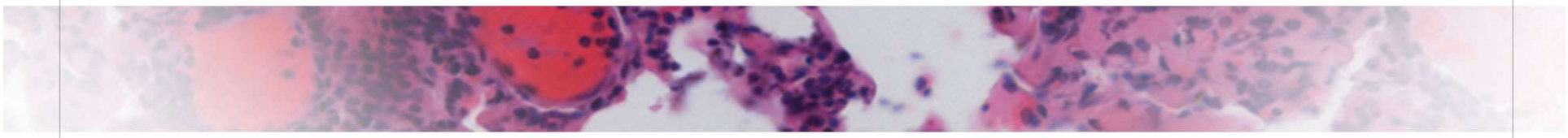
American Society *of* Hematology

Helping hematologists conquer blood diseases worldwide



Actionable Strategies for Addressing Health Inequities in SCD

Lori E. Crosby, PsyD

University of Cincinnati and Cincinnati Children's Hospital Medical Center

Acknowledgement: Some slides developed by faculty and students at the Medical College of Wisconsin

Disclosures for Lori E. Crosby, PsyD

In compliance with ACCME policy, ASH requires disclosures to the session audience:

- **Consultancy**: Forma Therapeutics
- **Research Funding**: Health Resources and Services Administration; National Center for Advancing Translational Sciences, National Institutes of Health; Patient-Centered Outcomes Research Institute

