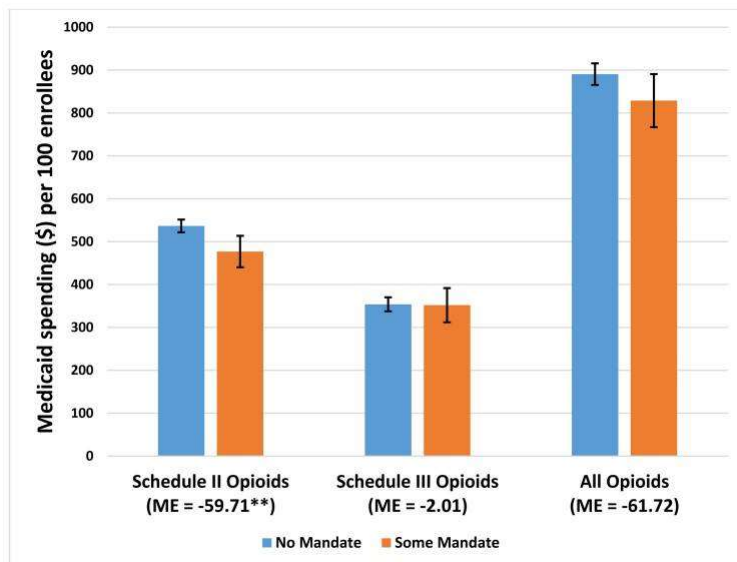


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PDMP's: Medicaid Beneficiaries

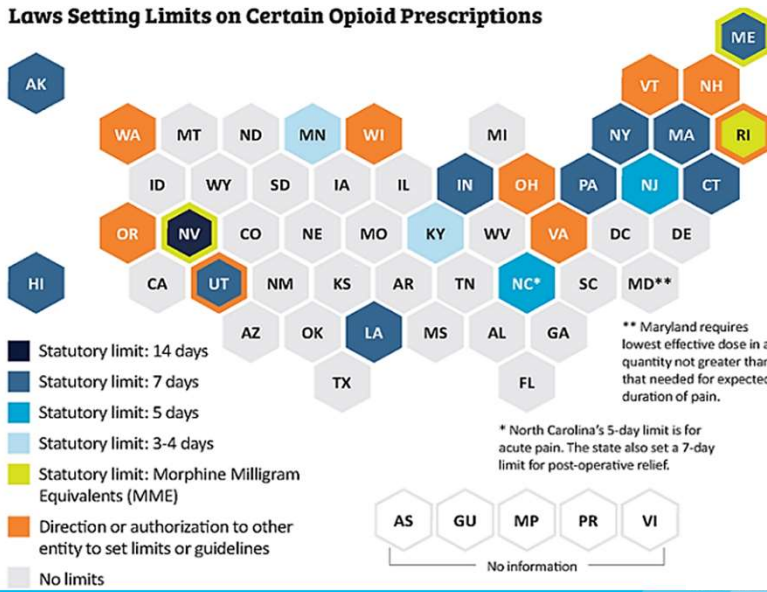


Wen H., et al. Health Aff. 2017 Apr 1; 36(4): 733-741

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System Barriers

Laws Setting Limits on Certain Opioid Prescriptions



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Walmart Enforces New Opioid Prescription Limit

BlueCross BlueShield

Cigna

Allina Health | aetna

CVS Health Plans to Limit Prescription Painkillers

CVS.com
Save time. Refill online.

Will it help stop the opioid crisis?

CVS pharmacy

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www.nytimes.com

New Opioid Limits Challenge the Most Pain-Prone - The New York Times

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Viscous Cycle



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Suggested Solutions

- Enhance access
- Address cultural differences
- Care coordination
- Address clinician bias
- Improve access to specialty palliative care

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**"The test of our progress is not whether we add more to the abundance of those who have much. It is whether we provide enough for those who have little."
-- FDR**

Time Is Up: Ending Disparities in Pain Treatment

TERRY ALTILIO LCSW, APHSW-C

1

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."

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Silence is not an Option

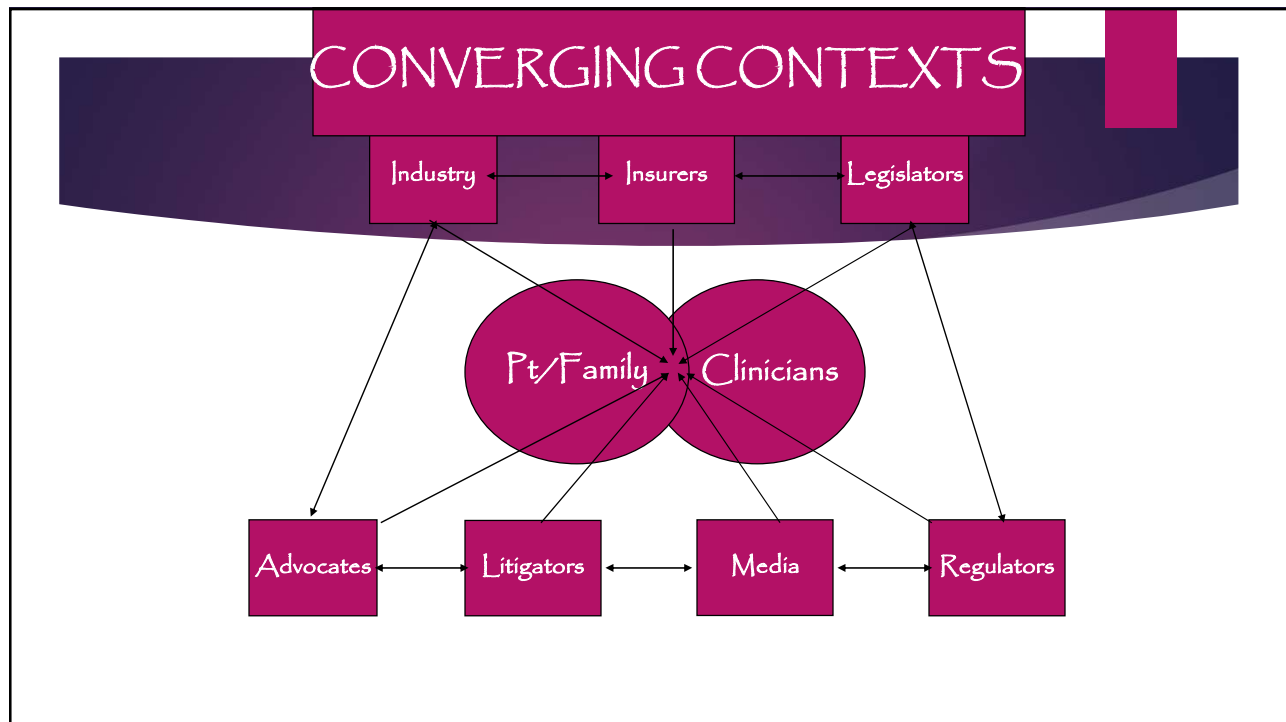
Care of patients who suffer, whether with
or without pain is a
Shared Responsibility
& yet the risk for each discipline is not
equal

