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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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

THANK YOU FOR JOINING TODAY!

Cardinale Smith, MD, PhD
Mount Sinai (Icahn)

Terry Altilio, LCSW
Palliative Social Worker

Lailea Noel, PhD
The University of Texas at Austin

Phylicia Woods, JD, MSW
Cancer Support Community

2

Please take a moment to visit each organization's website!

APOS
american psychosocial oncology society

AOSW
ASSOCIATION OF ONCOLOGY SOCIAL WORK
EXCELLENCE IN PSYCHOSOCIAL ONCOLOGY

ACCC
Association of Community Cancer Centers

apos-society.org | aosw.org | accc-cancer.org

3

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

Moderator

4

Association of Community Cancer Centers

ASSOCIATION OF ONCOLOGY SOCIAL WORK
EXCELLENCE IN PSYCHOSOCIAL ONCOLOGY

american psychosocial oncology society
Advancing the science and practice of psychosocial oncology.

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

5

ASSOCIATION OF
COMMUNITY
CANCER CENTERS

The leading education and advocacy organization for the cancer care community

ACCC-CANCER.ORG

Association of Community Cancer Centers

6

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

7

APOS

american psychosocial oncology society

www.apos-society.org

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

8

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

AOSW • APOS • ACCC Joint Virtual Conference 10.07.21 12-4:30 PM EST

Achieving Health Equity in the Psychosocial Treatment of Cancer Pain

9

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.

How to Get Your Certificate

1. Go to http://apos.cmecertificateonline.com
2. Click on the "Achieving Health Equity in the Psychosocial Treatment of Cancer Pain" link.
3. Evaluate the meeting.
4. Print all pages of your certificate for your records.
5. Questions? Email Certificate@AmedcoEmail.com

10

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

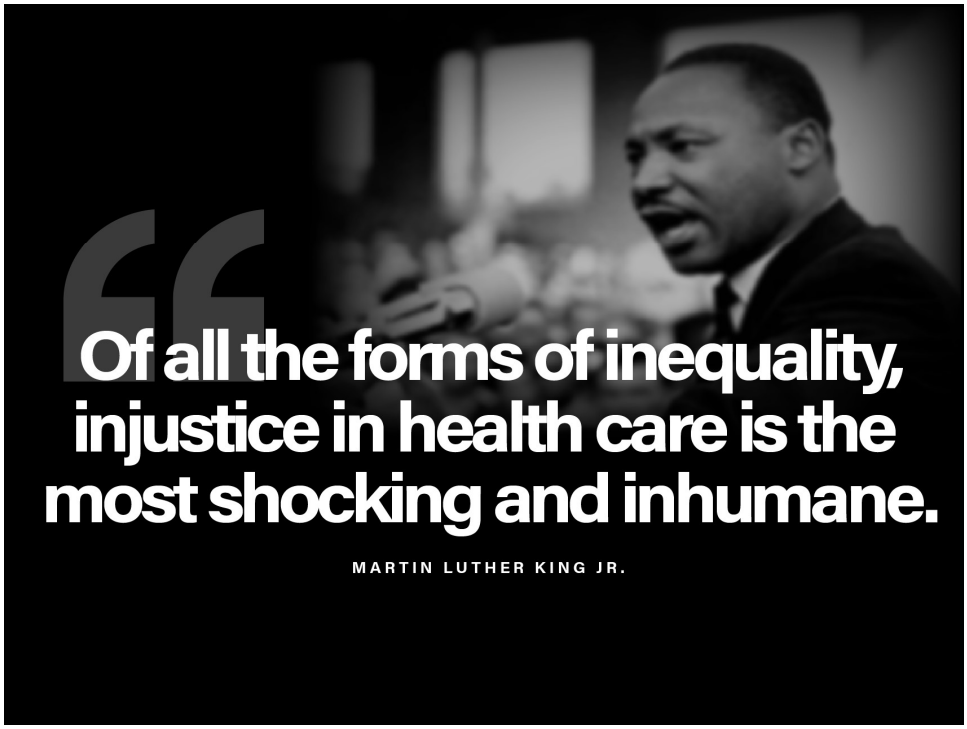
Mount Sinai

1

Objectives

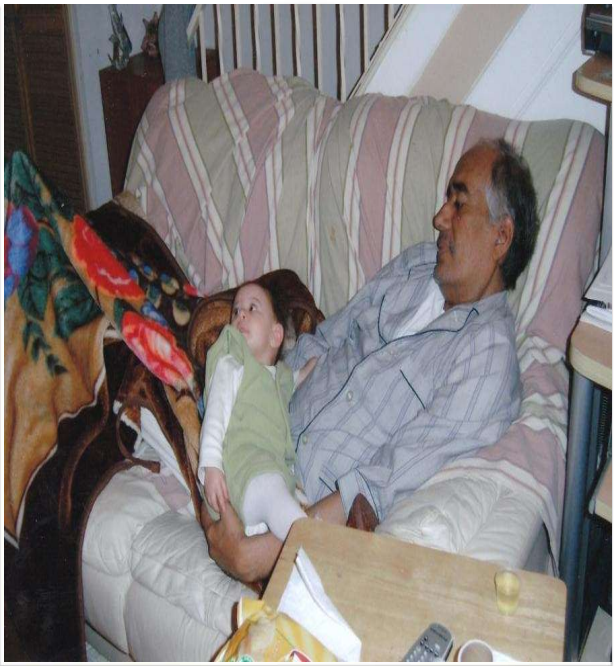
- Discuss historical and contemporary health injustice towards minorities
- Identify patient, provider, system, and regulatory barriers to effective pain management

2


Of all the forms of inequality, injustice in health care is the most shocking and inhumane.
MARTIN LUTHER KING JR.

3

My Sto



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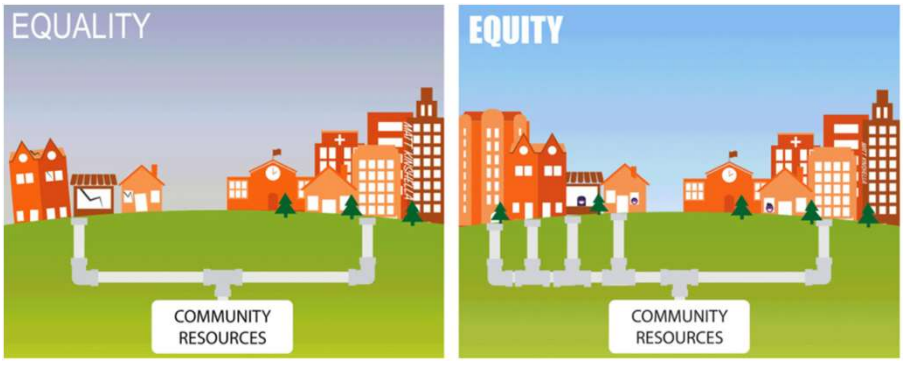
What is Health Equity?

"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

5

What is Health Equity?



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

6

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,

8

Barriers: Biological Differences

Item	Study 1 (n = 92) %	Study 2, %			
		1st yr (n= 63)	2nd yr (n= 72)	3rd 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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11