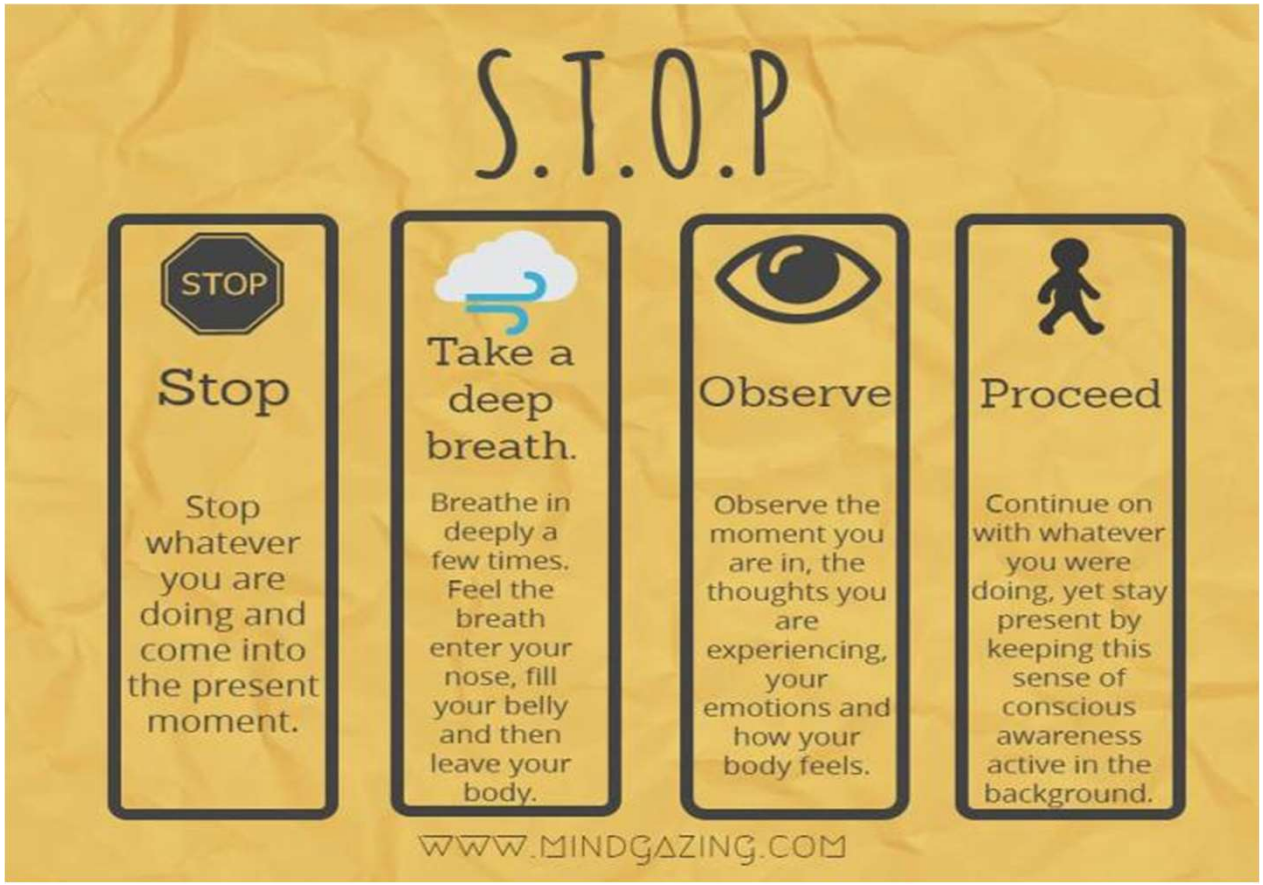
Discussion of off-label drug use: N/A

Acknowledgements

- Wally Smith, MD, Virginia Commonwealth University
- Emily McTate, PhD, LP, Mayo Clinic
- Elizabeth Muenks, PhD, University of Kansas Medical Center

Learning Objectives

- Describe why sickle cell disease (SCD) is a health care disparity
- Identify strategies informed by social justice and cultural humility to promote health equity in SCD
- Recognize the need for humility and our own vulnerability


S.T.O.P
STOP
Stop
Stop whatever you are doing and come into the present moment.
Take a deep breath.
Breathe in deeply a few times. Feel the breath enter your nose, fill your belly and then leave your body.
Observe
Observe the moment you are in, the thoughts you are experiencing, your emotions and how your body feels.
Proceed
Continue on with whatever you were doing, yet stay present by keeping this sense of conscious awareness active in the background.
WWW.MINDGAZING.COM

Case Study: Meet Adriana

- 19-year-old female with HBSS SCD
- Lived with several relatives throughout her childhood
- Has had several jobs since high school – currently working at a retail store
- History of marijuana use as a teenager
- Prescribed hydroxyurea but team is concerned she may not always be taking it (no recent prescription)
- Reports severe stomach pain during clinic visit and asks for pain medication but no visible signs that she is in pain – laughs and jokes
- Providing vague answers to the team members' questions

What are some things providers/teams might say/think about Adriana?

SCD and the "Difficult Patient" Conundrum

- Convergence of SCD's unique political, historical, cultural, medical, and psychological restrictions → blaming patients
- Often classified as "difficult"

Bergman EJ, Diamond NJ. *Am J Bioeth*. 2013;13(4):3-10.
doi: 10.1080/15265161.2013.767954. PubMed PMID: 23514384.

SCD and the “Difficult Patient” Conundrum (cont’d)

- Traditional designation as the “difficult” patient warrants reevaluation
  - Barriers to care unique to SCD
  - Need to redefine orthodox notions of the “difficult” patient

Bergman EJ, Diamond NJ. Sickle cell disease and the "difficult patient” conundrum. Am J Bioeth. 2013;13(4):3-10. doi: 10.1080/15265161.2013.767954. PubMed PMID: 23514384.

SCD: Two Major Overlapping Determinants

- Chronic Health Condition
  - Chronic Non-Cancer Pain (CNCP)
    - Common
    - Significant burden to adult patients
    - Known to lower quality of life[1,2]
    - May be poorly managed
      - → Anxiety and distress related to subsequent treatment
      - → Negative long-term psychological effects
- Racial and ethnic minoritized population

1. Kowal J et al. *Pain.* 2012;153(8):1735-1741.
2. Ferrell BR. *Nurs Clin North Am*. 1995;30(4):609-624.

WHY DOES THIS HAPPEN?