3

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 - yet risk is not equitable

4



5

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

6

An Early Nod to Social Determinants of Health

Social & political circumstances profoundly influence the health & well being of all people

7

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

8

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

9

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)

10

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)

11

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)

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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 & 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 knowledge

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Data 2019

- In U.S., 70,630 drug overdose deaths
- Opioid overdose death 49,860
- White non-Hispanic - 35,997; Black non-Hispanic - 7,464; Hispanic - 5,264
- Male - 34,635; female - 15,225

(www.kff.org/state-category/health-status/opioids)

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Impacts + & ~

As deaths increased in White communities; impact on stigma

- ▶ “public health crises” rather than “criminal response”
- ▶ Precipitous de-prescribing
- ▶ Emphasis on treatment resources & education
 - ▶ Johns Hopkins 4-day education for med students
 - ▶ Call for information on education curricula for health care professionals
- ▶ Organizations have disappeared & revised advocacy
 - ▶ Joint Commission, World Health Organization, American Pain Society, Academy of Integrative Pain Management...

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Deprescribing Amongst a Veterans Population

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

(Gaither et al., 2018)

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

17

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

(WAILOO 2020)

18

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

19

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)

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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

21

Delegitimation

A Narrative Review of the Impact of Disbelief in Chronic Pain B.J. Newton et al, 2013

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

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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

23

Delegitimation & Language

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

24

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

25

& 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)

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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)

27

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

28

A Sprinkling of *Barriers* ~ to be Understood Or Overcome?

29

Barriers - Clinician & System

- Absence of
 - Knowledge
 - Accountability
 - Empathy / trust
 - Time / interest
- Fear of
 - Regulatory scrutiny
 - Causing addiction
 - Threatening recovery
 - Hastening death

30

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

31

Barriers - Patient & Family

- | | |
|--|--|
| <ul style="list-style-type: none"> • Beliefs & Values <ul style="list-style-type: none"> • Pain is inevitable, necessary • Requires stoic response • Represents sacrifice • Intent of clinicians & medical system is suspect | <ul style="list-style-type: none"> • Fears <ul style="list-style-type: none"> • Distracting or bothering professionals • Medication side effects, handling meds • Addiction/ tolerance • Symbolic significance • Upsetting family |
|--|--|

32

Aspects of Patient Experience

- *Systems*
 - Influence of 3rd part payers; Prior approvals
 - Inequitable access
 - Historical & current racial & gender biases, differences & experiences, trauma
 - Poor communication & fractured systems of care
 - Insufficient resources including time
 - Increased accountability & inadequate knowledge
 - Worry about hastening death or side effects
 - Absence of trust, situational or trait?

33

Aspects of Patient Experience

- May infuse relationships & decisions - A Sampling
 - Psychosocial & attributed meanings (micro)
 - Ethno-cultural beliefs & traditions
 - Spiritual beliefs - redemption, punishment, noble
 - Chosen or imposed
 - Negotiation & respect for values. How much is necessary?

34

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

35

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

36

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 continued care
 - Ongoing evidence based risk assessment
 - Continuing therapy relates to benefit
 - Education re: withdrawal

37

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

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Structure for Safety

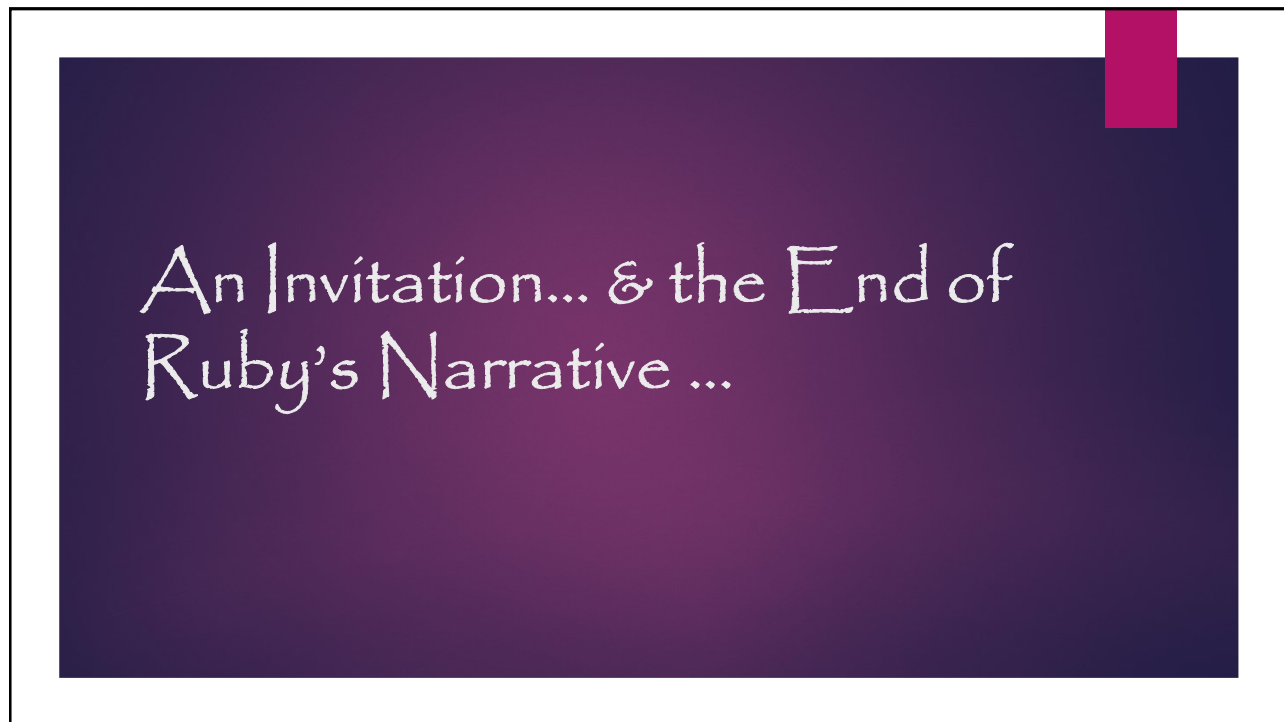
- Team approach
- Family involvement
- Frequent visits
- Honest, open communication
- Diaries & journals
- Agreements, contracts, Patient Provider Agreements (PPAs), Informed consent etc
- Urine toxicology - expert
- Pill counts, PMP programs
- Appropriate referrals
- Mediate access barriers