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

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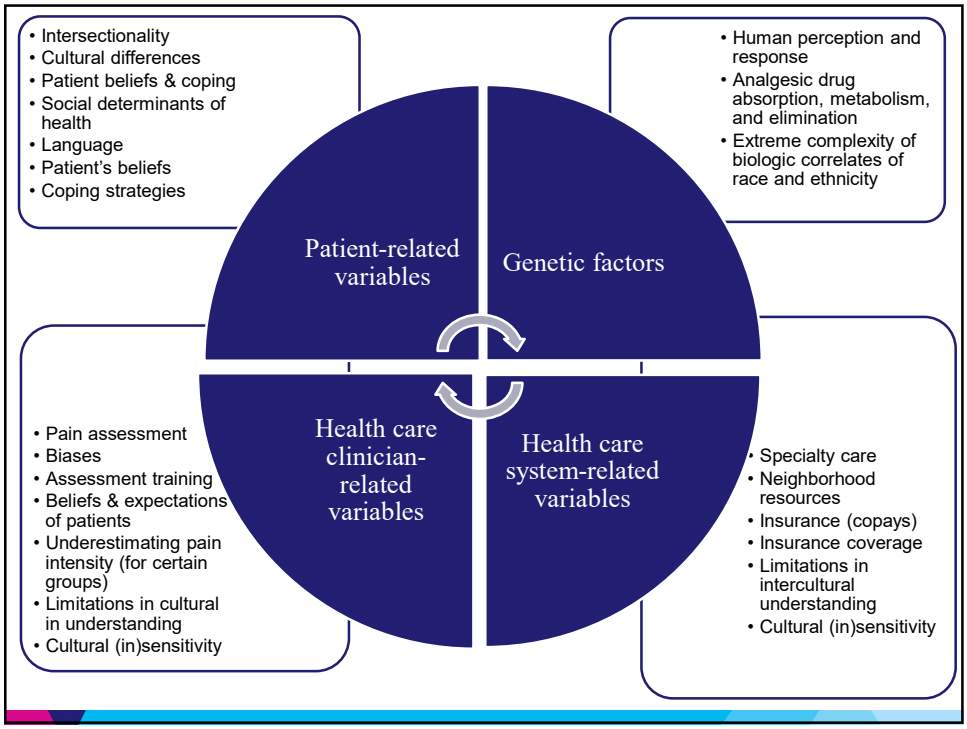
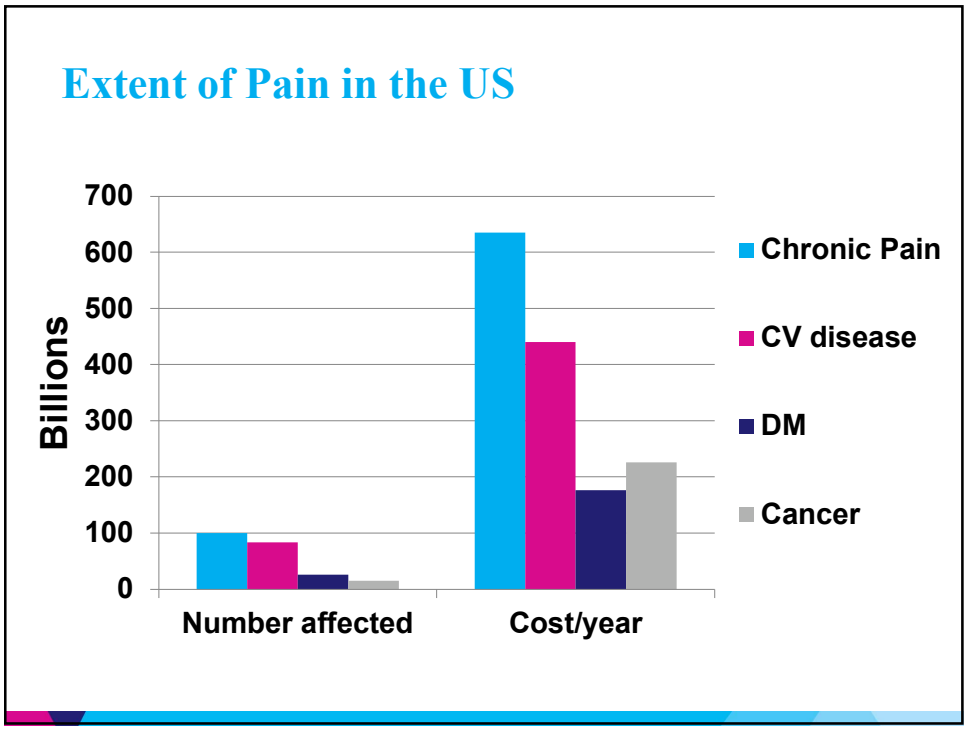
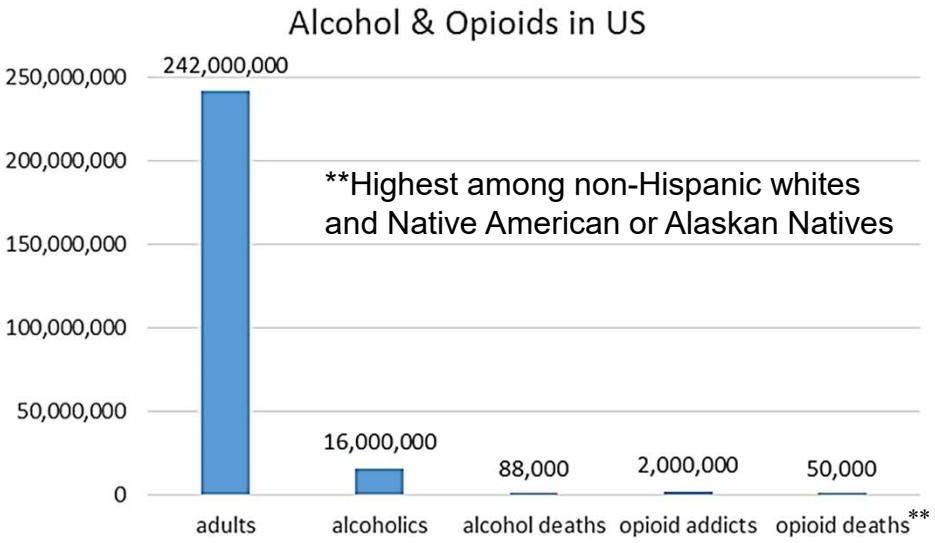

• Intersectionality
• Cultural differences
• Patient beliefs & coping
• Social determinants of health
• Language
• Patient's beliefs
• Coping strategies
• Human perception and response
• Analgesic drug absorption, metabolism, and elimination
• Extreme complexity of biologic correlates of race and ethnicity
Patient-related variables
Genetic factors
Health care clinician-related variables
Health care system-related variables
• Pain assessment
• Biases
• Assessment training
• Beliefs & expectations of patients
• Underestimating pain intensity (for certain groups)
• Limitations in cultural in understanding
• Cultural (in)sensitivity
• Specialty care
• Neighborhood resources
• Insurance (copays)
• Insurance coverage
• Limitations in intercultural understanding
• Cultural (in)sensitivity

13


Extent of Pain in the US
Billions
700
600
500
400
300
200
100
0
Number affected
Cost/year
Chronic Pain
CV disease
DM
Cancer

14

Scope of Problem



15

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%

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

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Consequences of Pain

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

17

The New York Times

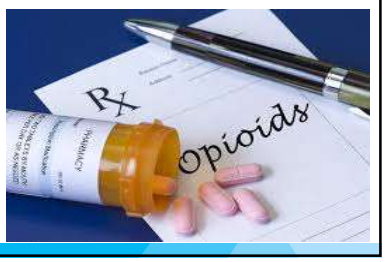
Finding Good Pain Treatment Is Hard. If You're Not White, It's Even Harder.

August 9, 2016

18

Factors Responsible for Disparities

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



19

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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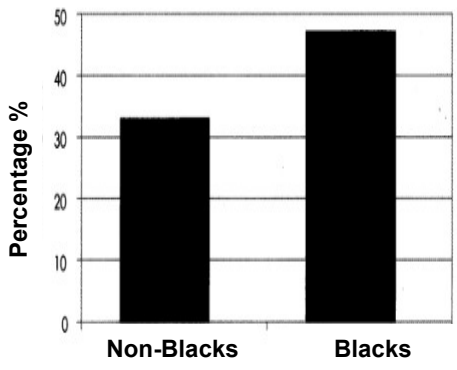
Clinician Barriers: Underestimation



- 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.

21

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

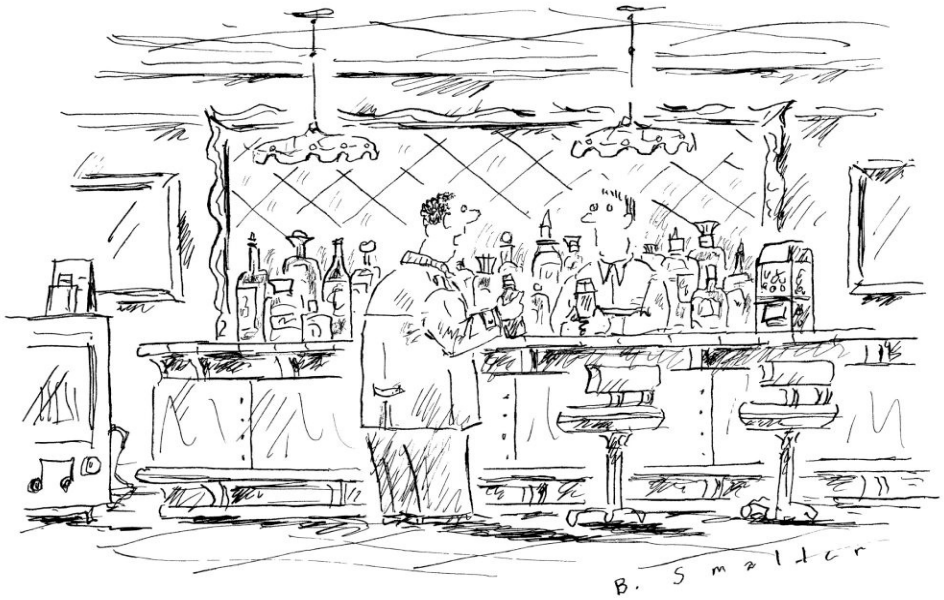
22

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

23



"The great thing about self-medicating is that there is a low co-pay"

New Yorker 6.16

24

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	
Black			<0.001
<10%	173	61	
10–19%	53	45	
20–39%	57	42	
≥40%	64	30	
Hispanic			0.002
<10%	89	56	
10–19%	108	54	
20–39%	70	50	
≥40%	80	34	
Asian			0.01
<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.

25

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.

