Center for Health Care Strategies
Better care where it's needed most

Words Matter: How Language Used in Health Care Settings Can Impact the Quality of Pediatric Care

February 17, 2022, 2:00-3:15pm ET

Made possible through support from the Robert Wood Johnson Foundation

Center for Health Care Strategies

Dedicated to strengthening the U.S. health care system to ensure better, more equitable outcomes, particularly for people served by Medicaid.

Together with our partners, our work advances:

- **Effective models for prevention and care delivery** that harness the field's best thinking and practices to meet critical needs.
- **Efficient solutions for policies and programs** that extend the finite resources available to improve the delivery of vital services and ensure that payment is tied to value.
- **Equitable outcomes for people** that improve the overall wellbeing of populations facing the greatest needs and health disparities.

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Accelerating Child Health Transformation

Key strategies to transform child health care, beyond medical care:

Adopting **anti-racist practices and policies** to advance health equity.

Co-creating **equitable partnerships** with patients, families, and providers.

Identifying **family strengths** and addressing **health-related social needs** to promote resilience.

Link to CHCS ACHT Synthesis Report

Center for Health Care Strategies

Agenda

- Welcome and Introductions
- The Link Between Stigmatizing Language and Patient Care
- Opportunities to Build Trust Between Patients, Families, and Providers
- Increasing Awareness Among Pediatric Providers
- Moderated Q&A

Welcome & Introductions

Meet Today's Speakers

Nikki Montgomery,
Project Director,
ACL Health Care Transition Project
Family Voices

Mary Catherine Beach,
Core Faculty, Johns Hopkins Berman Institute of Bioethics and Professor, Johns Hopkins School of Medicine and School of Public Health

Ben Danielson,
Pediatrician and Professor,
University of Washington
School of Medicine

Center for Health Care Strategies

Words Matter: A Framework for Reducing Bias and Stigma Through Respectful Language in Patient Medical Records

Mary Catherine Beach, MD, MPH
Professor of Medicine
Division of General Internal Medicine
Berman Institute of Bioethics
Center for Health Equity

Types of Stigmatizing Language

Negative Themes

Classifications	Examples
Difficult or Unpleasant Patient	• She persevered on the fact that "a lot of stuff is going on at home with my family" but that "you wouldn't understand." • Drinking Mountain Dew b/c it “helps her belch.”
Stereotyping	• Chief complaint - “I stay tired.” • Patient stated, “I should take my ass home.” • States that the lesion “busted open.” • Reports she was unable to fill prescription for the “sugar pill.”

Negative Themes

Classifications	Examples
Disapproval	• Reports that if she were to fall, she would just “lay there” until someone found her. • He was adamant that he does not have prostate cancer because his “bowels are working fine.”
Undermining Credibility	• He insists the pain is behind his knee. • He claims that nicotine patches don’t work for him. • I listed several fictitious medication names and she reported she was taking them, and that she takes “whatever is written there.”

Undermining Credibility

Direct statement: ***Patient has narcotic-seeking behavior***

Indirect: Conveyed by juxtaposing patient reports (considered subjective) w/ discrediting clinician reports (considered objective)

- *Patient reports 10/10 pain **but** labs are stable*
- *Patient **chatting** on phone, requesting pain medication*
- *Sleeping all night without complaints **but** rates pain 8/10*
- *Patient c/o pain 8/10 **although** no physical signs as patient conversing **lightheartedly** with visitor*

Undermining Credibility

Indirect: Use of quotes

- *States "I am in as much pain as before"*
- *Reports that pain medication is "not enough"*

Indirect: Use of discrediting verbs and adverbs

- ***Claims** he still has pain*
- ***Insists** her pain is not improved*
- ***Reportedly** had two seizures*

Placing Blame

Providers highlight nonadherence in a way that suggests judgment

- *Not wearing **mandatory** oxygen*
- *Uncooperative*
- ***Refuses** O2 for a 'short walk'*
- *Patient off unit **without notifying RN***

Positive Themes

Classifications	Examples
Compliment	• Mr. [Patient] is charming, pleasant, and kind. • Mrs. [Patient] is a delightful female.
Approval	• She has a physical/mental robustness that belies her age. She remembers both recent and distant events and is enjoyable to converse with on many subjects.