39

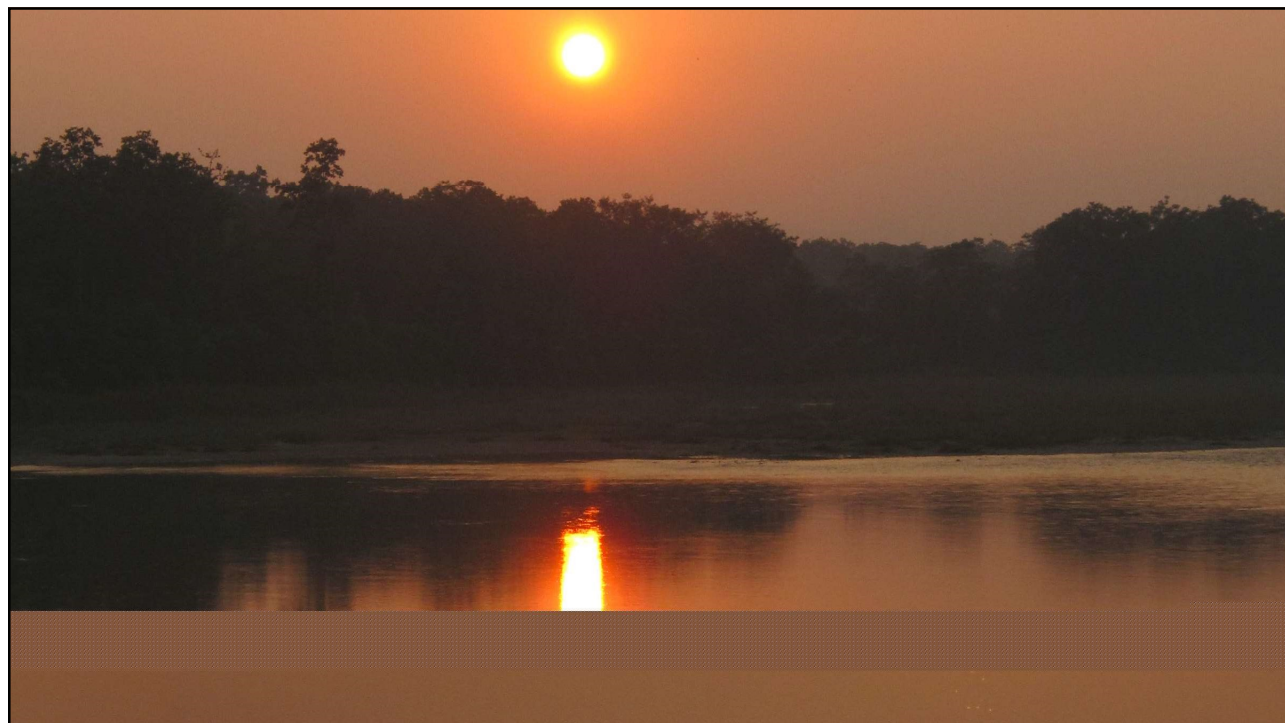
& What of Those Who Fear our Intentions & Medications

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

40



41



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Videos

- ▶ **Dr. Susan Moore: Black Female Doctors Condemn Racial Disparities in Healthcare | Democracy Now!**

https://www.democracynow.org/2020/12/30/joia_crear_perry_camara_phyllis_jones

- ▶ **John Oliver, Wanda Sykes & Larry David**

Bias in Medicine

<https://www.youtube.com/watch?v=TATSAHJKRd8>

- ▶ **Fact check – Bias in Medicine – Mikhail "Mike" Varshavski, MD**

[Doctor Reacts to John Oliver | Last Week Tonight: Bias in Medicine – YouTube](#)

- ▶ **Keith Wiloo, PhD. Whose Pain Matters; Reflections on Race, Social Justice and COVID-19's Revealed Inequities.**

www.youtube.com/watch?v=_arei42wnXc

Achieving Health Equity in Patient Supportive Care for Cancer Survivors

Lailea Noel, PhD, MSW
 Assistant Professor, Steve Hicks School of Social Work
 Affiliate Assistant Professor of Oncology and Health Social Work, Dell Medical School
 The University of Texas at Austin


1

Individual Stories of the lived experience

“I have worked really hard to make sure my boys are not caught up in what’s happening out there. You know what I mean? They are in school and doing well. If I am too sick to keep up with them who else will? I just don’t know...”

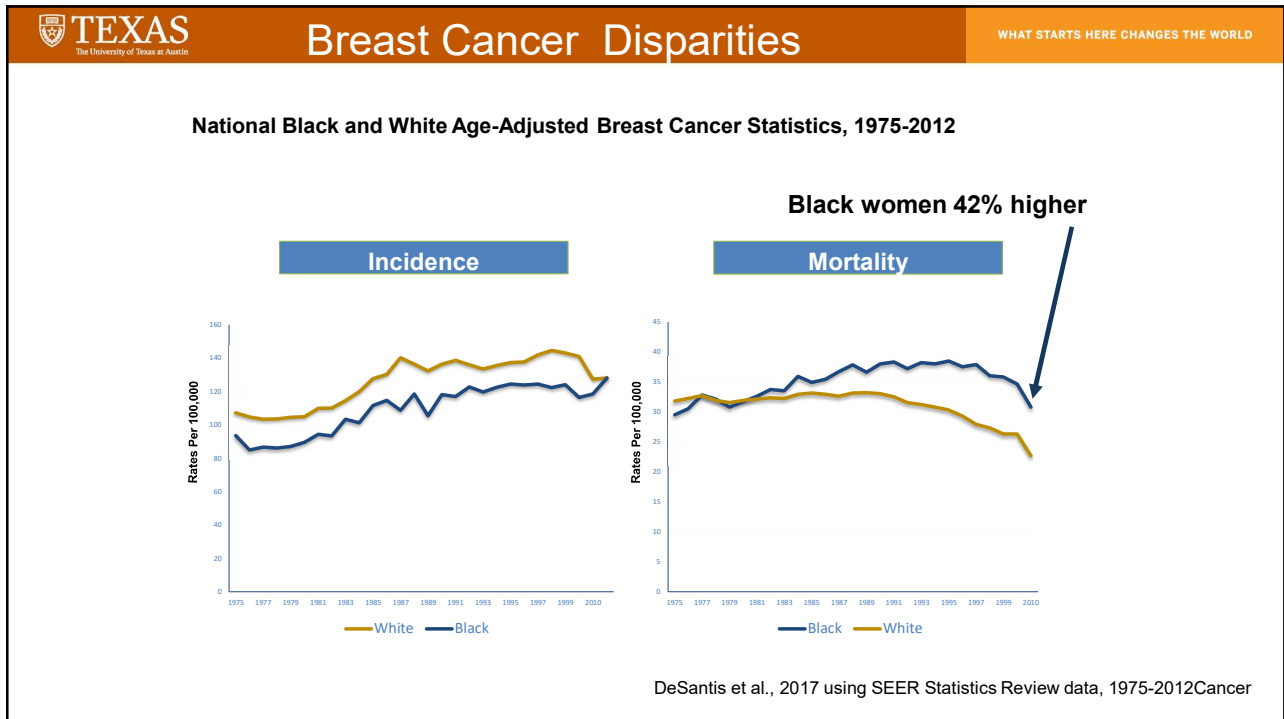
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Individual Stories of the lived experience