26

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.*

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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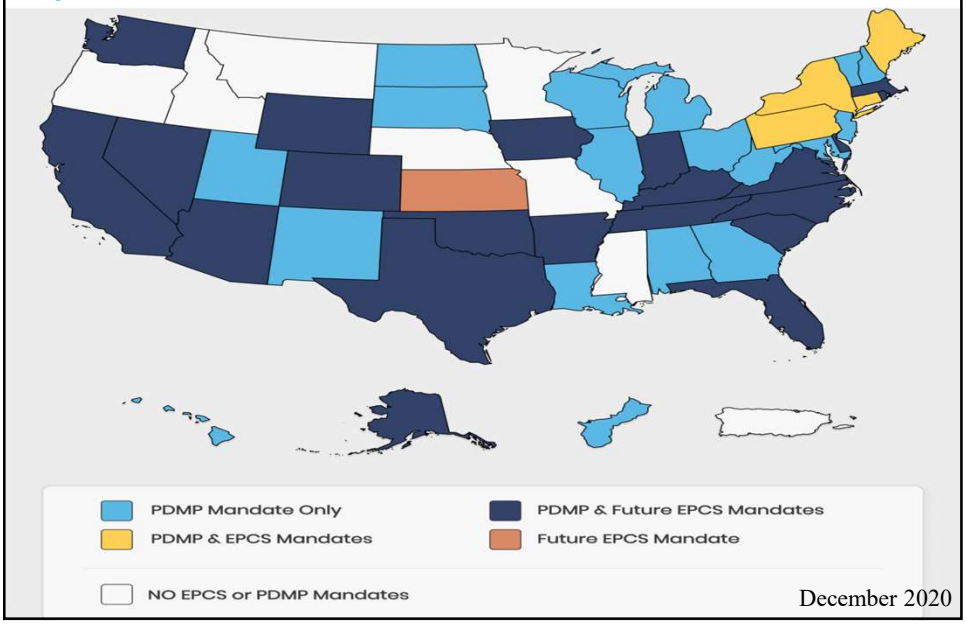
System Barriers: PDMP and EPCS



December 2020

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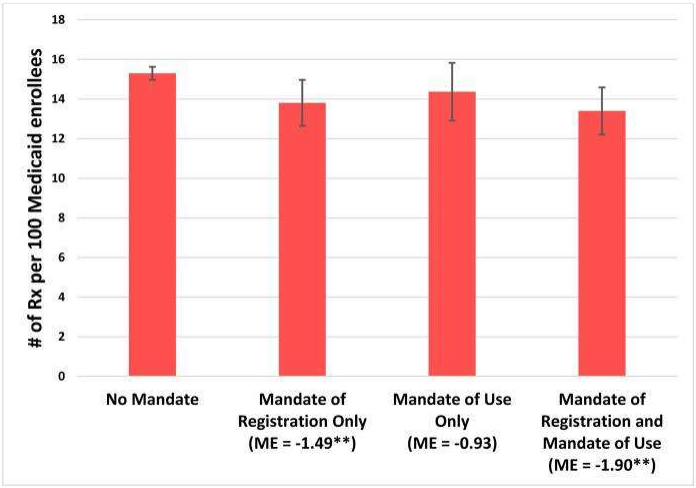
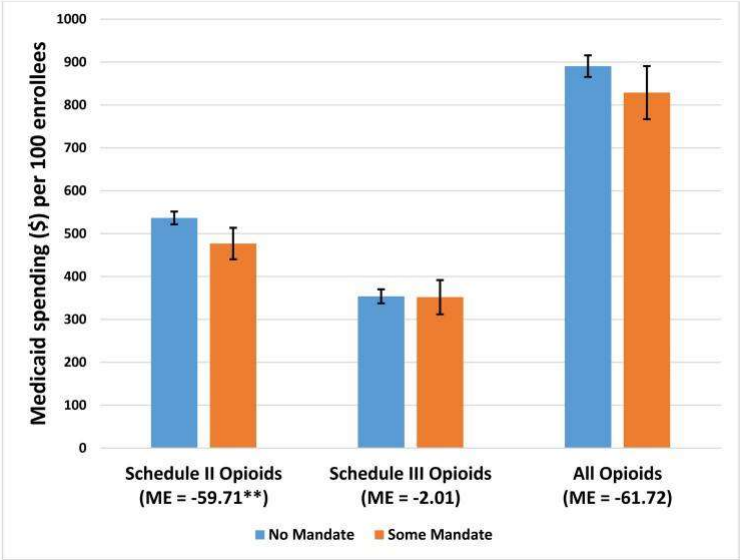
PDMP's: Medicaid Beneficiaries



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

30

PDMP's: Medicaid Beneficiaries



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

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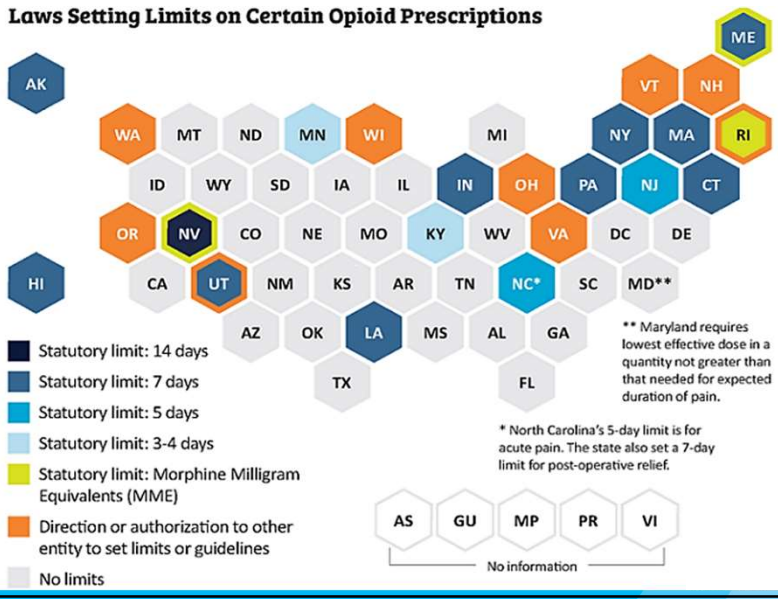
System Barriers



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www.nytimes.com

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

34

Viscous Cycle

35

Suggested Solutions

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

36

"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

37

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."

2

Silence is not an Option

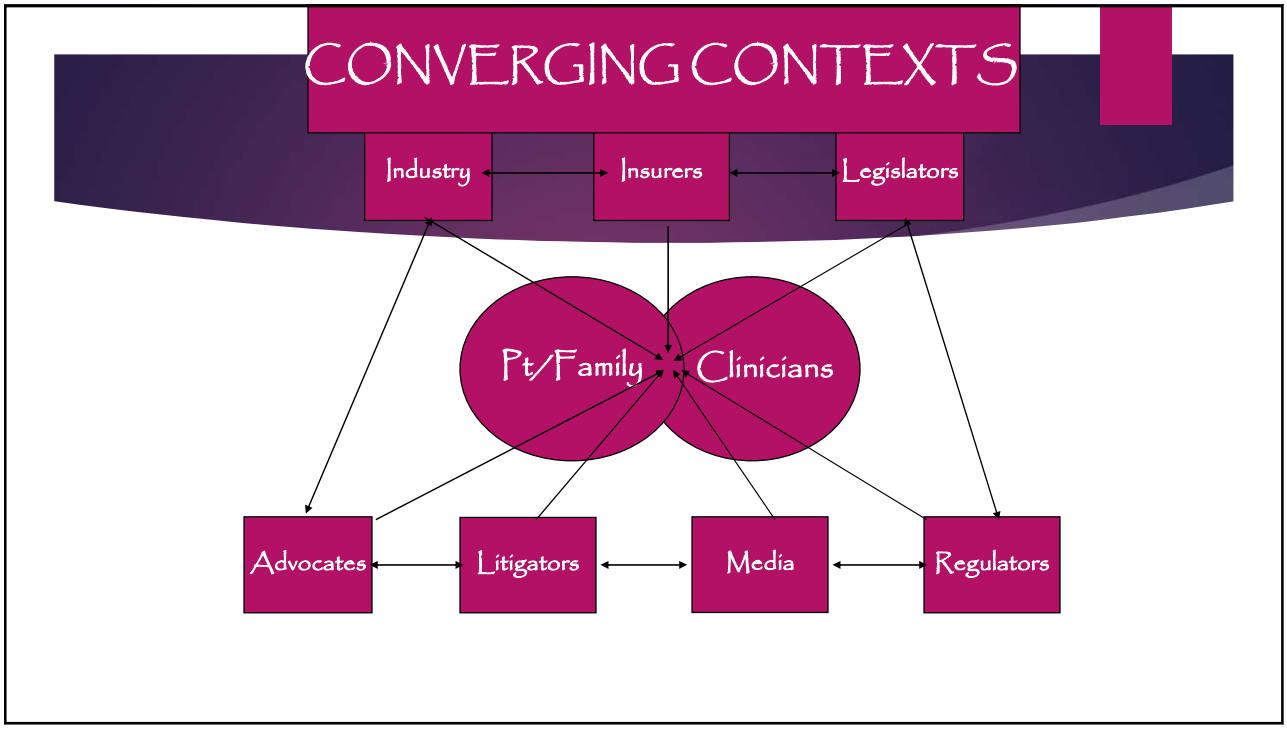
Care of patients who suffer, whether with or without pain is a Shared Responsibility & yet the risk for each discipline is not equal

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)

12

Principle of Balance

Opioids may be indispensible 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 expertsie

- 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

13

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)

14

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...