Positive Themes

Classifications	Examples
Minimizing Blame	• She has not been checking her morning glucose for a month because she lost her blood glucose monitor. • She has not been taking iron because it makes her constipated.
Personalize	• She enjoys walking with her fiancé and her dog named Scout.

Is Stigmatizing Language in the Medical Record Associated With a Subsequent Clinician's:

-- Attitudes towards a patient
-- Management of the patient's pain

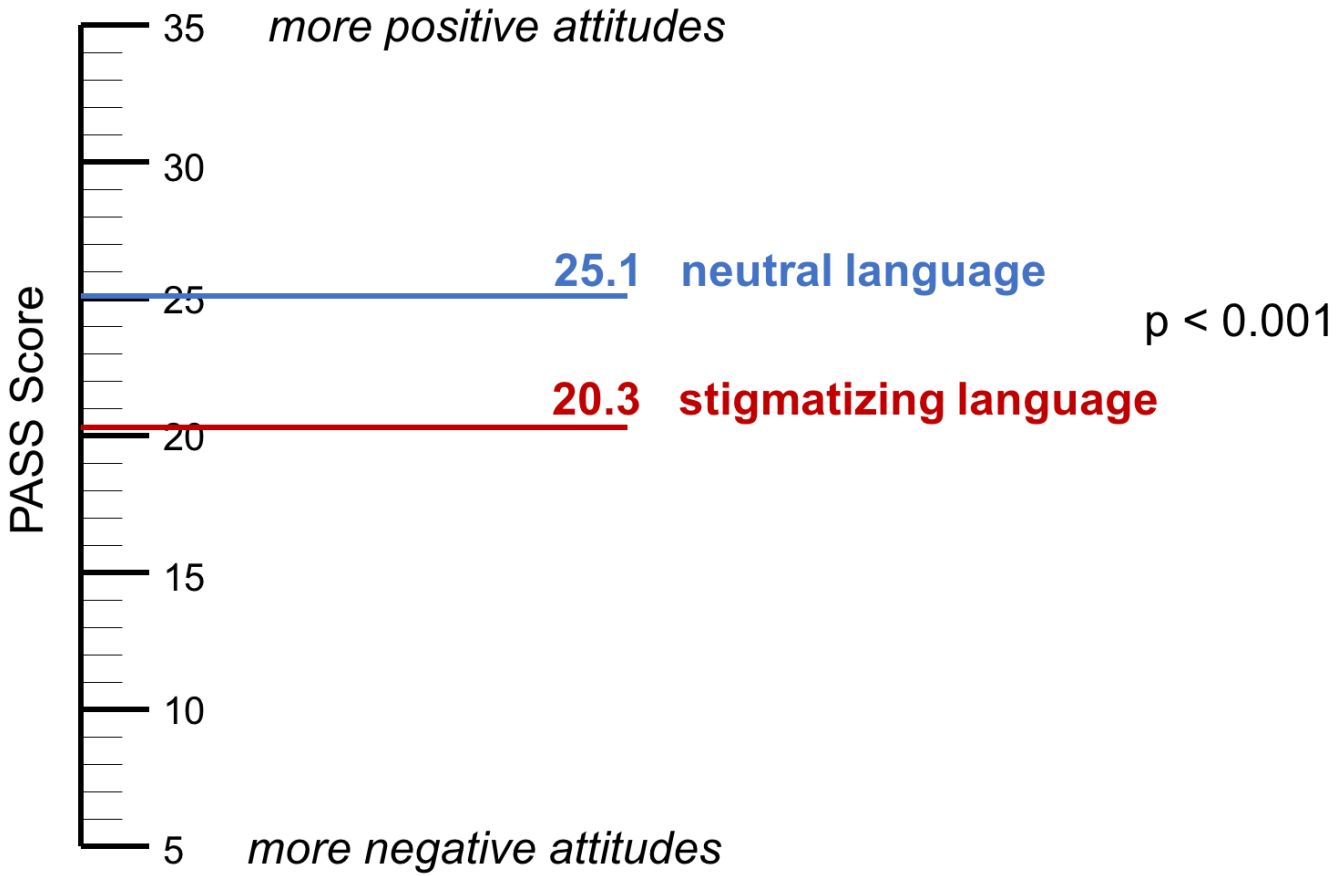
Do Words Matter? Stigmatizing Language and the Transmission of Bias in the Medical Record