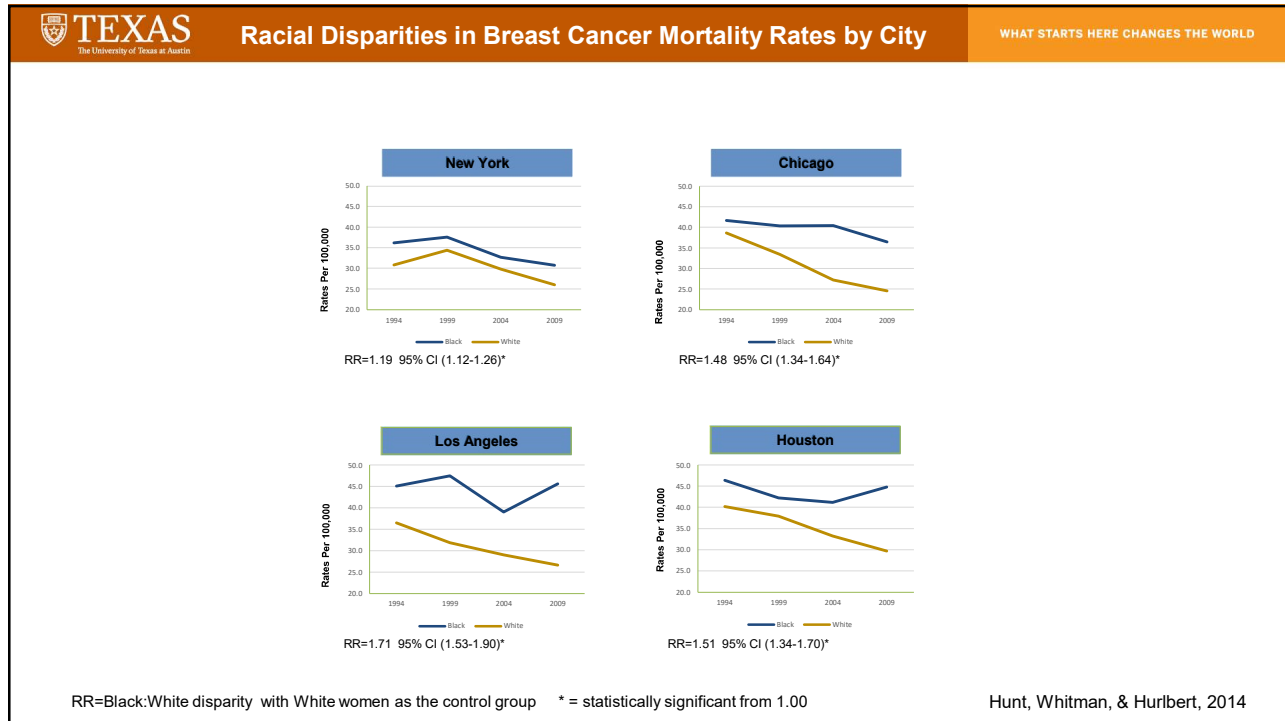


“I thought it might have been stress and all that I had to deal with on a daily basis... I knew it was something but I never thought it was cancer. They wanted to know from me how could you take a bath every day and not notice that you had tumors protruding through your skin. I said my kids are fed and clean every day. I get them to school on time. My house is clean. I take care of my grandmother and I work full time. I was able to pay my bills and take care of my kids. By the time I got in the bathroom to take a bath it would be after 10:00. I would jump in, shower and literally almost pass out being so tired because I worked full time so I didn't pay any attention to my own health because I was responsible for four other people.”

3



4



5

TEXAS
The University of Texas at Austin

WHAT STARTS HERE CHANGES THE WORLD

Health Equity

Principles

Health equity means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care.