15

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)

16

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)

20

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

22

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)

26

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

- Beliefs & Values
  - Pain is inevitable, necessary
  - Requires stoic response
  - Represents sacrifice
  - Intent of clinicians & medical system is suspect
- Fears
  - 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

38

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, PMPrograms
- Appropriate referrals
- Mediate access barriers

39

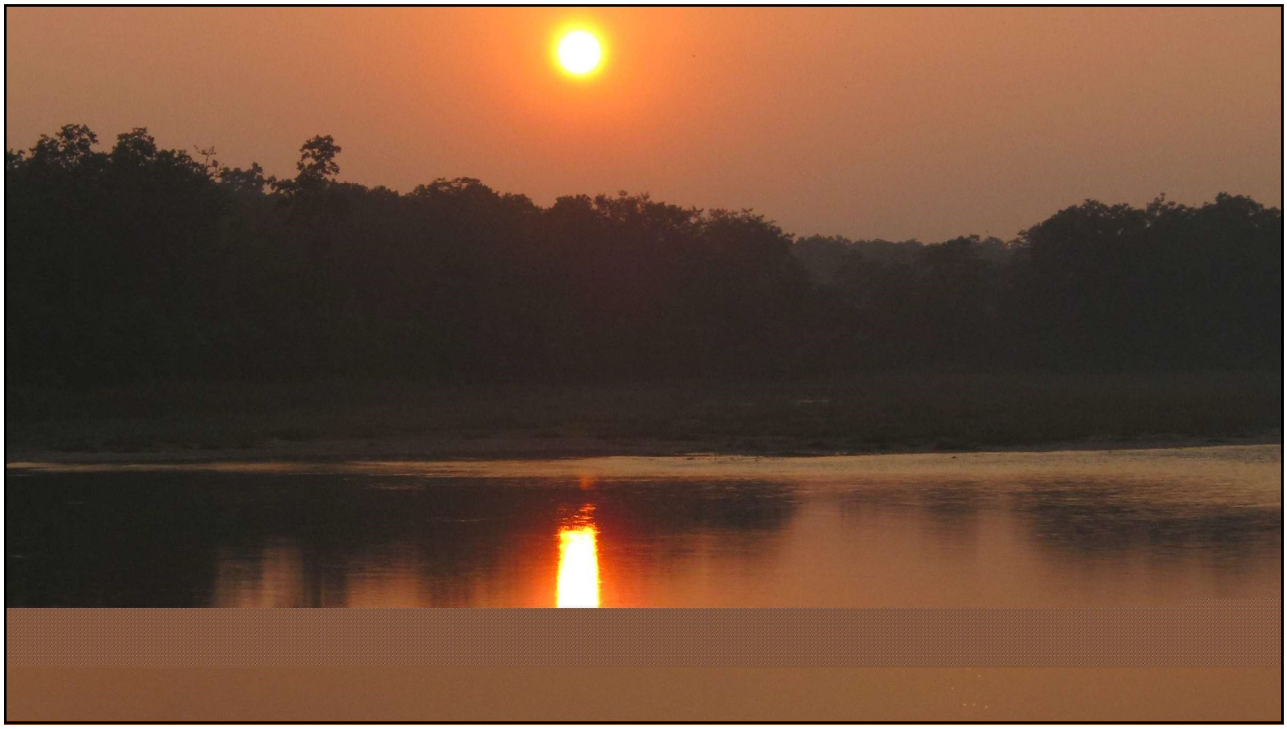
& What of Those Who Fear our Intentions & Medications

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

40

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

41



42

References & Resources

- Alford, D.(2017). Managing opioid disorders & chronic pain. Practical Pain Management. https://www.practicalpainmanagement.com/issue/1702
- Altilio, T., & Doran, M.P. (2013). Pain. Encyclopedia of Social Work. Retrieved from http://socialwork.oxfordre.com/view/10.1093/acrefore/9780199975839.001.0001/acrefore-9780199975839-e-276
- Altilio, T., Doran, M.P., Leimena, M.L. "Pain Management." In Oxford Bibliographies in Social Work. Ed. Edward J. Mullen. New York: Oxford University Press, 2016-10-27 http://www.oxfordbibliographies.com/view/document/obo-9780195389678/obo-9780195389678-0242.xml?rskey=JjaSnP&result=141
- American Academy of Pain Medicine. Use of Opioids for the Treatment of Chronic Pain A statement from the American Academy of Pain Medicine - file:///C:/Users/Owner/Desktop/use-of-opioids-for-the-treatment-of-chronic-pain.pdf
- CDC Guideline for Prescribing Opioids for Chronic Pain—United States, 2016. *Recommendations and Reports* / March 18, 2016 / 65(1);1–49.

43

References & Resources

- Center for Practical Bioethics. Chronic pain resources, Pain policy briefs. www.practicalbioethics.org/resources/chronic-pain-resources.html; ttps://www.practicalbioethics.org/events-education/videos/lecture-videos.htm
- Cohen., Quintner, J. & vanRysewyk, S. (2018) Reconsidering the IASP definition of pain. *Pain Reports*, 3(2): 634.
- Dahlhamer J. et al . Prevalence of chronic pain and high impact chronic pain among adults – United States, 2016. *MMWR*. September 14, 2018. [Epub ahead of print.]
- Faull M, Bohm M, Alexander C. Methadone Prescribing and Overdose and the Association with Medicaid Preferred Drug List Policies—United States, 2007–2014. MMWR Morb Mortal Wkly Rep 2017;66:320–323. //dx.doi.org/10.15585/mmwr.mm6612a2
- Gaither et al. (2018). Racial disparities in discontinuation of long term opioid therapy following illicit drug use among black and white patients, *Drug and Alcohol Dependence*. 192(1):371-376. //www.sciencedirect.com/science/article/pii/S0376871618303855?via%3Dihub#abs0005
- Goddu, P. et al. (2018). Do Words Matter? Stigmatizing Language and the Transmission of Bias in the Medical Record. *Journal of general internal medicine*, 33(5), 685–691. https://doi.org/10.1007/s11606-017-4289-2
- Green, C. R., Anderson, K. O., Baker, T. A., Campbell, L. C., Decker, S., Fillingim, R. B., et al. (2003). The unequal burden of pain: Confronting racial and ethnic disparities in pain. Pain Medicine, 4(3), 277–294.

44

References & Resources

- Hoffman, K.M., Trawalter, S., Axt, J.R. & Norman Oliver, M. (2016) Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. PNAS 113 (16) 4296-4301. https://doi.org/10.1073/pnas.1516047113
- IASP Curriculum Outline for Pain in Social Work Task Force Members: Terry Altilio (Co-chair, USA), John Cagle (USA), Kerryn Coombe (Australia), Maris Pasquale Doran (Co-Chair, USA), Andy Sim Gim Hong (Singapore)
- Institute of Medicine(2011). Relieving Pain in America. www.nationalacademies.org/hmd/Reports/2011/Relieving-Pain-in-America-A-Blueprint-for-Transforming-Prevention-Care-Education-Research.aspx
- Lasch, K.E. (2002). Pain clinical updates: Culture and pain. International Association for the Study of Pain, 10(5).
- Mendenhall, M. (2003). Psychosocial aspects of pain management: A conceptual framework for social workers on pain management teams. Social Work in Healthcare, 36(4), 35-51.
- Mental Health and Substance Use Disorders. (2019). http://www.samhsa.gov/disorder
- National Institute of Health (2014) The role of opioids in the treatment of chronic pain. www.prevention.nih.gov/sites/default/files/documents/programs/p2p/ODPPainPanelStatementFinal_10-02-14.pdf

45

References & Resources

- Otis-Green, S. Psychosocial Pain Assessment Tool. Pain Resource Center, City of Hope. prc.coh.org/pain_assessment.asp
- Otis-Green, S., Lucas, S., Spolum, M., Ferrell, B., & Grant, M. (2008). Promoting excellence in pain management and palliative care for social workers. Journal of Social Work in End-of-Life & Palliative Care, 4(2), 120-134.
- Pains Project Educational Brief #4. Opioid treatment agreements or "contracts", Proceed with caution. www.practicalbioethics.org/files/pain/pain-policy-issue-4-spring-2014.pdf
- Pains Project Educational Brief # 6. What is biopsychosocial pain care; Why should you care. www.practicalbioethics.org/files/pain/pain-july-2015-psychosocial-issue-6.pdf
- Payne, R. (2015). Chronic pain: The invisible public health crises: A call for moral leadership. practicalbioethics.blogspot.com/2015/02/chronic-pain-invisible-public-health.html
- Rich, B. (2000). An ethical analysis of the barriers to effective pain management. *Cambridge Quarterly of Healthcare Ethics. 9*, 54-70.
- Twillman, R. (2019). Have a real conversation: Informed consent vs contracts for opioid therapy. PPM, Practical Pain Management. Have a Real Conversation: Informed Consent vs Contracts for Opioid Therapy (practicalpainmanagement.com)

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

www.youtube.com/watch?v=_arei42wnXc

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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