Link to Research: Anna P. Goddu, Katie J. O'Conor, Sophie Lanzkron, Mustapha O. Saheed, Somnath Saha, Monica E. Peek, Carlton Haywood, and Mary Catherine Beach

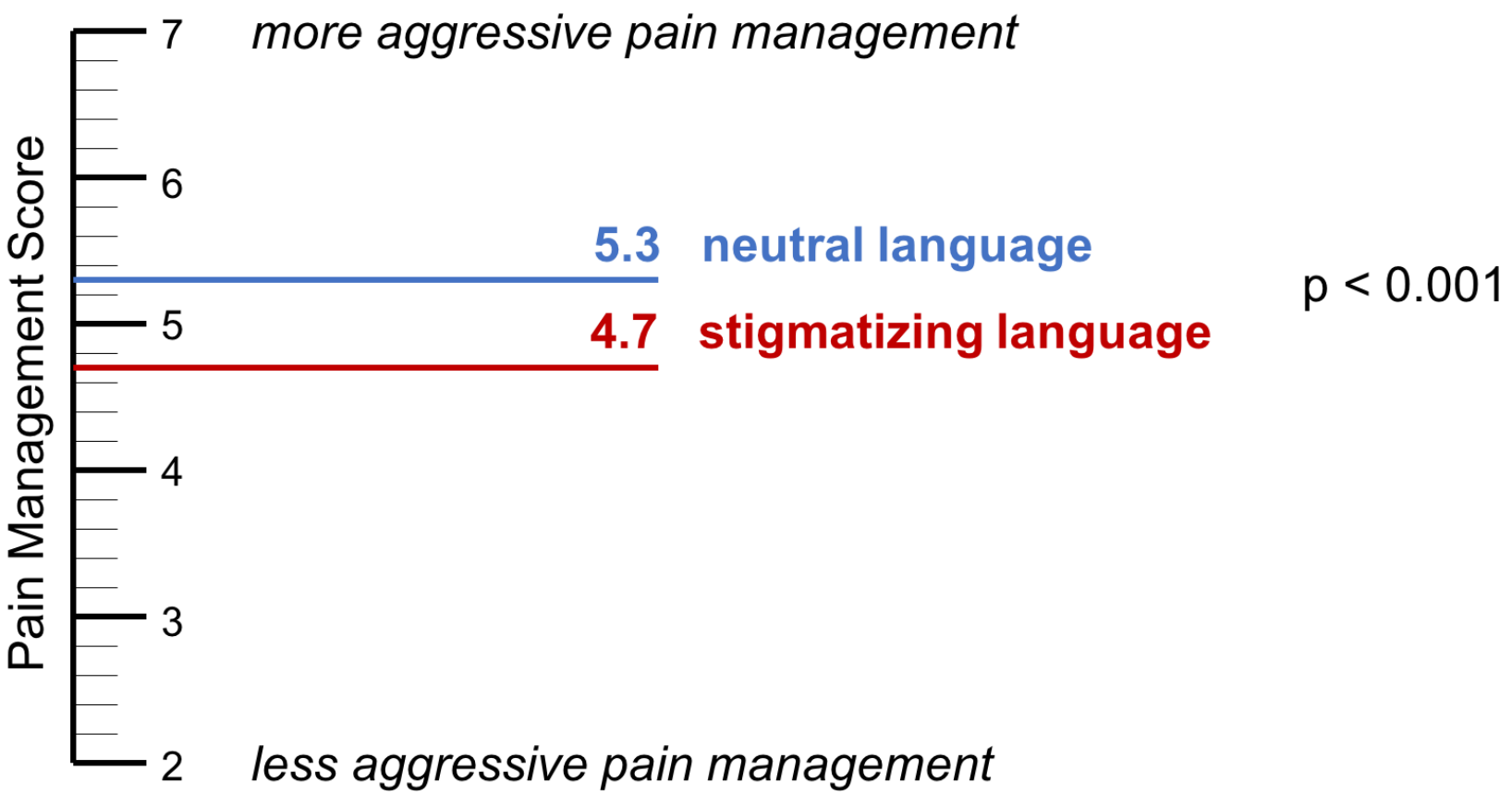
Vignette Examples

Neutral	Stigmatizing
He still has pain rated 10/10. His girlfriend is by his side but will need to go home soon.	He is insisting that his pain is "still a 10." His girlfriend is lying on the bed with her shoes on and requests a bus token to go home.