Robert Wood Johnson Foundation

6

TEXAS
The University of Texas at Austin

WHAT STARTS HERE CHANGES THE WORLD

True Health Equity also Requires Addressing the System

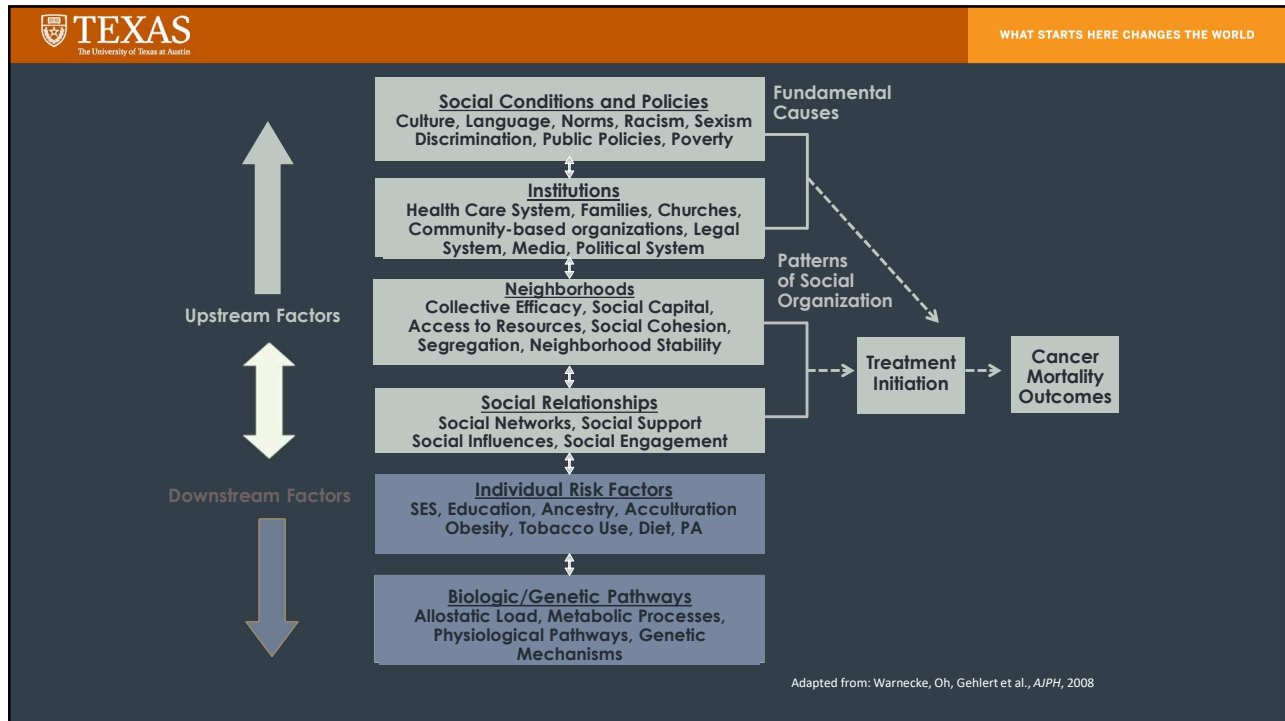
Inequality
Unequal access to opportunities

Equality?
Evenly distributed tools and assistance

Equity
Custom tools that identify and address inequality

Justice
Fixing the system to offer equal access to both tools and opportunities

7




8


TEXAS
 The University of Texas at Austin

WHAT STARTS HERE CHANGES THE WORLD

RURAL COMMUNITIES AND DISPARITIES


9


TEXAS
 The University of Texas at Austin

Community: The Importance of Place


WHAT STARTS HERE CHANGES THE WORLD

- 20% of the US lives in rural communities
- 27% of Texans (7.6 million) live in rural communities
- 233 out of 254 Counties in Texas are considered rural
- 23 out of 30 counties in Central Texas



State of Texas Department of Health and Human Services Data
Retrieved February 2021

10



Medical Services


WHAT STARTS HERE CHANGES THE WORLD

Rural residents travel nearly three times longer than urban residents to access medical services


Rural residents experience comorbid conditions, yet in comparison to urban areas, rural communities have fewer numbers of residents covered by employer-sponsored health insurance

Approximately 3% of medical oncologists provide onsite care in rural areas

Ward MM, Ullrich F, Matthews K, et al. Where do patients with cancer in Iowa receive radiation therapy? J Oncol Pract. 2014;10:20-5.



11




Social Determinants

WHAT STARTS HERE CHANGES THE WORLD

- Rural Communities face disparities in social determinants
 - housing insecurity
 - food insecurity
 - financial toxicity
 - inability to afford medication to treat the side effects of medical treatments and medicines for co-existing healthcare conditions

Cancer Network (2017) Challenges of Rural Cancer Care in the United States. <https://www.cancernetwork.com/view/challenges-rural-cancer-care-united-states>; retrieved on February 4, 2021



12

TEXAS
The University of Texas at Austin

Mental Health Services

WHAT STARTS HERE CHANGES THE WORLD

- Rural cancer survivors experience lower mental health functioning and more significant anxiety, depression, distress, and emotional problems than urban cancer survivors
- Only 2% of health social workers practice in rural communities, with very few if any who specialize in oncology

Burris JL, Andrykowski M. Disparities in mental health between rural and nonrural cancer survivors: a preliminary study. *Psychooncology*. 2010;19:637-45.

13

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Dynamic Systems

WHAT STARTS HERE CHANGES THE WORLD

14

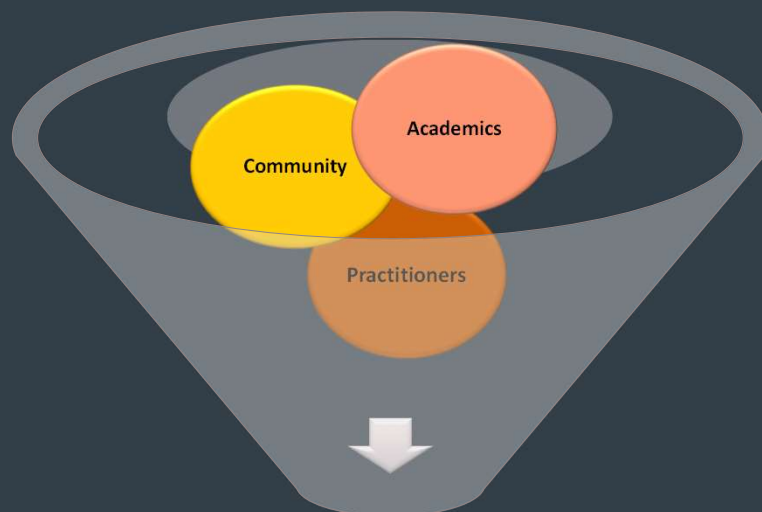
ENGAGING COMMUNITIES

15

Group Model Building

A process for engaging stakeholders to foster learning about the complexity of a problem


AND to decide on a course of action through consensus



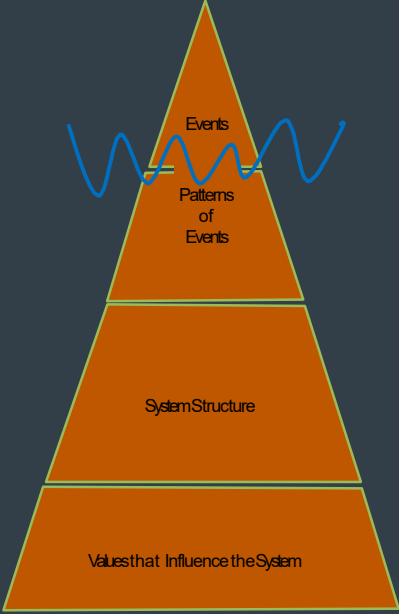
16

TEXAS
The University of Texas at Austin

WHAT STARTS HERE CHANGES THE WORLD



Group Model Building



Events

Patterns of Events

System Structure

Values that Influence the System


17

TEXAS
The University of Texas at Austin

WHAT STARTS HERE CHANGES THE WORLD

The groups modeled the components of a system that delivers the equal distribution of services for Rural Texans