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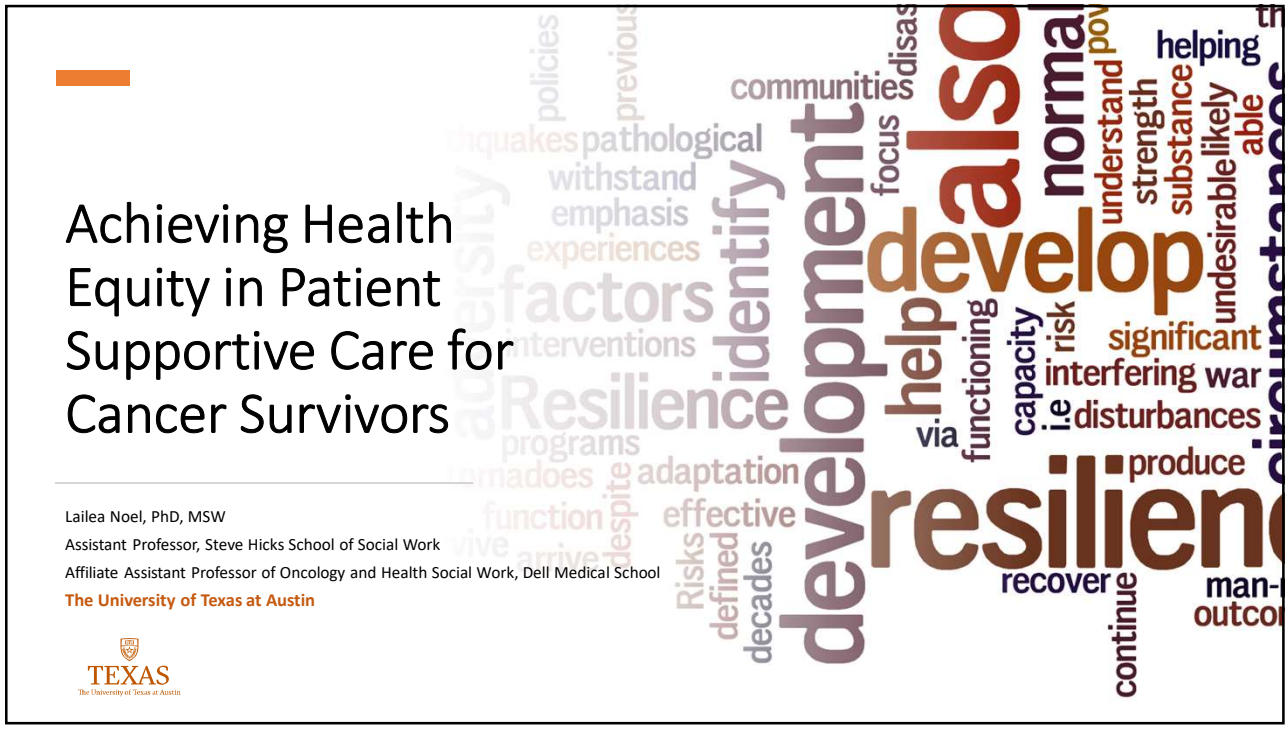

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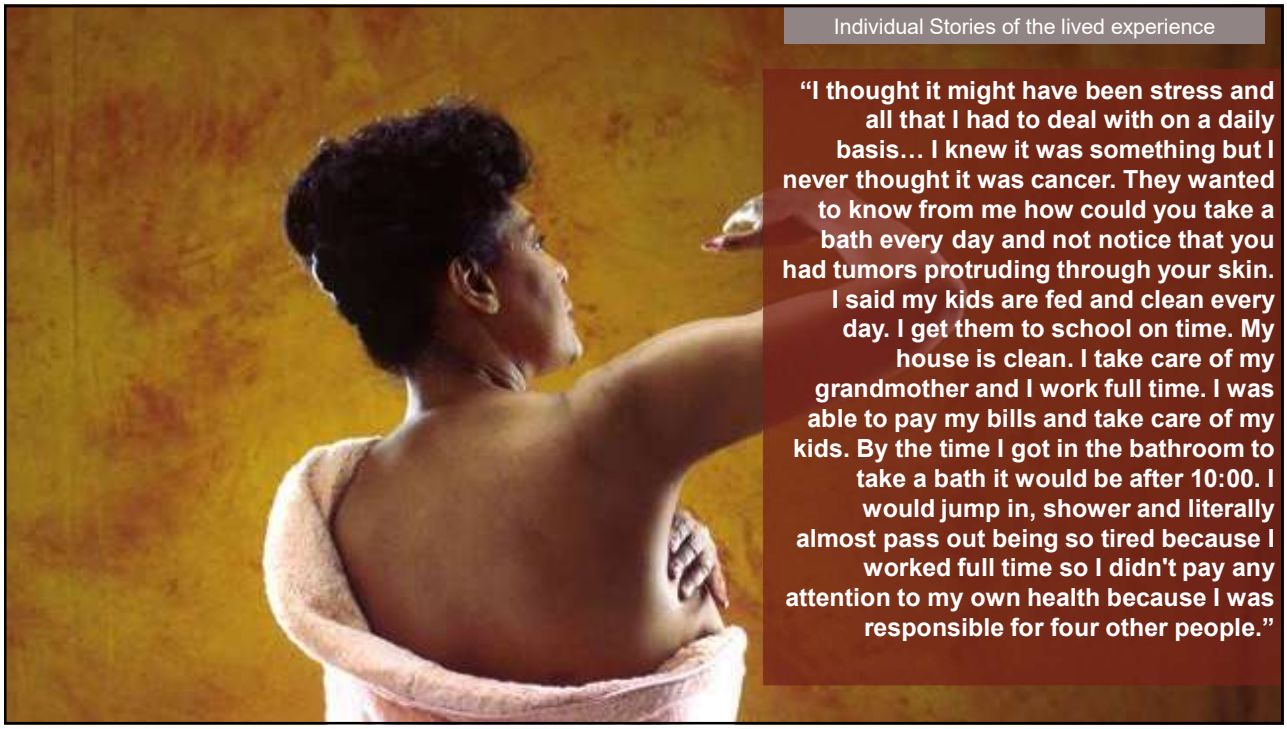

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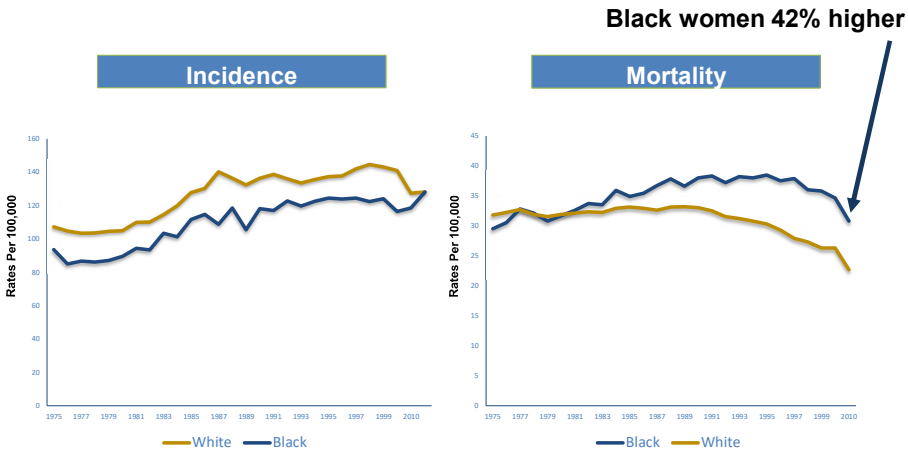
Breast Cancer Disparities

WHAT STARTS HERE CHANGES THE WORLD

National Black and White Age-Adjusted Breast Cancer Statistics, 1975-2012



DeSantis et al., 2017 using SEER Statistics Review data, 1975-2012Cancer

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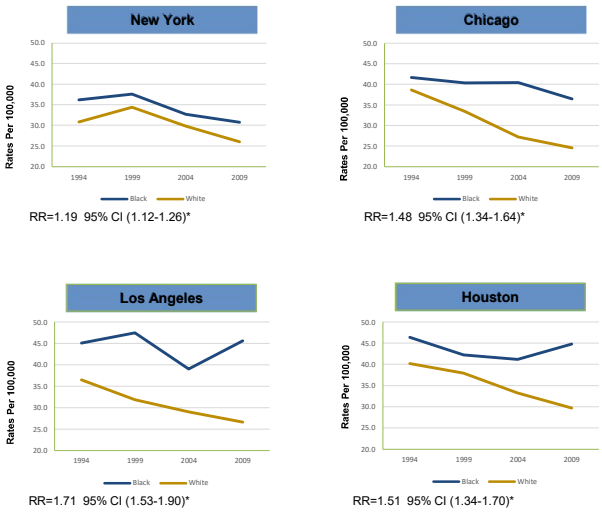
Racial Disparities in Breast Cancer Mortality Rates by City

WHAT STARTS HERE CHANGES THE WORLD



RR=1.19 95% CI (1.12-1.26)*

RR=1.48 95% CI (1.34-1.64)*

RR=1.71 95% CI (1.53-1.90)*

RR=1.51 95% CI (1.34-1.70)*

RR=Black:White disparity with White women as the control group * = statistically significant from 1.00

Hunt, Whitman, & Hurlbert, 2014

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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