Racism as a Public Health Crisis: Inequities and Health Disparities

Inequities

- Differences in outcomes across access, pay, housing, etc.
- Avoidable, unfair, unjust
- Result of social, economic, and environmental conditions

- Health Equity Institute at San Francisco State University, Health policy Institute of Ohio

Disparities

- Differences in incidence and prevalence of health conditions/status between groups
  - Overall health status
  - Prevalence of chronic conditions
  - Premature death
- Adversely affect groups with characteristics linked to discrimination, exclusion, and systematic experience of obstacles

Defining Racism

- How do you define **race**?
  - Race is "generally understood as *a social construct*. Although *biologically meaningless* when applied to humans – physical differences such as skin color have no natural association with group differences in ability or behavior – race nevertheless has tremendous significance in structuring social reality"
- What is **racism**?
  - "An ideology of racial domination" in which the presumed biological or cultural superiority of one or more racial groups is used to justify or prescribe the inferior treatment or social position(s) of other racial groups through the process of racialization
  - Interpersonal: racial prejudice or discrimination; Institutional: laws, policies, and practices

Racial Stress & Trauma

- Racial Stress
  - Emerges from direct and/or vicarious discriminatory racial encounters
- Racial Trauma
  - PTSD like symptoms that emerge because of exposure and re-exposure to racial stressors.

Racial Stress & Trauma (RST)

- Preschool and school age (3-11 yrs)
  - Skin color can be a threat to safety and security for self and caregivers
- Middle school (12-14 yrs)
  - May begin to internalize RST
- High school (15-18 yrs)
  - More able to make meaning of racial encounters and advanced forms of racism

How does this show up?

- How might you see the impact of racial trauma, structural racism, and implicit bias in clinical care?
  - Mistrust/hesitance in trusting the medical system
  - Emotional dysregulation
  - Defensive language
- Remember variation!
  - Different ACEs
  - Different protective factors
  - Different lived experiences

Let's Revisit Adriana

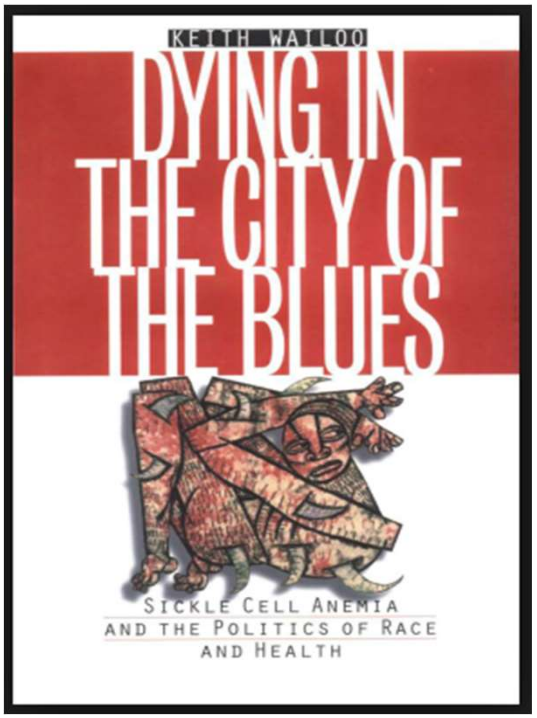
- 19-year-old female with HBSS
- Lived with several relatives throughout her childhood
- Has had several jobs since high school – currently working at a retail store
- History of marijuana use as a teenager
- Prescribed hydroxyurea but team is concerned she may not always be taking it (no recent prescription)
- Reports severe stomach pain during clinic visit and asks for pain medication but no visible signs that she is in pain – laughs and jokes
- Providing vague answers to the team members' questions

Reflection

- How might racism be impacting this individual patient's presentation?

- How can we use our understanding of racism and structural inequities to reframe how we think about this patient?