- Identify current community assets important to connecting rural Texans with care
- Identify gaps in existing community assets
- Identifying barriers to connecting the community to services
- Identify breaks in services we haven't thought about before
- Share places where care has been received
- Times when care was needed and perhaps delayed



18

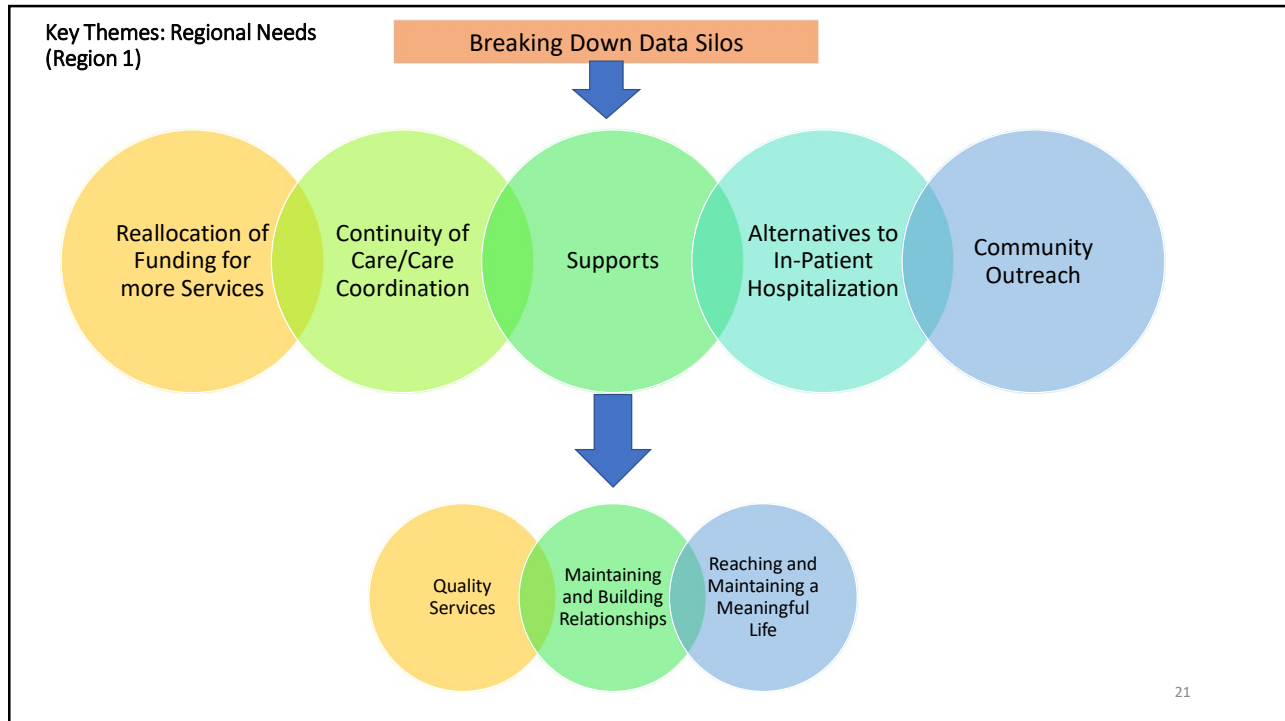
RESULTS

19

Regional Key Themes

20

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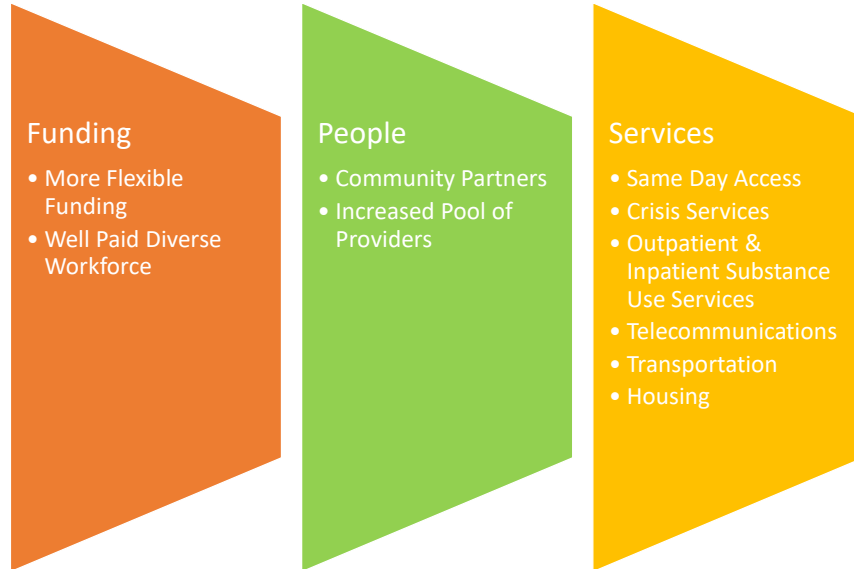


21



22

Key Themes: Regional Needs (Region 3)



23

23

Key Themes: Regional Needs (Region 4)



Environmental Influences on Operational Influences

- Access to Higher Education
- Affordable Childcare
- Communication in Language of Customer
- Family Support
- Proximity to services
- Transportation

Operational Influences on Services

- Data
- Connectivity/ Telehealth/ Infrastructure
- Staff recruitment and retention of Professional Staff
- Collaboration/Interlocal Collaboration
- Ancillary Services/Non-Traditional Services
- Advocacy/Political Support
- Stigma Reduction
- Law Enforcement Training and Education

Services

- 1-Stop Shop Accessibility
- COC Services
- Community Education on mental health
- Crisis Respite Group Homes
- Person Centered Care
- Psych Hospital Access
- Youth Services