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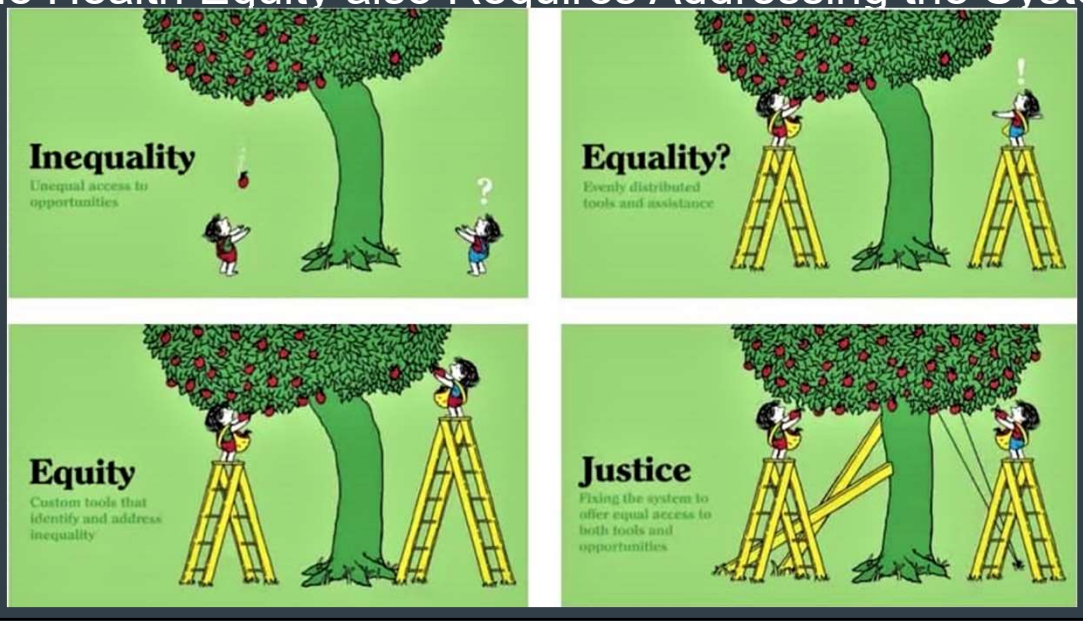
True Health Equity also Requires Addressing the System



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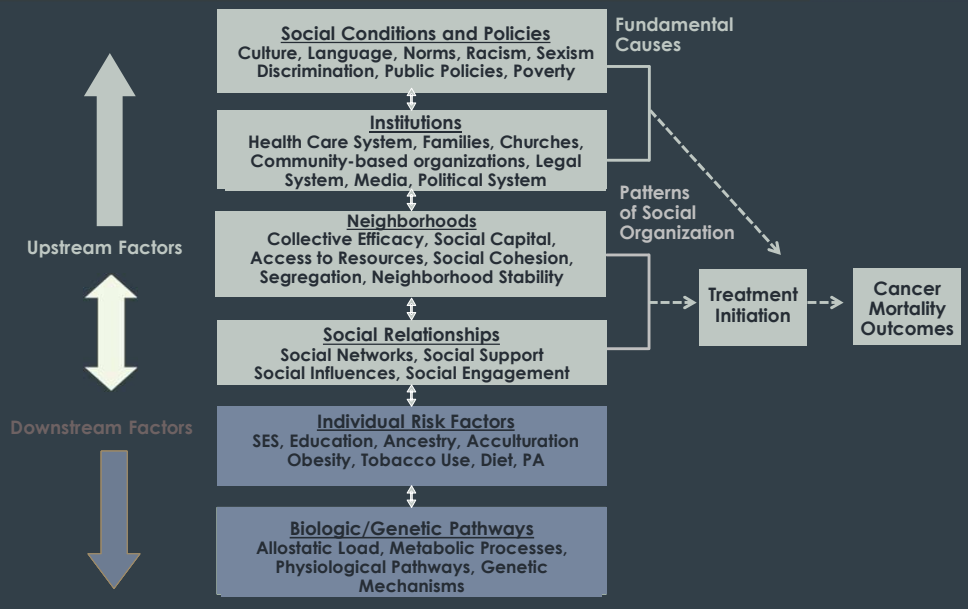

Adapted from: Warnecke, Oh, Gehlert et al., *AJPH*, 2008

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WHAT STARTS HERE CHANGES THE WORLD

RURAL COMMUNITIES AND DISPARITIES

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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

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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.

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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

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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.

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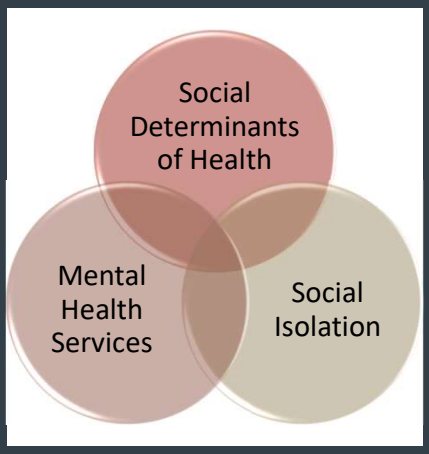
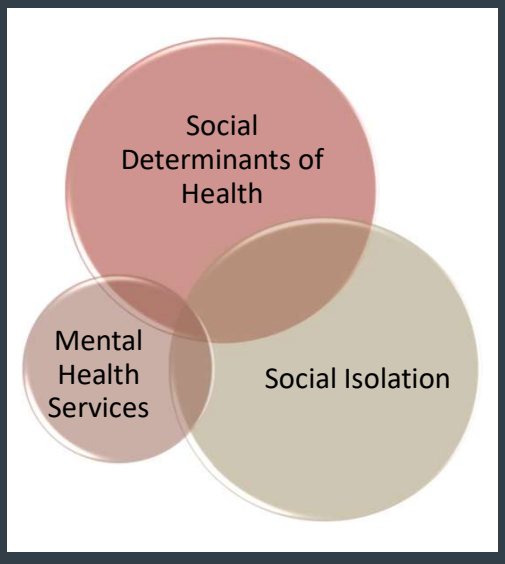
Dynamic Systems

WHAT STARTS HERE CHANGES THE WORLD





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WHAT STARTS HERE CHANGES THE WORLD

ENGAGING COMMUNITIES

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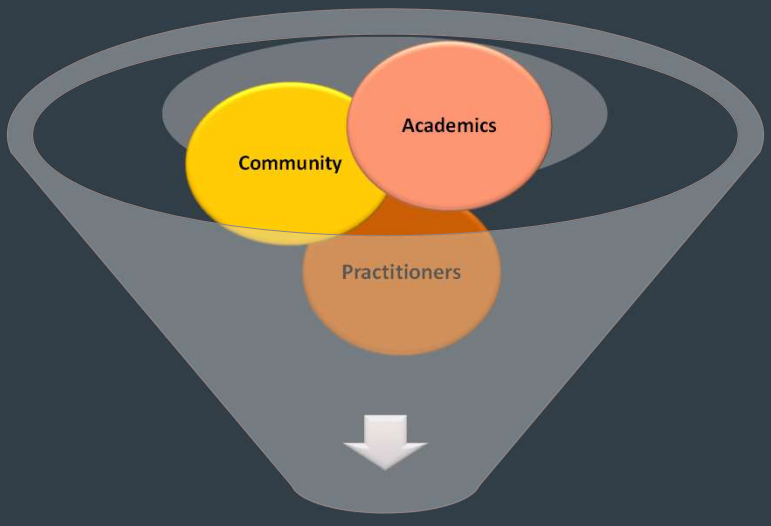
Group Model Building

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

AND to decide on a course of action through consensus



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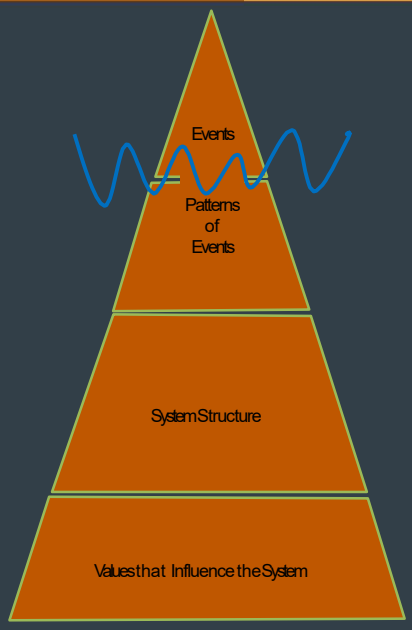
Group Model Building



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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

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WHAT STARTS HERE CHANGES THE WORLD

RESULTS

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Regional Key Themes

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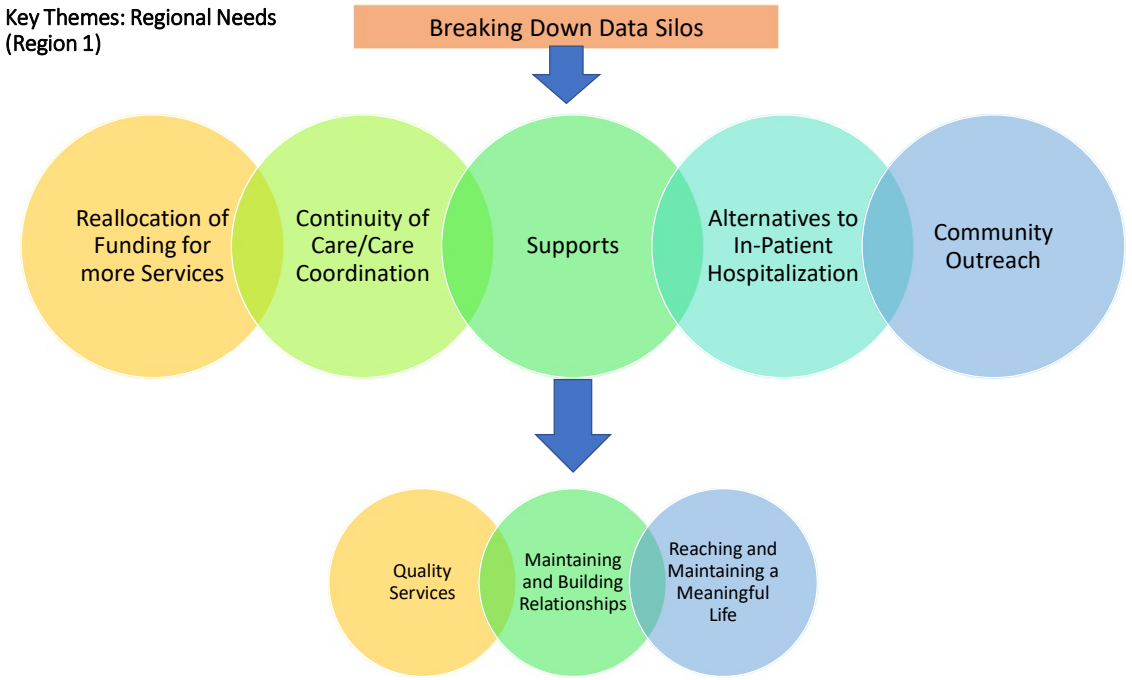
Key Themes: Regional Needs (Region 1)