SCD: A health disparities and health care disparities disease



- "…in the 1960s the history of sickle cell disease also intersected with the national politics of race, inequality, and health care in America."
  - Wailoo K, Dying in the City of the Blues, p. 7

SCD a Health Disparity

- CDC designation
- NAS report
  - Population affected
  - Disparities in health outcomes
  - Barriers to health equity
    - Implicit bias and microaggressions
    - Policies – structural inequities

Your Role

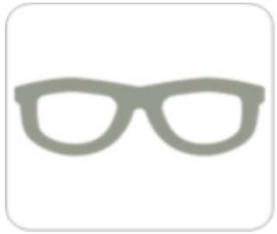
- Care for your patient/family
- Appreciate racial stress and trauma in clinical work with families
- Engage in difficult dialogues
- Focus on patient and family centered care
  - Build trust by listening
  - Provide culturally tailored care
- Is NOT to:
  - Have all the answers
  - Fix their experience of racism
  - Justify the behavior
  - Change the family's narrative

Your Role…

- It's OK to be nervous or to feel uncertain
  - The most important thing is to open the door to the conversation, listen, validate, and acknowledge your patient's experience

- Offer the invitation
  - It's OK if they decline

Clinician Actionable Strategies



OBSERVE

- Objective description of what you are seeing in the room
- Non-verbal communication?
- Effect?
- Behaviors?

PAUSE

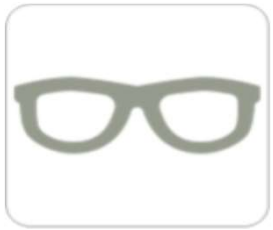
CONSIDER

- What are the considerations that you have in the context of this patient's various identities, experiences, and intersectionality
- What are you bringing into the room?

UNPACK

- With the integration of your observations and considerations, what might you be curious about?
- What else is here?

Clinician Actionable Strategies (OPCU)



OBSERVE

- Refusal to answer some questions

PAUSE

CONSIDER

- I wonder why she might not be answering questions
- Judgment received in the past?
- Fear of information being used against her?

UNPACK

- I am getting frustrated as I am trying to help and I need to change my approach
- How can I validate and acknowledge that I am considering?

Clinician Actionable Strategies (OPCU)

OBSERVE

- Laughing and joking behaviors
- Effect inconsistent with content

PAUSE

CONSIDER

- Could this be a part of coping ?
- This is a serious evaluation, why might someone appear not serious?

UNPACK

- What valuable information could this behavior be giving me?

Debrief

How can you use this framework to describe Adriana to your team?

- Our Thinking Matters but Words Matter Too
- Bias Rounds
  - Anything else we need to consider
  - Same treatment approach for friends and family

Implicit Bias

- Occurs at the individual level
- "Ingrained habits of thought that lead to errors in how we perceive, reason, remember, and make decisions"