24

24

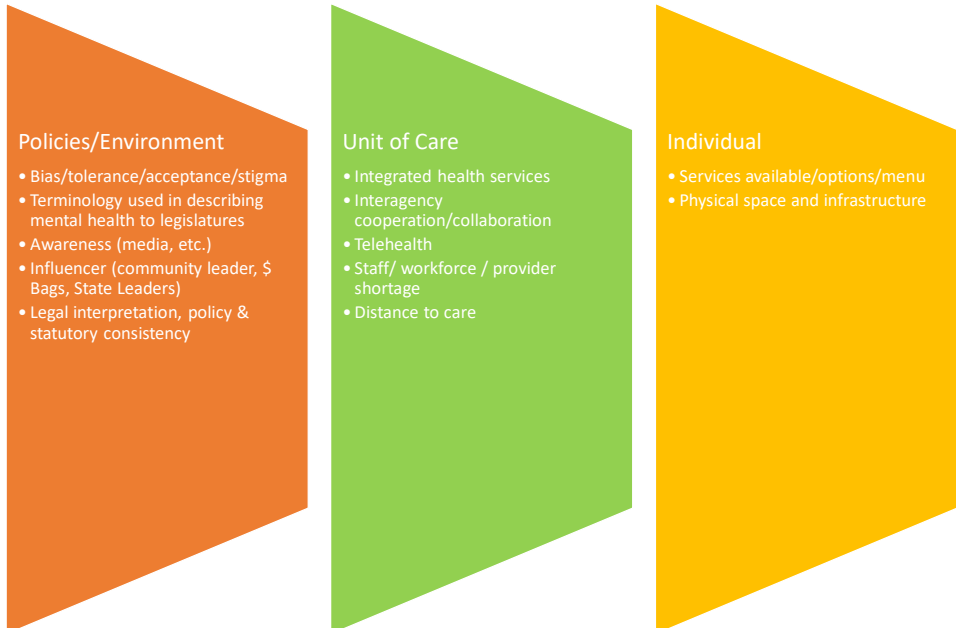
Key Themes: Regional Needs (Region 5)



25

25

Key Themes: Regional Needs (Regional 6)



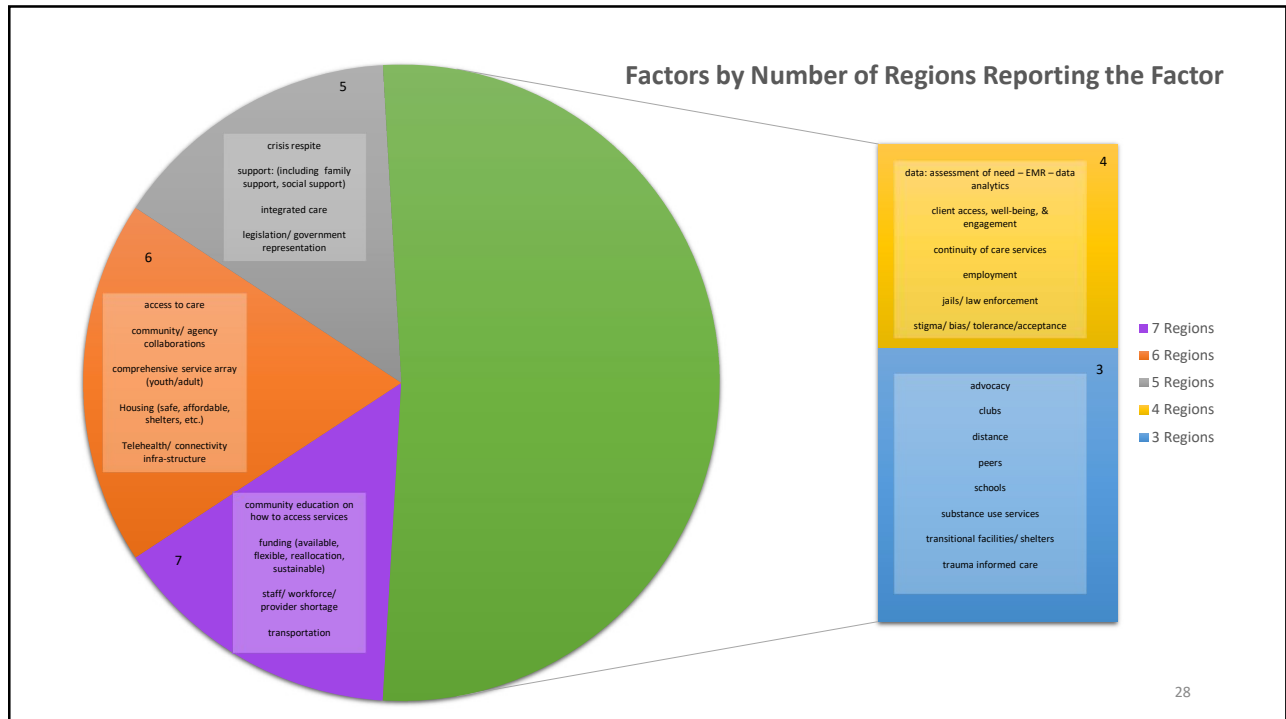
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State of Texas Key Themes

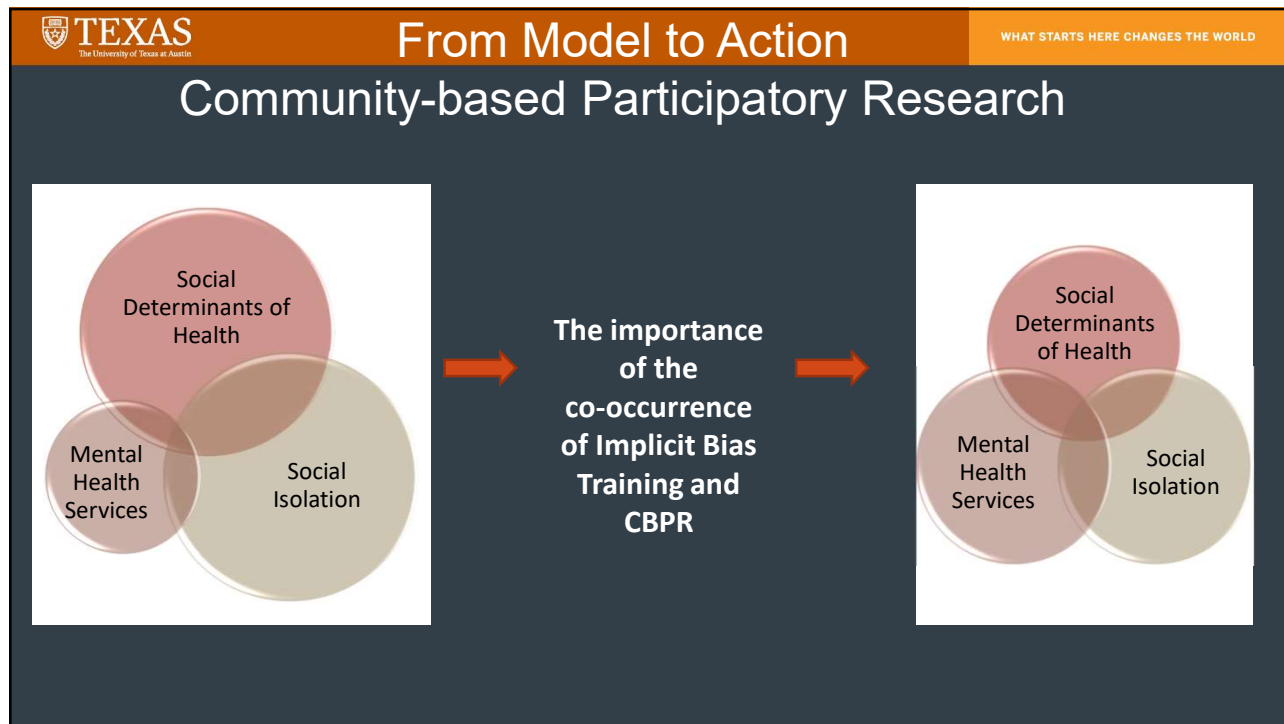
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TEXAS
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Implications