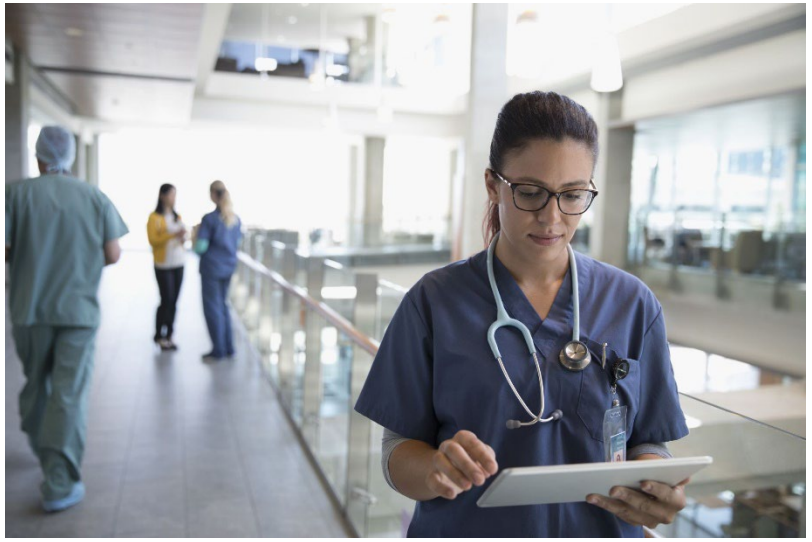
Stigmatizing Language Results in More Negative Attitudes



Stigmatizing Language Results in Less Aggressive Pain Management



Is There A Systematic Pattern Demonstrating Racial Bias In The Use Of Stigmatizing Language?



Negative Patient Descriptors: Documenting Racial Bias in the Electronic Medical Record

Link to Report: Michael Sun, Tomasz Oliwa, Monica E. Peek and Elizabeth L. Tung

(Non) adherent	Confront
Aggressive	(Non) cooperative
Agitated	Defensive
Angry	Exaggerate
Challenging	Hysterical
Combative	(Un) pleasant
(Non) compliant	Resist

Association of negative patient descriptor use in electronic health records with patient and encounter characteristics at a large urban academic medical center in Chicago, Illinois, odds ratios, January 2019–October 2020

Characteristics	Unadjusted odds ratio	Adjusted odds ratio
Race and ethnicity (ref: non-Hispanic White)		
Non-Hispanic Black	2.84****	2.54****
Hispanic or Latino	1.34***	1.51*
Other	0.89	1.07

Xavier Ramey
CEO, Justice Informed
https://www.xavierramey.com/

“Nine times out of 10, I was completely brushed off. If there was ever a book on medical racism, it should probably just be called, ‘They Don’t Believe Us.’”

Lisa Schencker. ‘Nine times out of 10, I was completely brushed off’: Black Chicagoans confront bias in health care, hope for change. *Chicago Tribune*. http://www.chicagotribune.com/news/breaking/ct-chicago-health-care-racism-george-floyd-implicit-bias

Testimonial Injustice, Race and Healthcare

African American focus group participants on meaning of respect:

- *"You know your body. When you come in, in a position of being in control, and know yourself."*
- *"You can NOT tell me wasn't nothing wrong ...I mean, I feel like that's disrespect, you know, it's like, you know what's wrong with you."*
- *"We know, like I said, we know what's wrong with us, we know what's hurting, <u>whether they want to believe it or not</u>."*

...patient reports 10/10 pain but labs are stable.
...claims the nicotine patches don't work for him.
...reports unbearable pain but cervix unchanged.

Testimonial Injustice: Linguistic Bias in the Medical Records of Black Patients and Women

Link to Research: Mary Catherine Beach, Somnath Saha, Jenny Park, Janiece Taylor, Paul Drew, Eve Plank, Lisa A Cooper, and Brant Chee

Linguistic Feature	Race		Adjusted Black-White Difference
	White	Black	
			Odds Ratio
Judgment Words	21%	29%	1.25* (1.02, 1.53)
Quotes	30%	45%	1.48*** (1.20, 1.83)

*p<0.05; ** ***p<0.001

Judgment words (e.g. insists, claims, apparently, etc.)