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Key Themes: Regional Needs (Region 2)

Collaboration Influences on Services

Integrated Care
Community Partners
Expanded Mental Health Workforce
Communication in Language of Customer

Operational Influences on Services

Availability of Services when needed
Data Sharing
Connectivity/ Telehealth/ Infrastructure

Community Influences on Services

Prevention
Education

22

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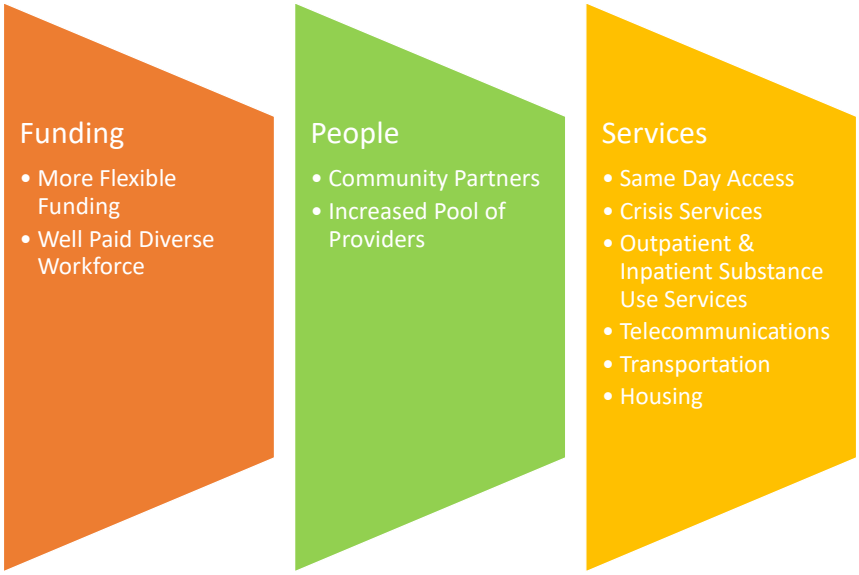
Key Themes: Regional Needs (Region 3)



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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

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Key Themes: Regional Needs (Region 5)

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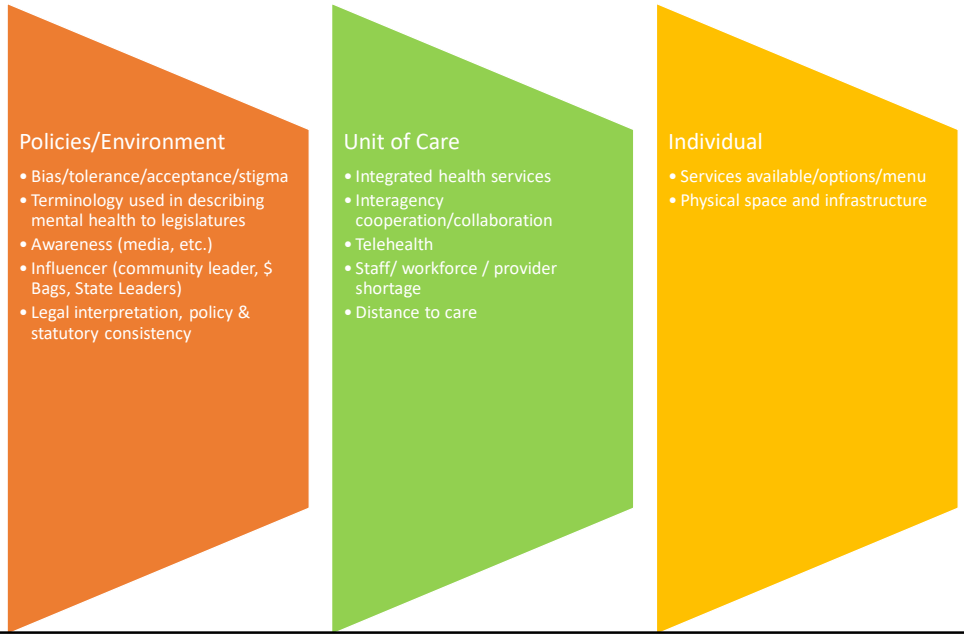
Key Themes: Regional Needs (Regional 6)



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State of Texas Key Themes

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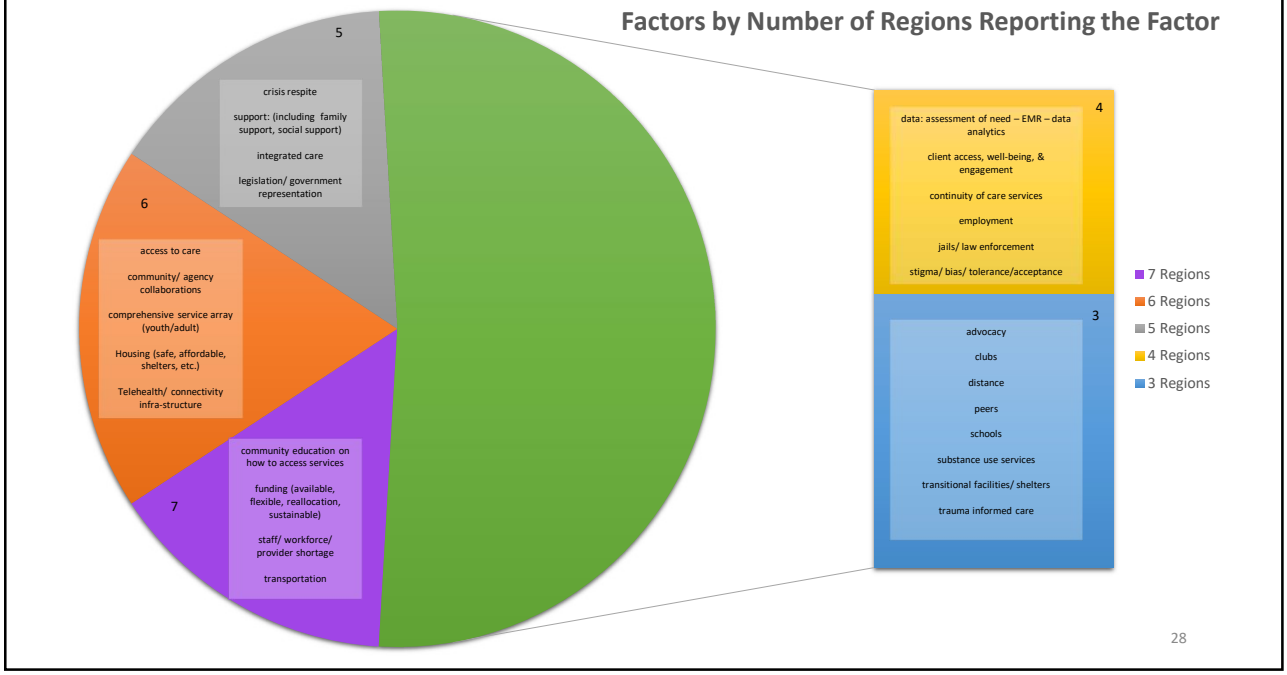

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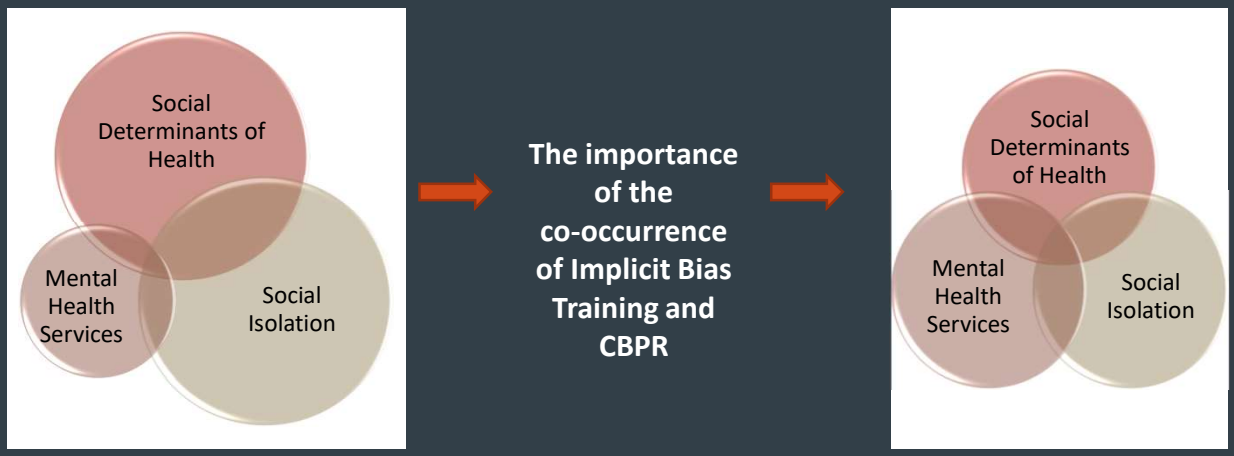
From Model to Action