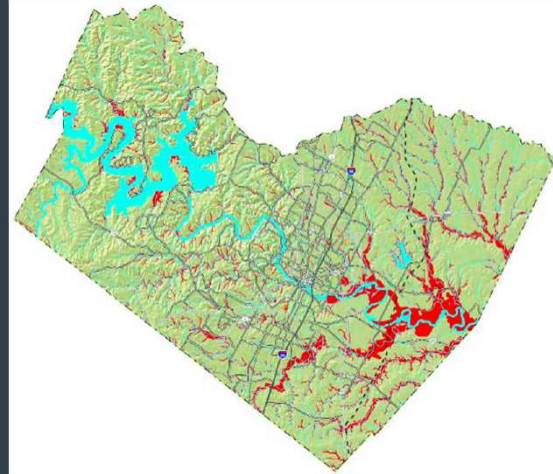
WHAT STARTS HERE CHANGES THE WORLD

Build Bridges

- Collaborate with Mental Health and Community Leaders
- Model systems of care delivery in socially isolated communities throughout rural areas

30

- Engage in Community Asset Building/ Empowering and equipping communities
- Explore the impact of these system ties on socially isolated communities and rural areas



31



...their voice is so quiet; I'm compelled to lean in...

32

Thank you



1



Phylicia L. Woods, JD, MSW

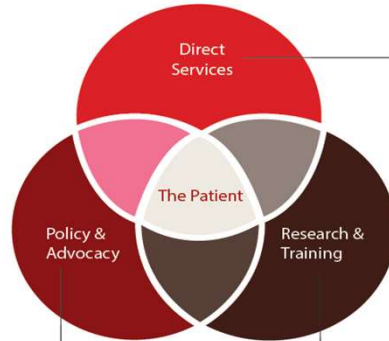
Executive Director, Cancer Policy Institute
Cancer Support Community

Cancer, Pain, Communities of Color: Policy and Advocacy Perspective

2

CANCER SUPPORT COMMUNITY

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.



- More than 500,000 visits by patients and loved ones to our 175 locations each year
- The Cancer Support Helpline (CSH) responds to nearly 40,000 support and resource navigation inquiries (calls, emails, and chats) each year
- 3.2 million unique visitors to our website annually
- Nearly 40,000 users of MyLifeLine digital community platform

Our Three Pillars: Patient Services Insight Advocacy

- Focused on three major pillars: Quality, Access, and Research
- Grassroots Network has thousands of patients and supporters

- Nearly 15,000 participants in the Cancer Experience Registry
- More than 1 million data points on these patients
- Innovative ways to measure patient experience
- Program development and testing
- Qualitative and quantitative Patient Insights



3

3

Agenda

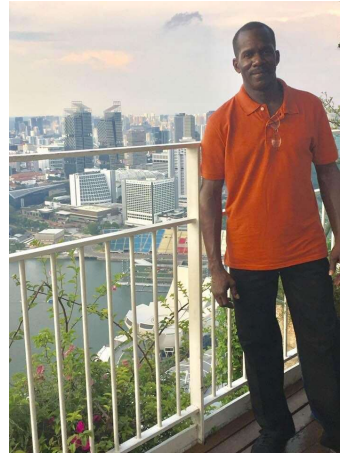
- 1** Phil's Journey
Personal stories are influential in changing policy
- 2** Unequal Pain Management
Current pain policy landscape
- 3** Eliminated Pain Care Disparities
Need for more advocates



4

4

Phil's Pain Journey



5



5

Unequal Pain Management: Current Policy Landscape



**Bias in
Pain Policy**



**Opioids
Epidemic**



**PCHETA
Legislation**

6



6

Eliminating Pain Care Disparities in Policy: United Advocacy Agenda



Social Determinants of Health*



Cultural Competence



Community Engagement



Educating Policymakers

*Source: Healthy People 2030, U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Retrieved [date graphic was accessed], from <https://health.gov/healthypeople/objectives-and-data/social-determinants-health>

7



7

Revisiting Phil's Pain Journey

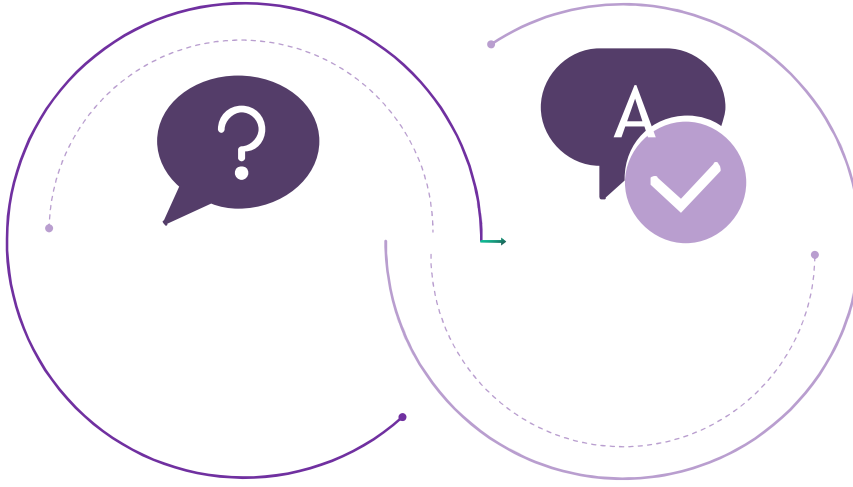



8



8

Q&A






9

9

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Thank You!

www.cancersupportcommunity.org

Social Media: @CSCCancerPolicy @CancerSupportHQ