http://www.ihi.org/communities/blogs/how-to-reduce-implicit-bias

Microagressions

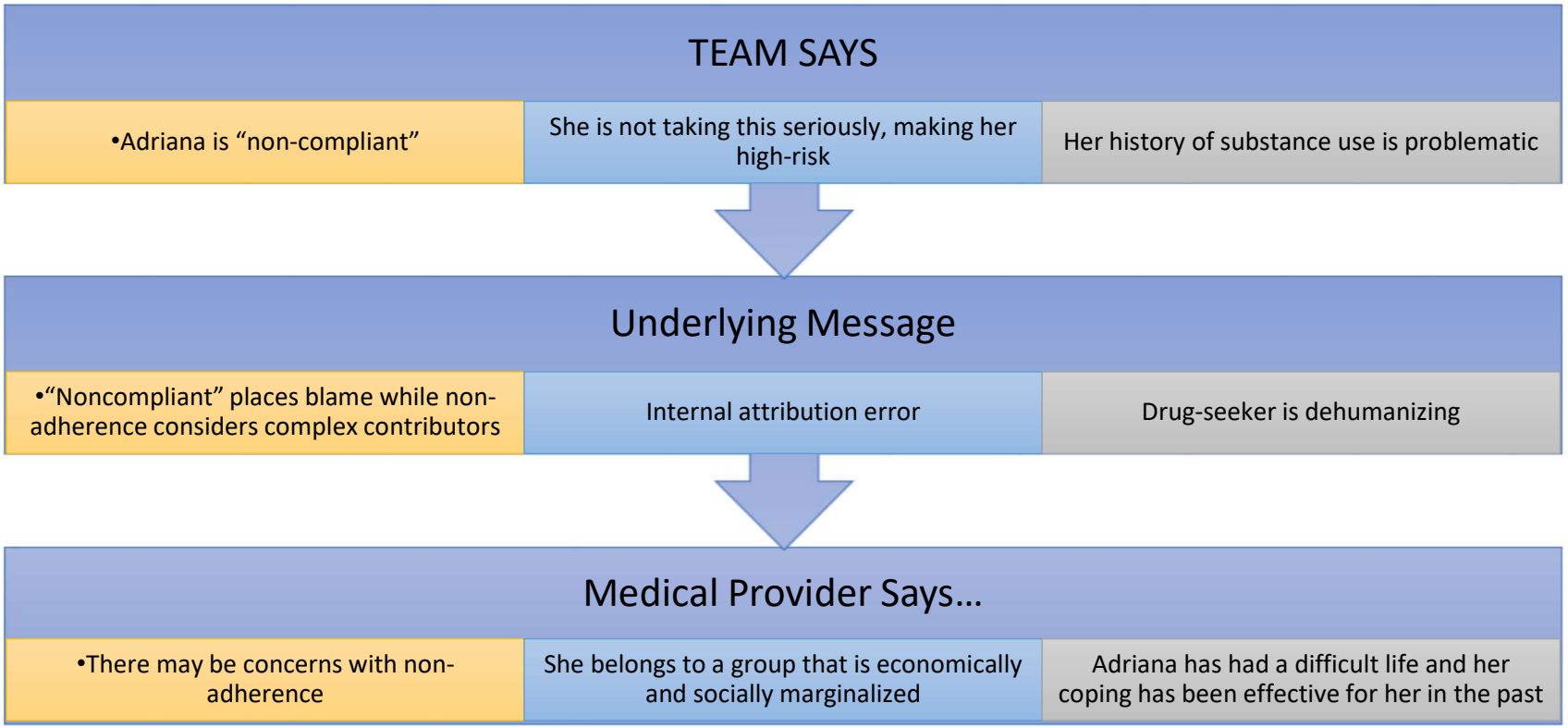
- Microassaults (eg, purposeful actions of discrimination such as name-calling)
- Microinsults (eg, subtle communications that demean a person's cultural identity)
- Microinvalidations (eg, subtle communications that negate a person's cultural reality, such as displaying colorblind attitudes or telling a person of color that you don't see color)

Sue & colleagues (original source)
Current source: https://ct.counseling.org/2016/12/practicing-cultural-humility/

Self-Awareness & Humility

- Examine your own values, beliefs, and traditions
- Explore ways in which health, illness, and healing are understood by different people
- Set aside your own bias in order to deliver effective care to diverse populations

Unpacking with Medical Team



Let’s Discuss

How would you describe Adriana in your note?

Communication

Documentation that is sensitive to bias

Providing context

Language that focuses on advancing health equity

Intersectionality

"Intersectionality is simply about how certain aspects of who you are will increase your access to the good things or your exposure to the bad things in life."

-Kimberly Crenshaw

Intersectionality

How do you see intersectionality affecting individuals with SCD?

Provider Strategies

- Be Authentic
- Foundation of Curiosity and Partnership
- Give Patients the Benefit of the Doubt
- Strive to provide the Best Care possible

Conclusions

1. SCD patients are often seen as difficult rather than disadvantaged
2. SCD is a health disparities disease
    a. Care provided
    b. Health outcomes
3. Inequities such as systematic racism, bias, and other determinants (socioeconomic disadvantage) are the major drivers of health disparities
4. Implicit bias and microaggressions are individual-level contributors to inequities that we can counteract
5. Clinician-focused actionable strategies (OPCU) based on cultural humility and social justice can facilitate equitable health care for individuals with SCD

We may not have chosen the time, but
the time has chosen us.