WHAT STARTS HERE CHANGES THE WORLD

Community-based Participatory Research



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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

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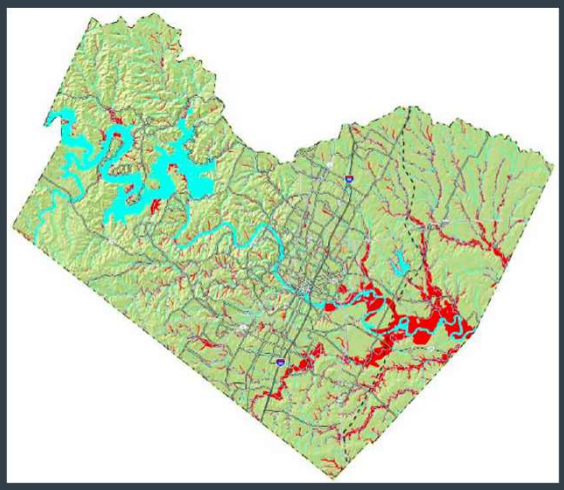
Implications

WHAT STARTS HERE CHANGES THE WORLD

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



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TEXAS The University of Texas at Austin

WHAT STARTS HERE CHANGES THE WORLD

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

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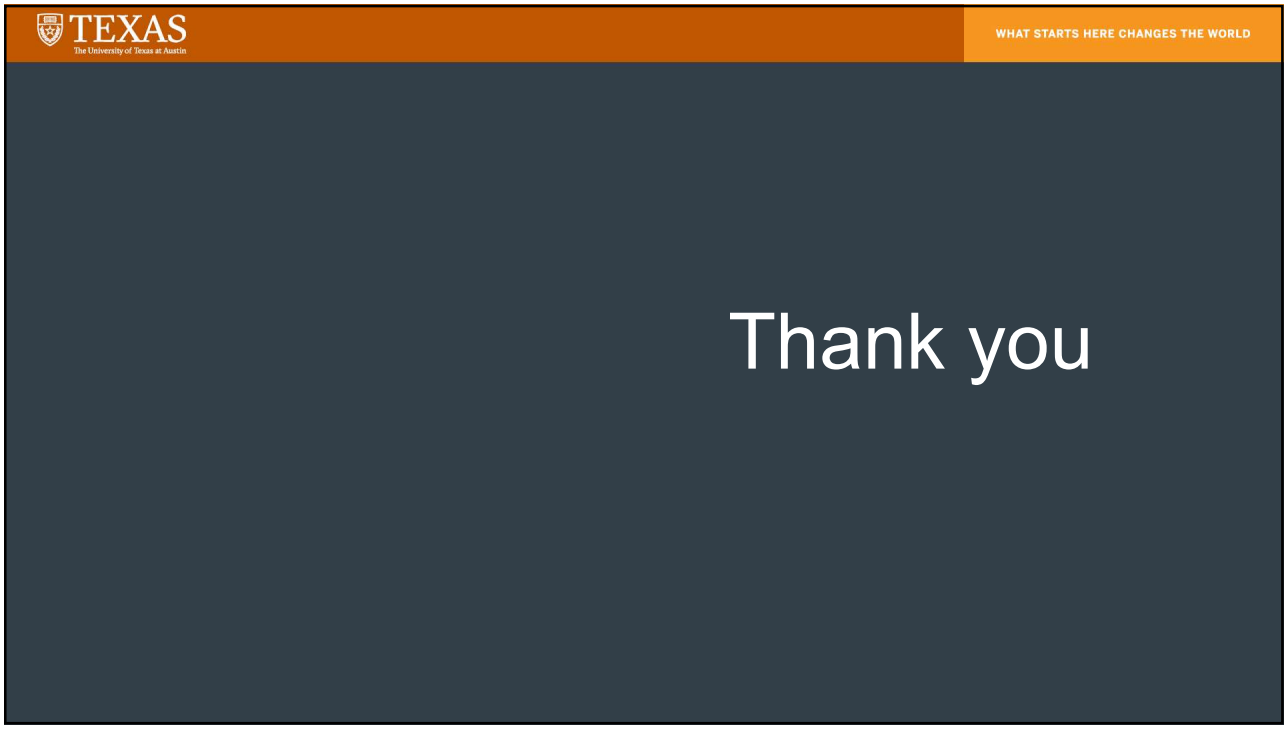
TEXAS
The University of Texas at Austin
WHAT STARTS HERE CHANGES THE WORLD
Thank you

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1

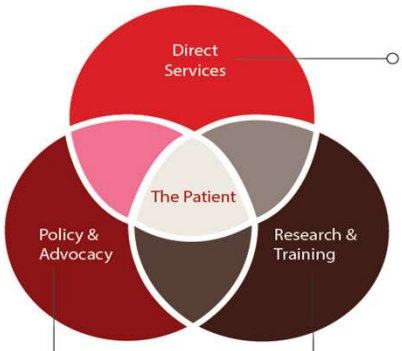
Phylicia L. Woods, JD, MSW
Executive Director, Cancer Policy Institute
Cancer Support Community

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

CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

3

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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

CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

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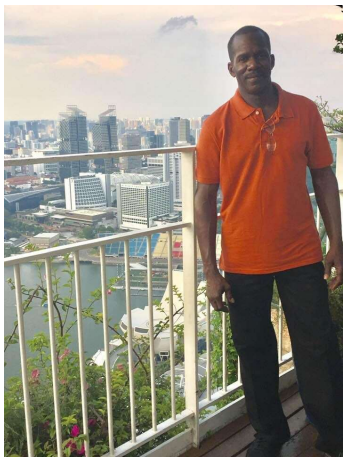
Phil's Pain Journey



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Unequal Pain Management: Current Policy Landscape

- Bias in Pain Policy
- Opioids Epidemic
- PCHETA Legislation

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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

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Revisiting Phil's Pain Journey

8

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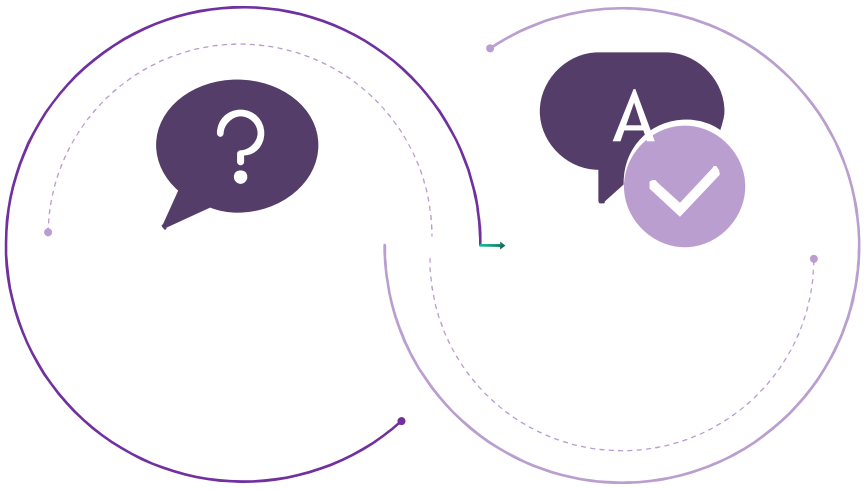
Q&A



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References

- Ghoshal, M RPH, MS (2020). Race, Pain Management, and the System. *Practical Pain Management, 20(5), retrieved from https://www.practicalpainmanagement.com/resources/practice-management/special-report-race-pain-management-system*
- Hoffman, K. M., Trawalter, S., Axt, J. R., & Oliver, M. N. (2016). Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. Proceedings of the National Academy of Sciences of the United States of America, 113(16), 4296-4301.
- Salimah H. Meghani, PhD, MBE, CRNP, Rosemary C. Polomano, PhD, FAAN, Raymond C. Tait, PhD, April H. Vallerand, PhD, FAAN, Karen O. Anderson, PhD, MPH, Rollin M. Gallagher, MD, MPH (2012). Advancing a National Agenda to Eliminate Disparities in Pain Care: Directions for Health Policy, Education, Practice, and Research. *Pain Medicine*, 13(1), 5-28m
- Tait, R. C., & Chibnall, J. T. (2014). Racial/ethnic disparities in the assessment and treatment of pain: psychosocial perspectives. *The American psychologist*, *69*(2), 131-141.

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Thank You!

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Social Media: @CSCCancerPolicy @CancerSupportHQ

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