Quotes (e.g. “still in pain”)

Summary, Reflections and Recommendations

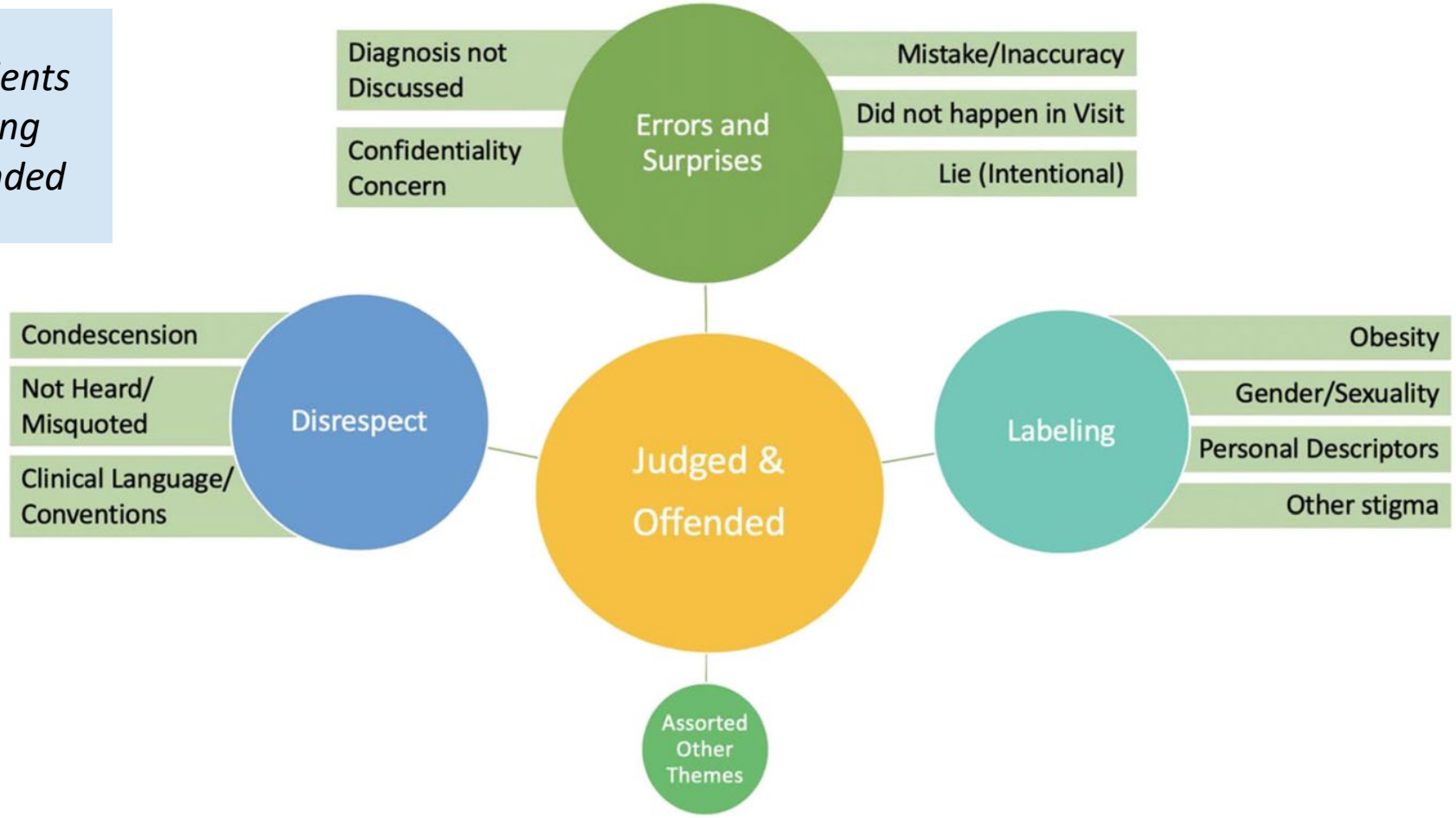
Language Within Medical Records May:

- Convey providers' unconscious (or conscious) biases
- Perpetuate stigma that influences subsequent providers who care for the patient
- May reflect and/or perpetuate testimonial injustice, especially for African American patients

Words Matter: What Do Patients Find Judgmental or Offensive in Outpatient Notes?

Link to Research: Leonor Fernández, Alan Fossa, Zhiyong Dong, Tom Delbanco, Joann Elmore, Patricia Fitzgerald, Kendall Harcourt, Jocelyn Perez, Jan Walker, and Catherine DesRoches

1 in 10 respondents reported feeling judged or offended



Framework for thematic analysis: overarching domains and specific codes.

Recommendations for Clinicians

1. Stay aware of and avoid including language that reflects personal frustration or negative judgments
2. Strive for testimonial justice
   - Be thoughtful and reflective; check assumptions
   - Never use exaggerated words (e.g. “claims”, “insists”)

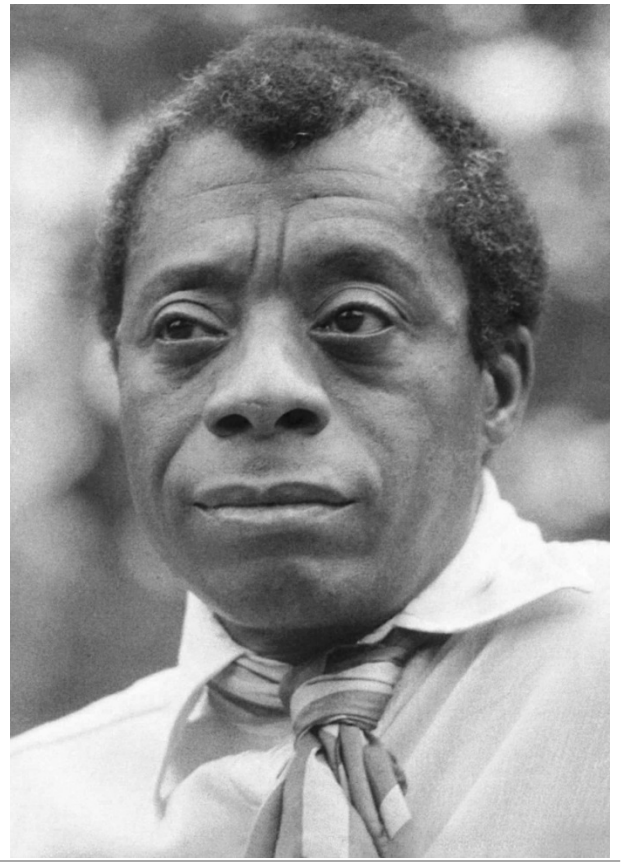
Recommendations for Clinicians

1. Stay aware of and avoid including language that reflects personal frustration or negative judgments
2. Strive for testimonial justice
3. Try to include reasons for nonadherence
4. Think carefully before using quotes

Quoting Patients in Clinical Notes: First, Do No Harm

Link to Research: Mary Catherine Beach and Somnath Saha

Thank you



NOT EVERYTHING THAT IS FACED CAN BE CHANGED, BUT NOTHING CAN BE CHANGED UNTIL IT IS FACED.

JAMES BALDWIN

Opportunities to Build Trust Between Patients, Families, and Providers

Nikki Montgomery, M.A., M.Ed., GPAC

Family Voices

Family Advisor, Accelerating Child Health Transformation, CHCS

Executive Director, Madvocator Educational and Healthcare Advocacy Training

Author of Super Safe Kids pediatric complex care curriculum series

Of all the forms of inequality, injustice in healthcare is the most shocking and inhumane.

Dr. Martin Luther King, Jr.

Definitions

TRUST

(NOUN) BELIEF THAT SOMEONE OR SOMETHING IS RELIABLE, GOOD, HONEST, EFFECTIVE, ETC.

MISTRUST

(VERB) TO DOUBT THE TRUTH, VALIDITY, OR EFFECTIVENESS OF

DISTRUST

(NOUN) THE LACK OR ABSENCE OF TRUST

Merriam-Webster Dictionary

A Story About Trust

TRUST

DOCTOR ASKING FOR PATIENT EXPERTISE

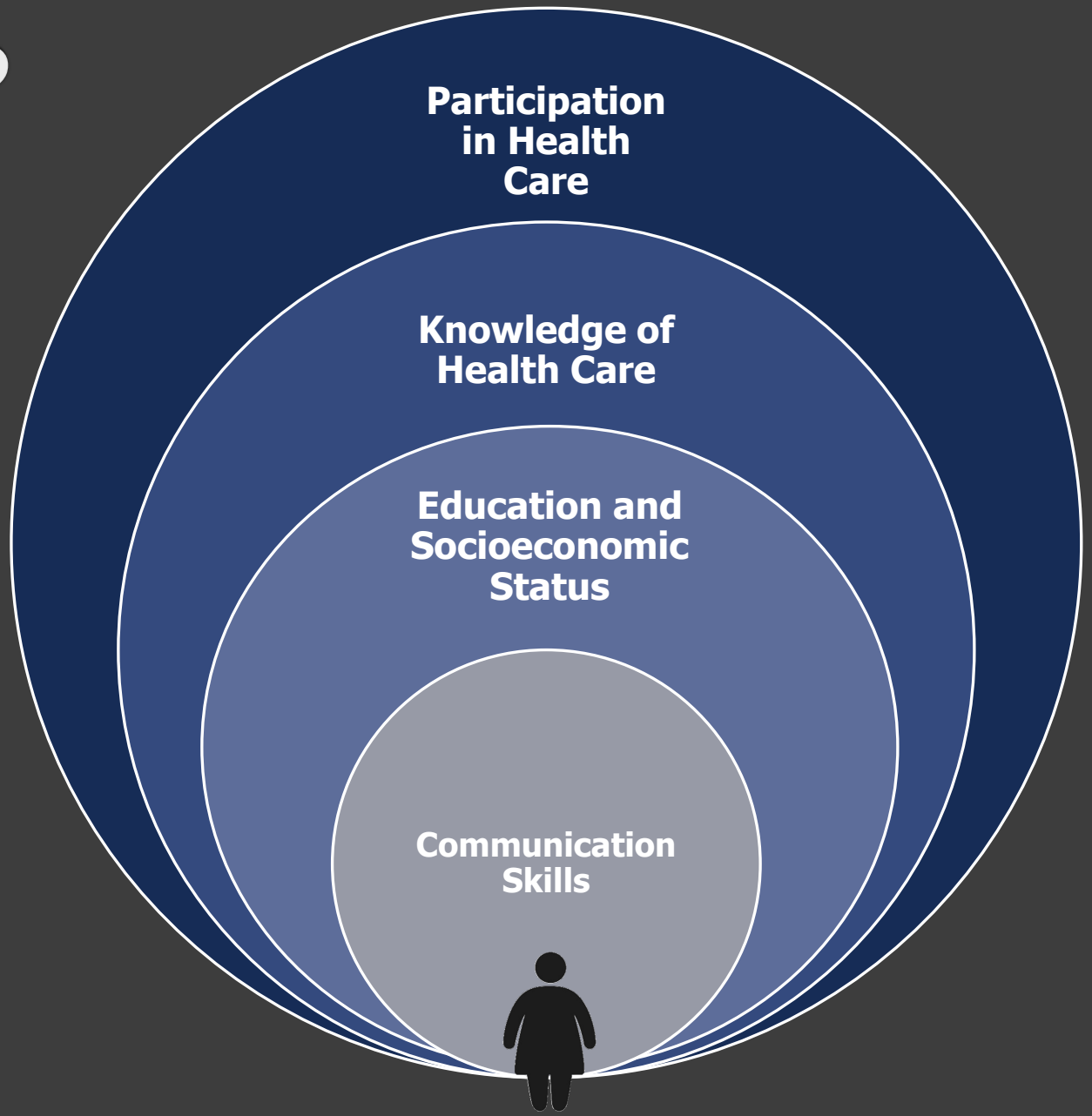
MISTRUST

DOCTOR DOUBTING SYMPTOMS, STIGMATIZING PATIENT

DISTRUST

PATIENT RECOGNIZES BIAS AND DIFFERENTIAL CARE

Unbelievable?



The Direction of Trust

- Trust conversations focus on increasing trust among Black patients
- How can health care providers (un)**learn** to (mis)**trust** Black patients?

"Tell me who I have to be to get some reciprocity."

Lauryn Hill

“The Performance”

ADAPTATIONS

- Speech and posture
- Eye contact and attention
- Charisma
- Preparation
- Credentialing

INTENDED OUTCOMES

- Humanizing
- Capable
- Credible
- Needs met

What Black Patients Know

- Personal experiences of anti-Black bias in society
- History of poor treatment and outcomes in health care
- Institutions with a legacy of poor treatment of Black patients
- Vulnerability to bias and not being seen as credible in health care settings

"I can't believe what you say because I see what you do."

Ike & Tina Turner

Changing the Default Setting

EXAMINE THE IMPULSE TO DISBELIEVE PATIENTS.

- What layers of privilege make a patient more believable to you?
- What kinds of patients do *you* have trouble believing?
- How do your doubts affect the patient's experience?
- How do your doubts influence the care you provide?

Building (Your) Trust

SET THE STAGE

- Understand patients' layers of privilege
- Communicate clearly and ensure common understanding

DEMONSTRATE TRUST

- Ask patients what they think about health concerns
- Assure patients that you will listen to their concerns
- Prompt two-way discussions and relationships

Increasing Awareness Among Pediatric Providers

Ben Danielson, MD
Pediatrician and Professor,
University of Washington School of Medicine

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Questions?

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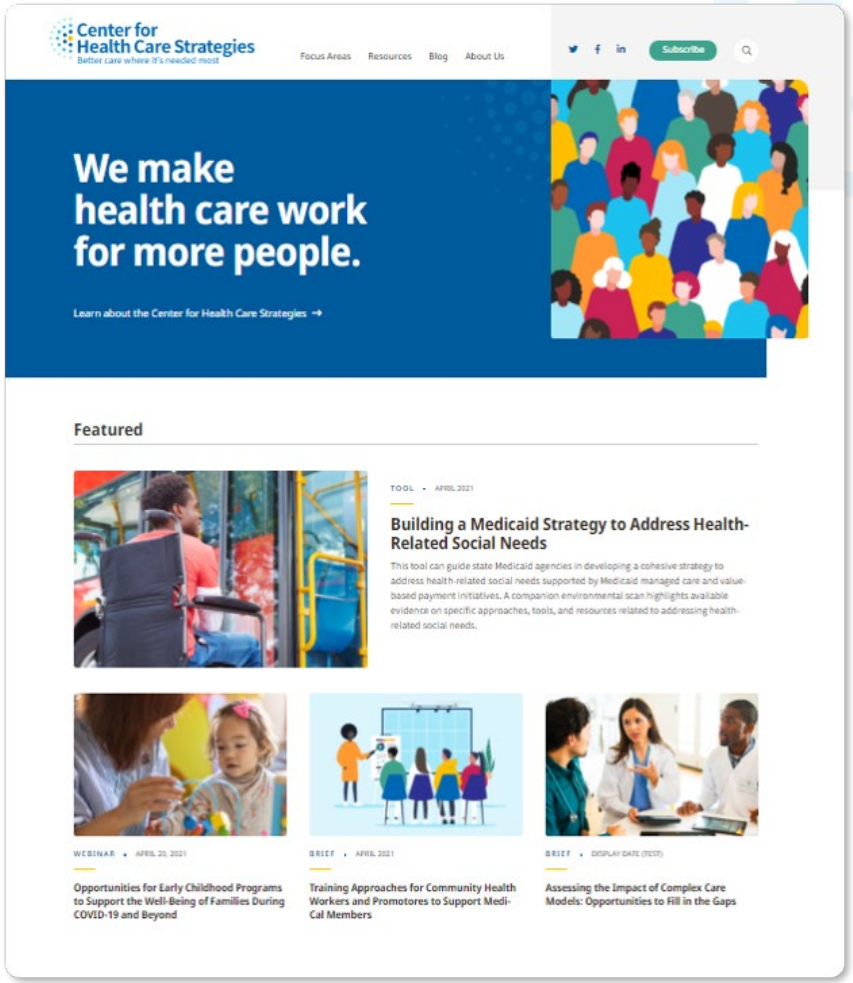

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