- John Lewis -

STORM TeleECHO Resources/References 1

Al-Nasseri, K., Joseph, J., Al Nasiri, Y., Al Mawali, A., & Jacob, E. (2019). Do young Omani adults with sickle cell disease experience stigma from having the disease? *Iraq Medical Journal*, *3*(3).

Bulgin, D., Tanabe, P., & Jenerette, C. (2018). Stigma of Sickle Cell Disease: A Systematic Review. *Issues in Mental Health Nursing*, *39*(8), 675–686.

Haywood, C., Lanzkron, S., Hughes, M. T., Brown, R., Massa, M., Ratanawongsa, N., & Beach, M. C. (2011). A video-intervention to improve clinician attitudes toward patients with sickle cell disease: the results of a randomized experiment. *Journal of General Internal Medicine*, *26*(5), 518–523.

Haywood, C., Beach, M. C., Lanzkron, S., Strouse, J. J., Wilson, R., Park, H., Witkop, C., Bass, E. B., & Segal, J. B. (2009). A systematic review of barriers and interventions to improve appropriate use of therapies for sickle cell disease. *Journal of the National Medical Association*, *101*(10), 1022–1033.

Hsu, L. L., Green, N. S., Ivy, E. D., Neunert, C. E., Smaldone, A., Johnson, S., Castillo, S., Castillo, A., Thompson, T., & Hampton, K. (2016). Community health workers as support for sickle cell care. *American Journal of Preventive Medicine*, *51*(1), S87–S98.

STORM TeleECHO Resources/References 2

Jenerette, C. M., A. Brewer, C., Crandell, J., & I. Ataga, K. (2012). Preliminary validity and reliability of the sickle cell disease health-related stigma scale. *Issues in Mental Health Nursing*, *33*(6), 363–369.

Jenerette, C. M., Brewer, C. A., Edwards, L. J., Mishel, M. H., & Gil, K. M. (2014). An intervention to decrease stigma in young adults with sickle cell disease. *Western Journal of Nursing Research*, *36*(5), 599–619.

Lee, L., Smith-Whitley, K., Banks, S., & Puckrein, G. (2019). Reducing Health Care Disparities in Sickle Cell Disease: A Review. *Public Health Reports*, 0033354919881438.

Martin, S. R., Cohen, L. L., Mougianis, I., Griffin, A., Sil, S., & Dampier, C. (2018). Stigma and pain in adolescents hospitalized for sickle cell vasoocclusive pain episodes. *The Clinical Journal of Pain*, *34*(5), 438–444.

Nelson, S. C., & Hackman, H. W. (2013). Race matters: Perceptions of race and racism in a sickle cell center. *Pediatric Blood & Cancer*, *60*(3), 451–454.

STORM TeleECHO Resources/References 3

Pachter, L. M., Szalacha, L. A., Bernstein, B. A., & García Coll, C. (2010). Perceptions of Racism in Children and Youth (PRaCY): Properties of a self-report instrument for research on children's health and development. *Ethnicity & Health*, *15*(1), 33–46.

Rao, A. N., Warad, D., & Rodriguez, V. (2017). Cross-cultural care training for pediatric hematology/oncology fellows. *MedEdPORTAL: The Journal of Teaching and Learning Resources*, *13*.

Wakefield, E. O., Pantaleao, A., Popp, J. M., Dale, L. P., Santanelli, J. P., Litt, M. D., & Zempsky, W. T. (2018). Describing Perceived Racial Bias Among Youth With Sickle Cell Disease. *Journal of Pediatric Psychology*.

Wakefield, E. O., Popp, J. M., Dale, L. P., Santanelli, J. P., Pantaleao, A., & Zempsky, W. T. (2017). Perceived racial bias and health-related stigma among youth with sickle cell disease. *Journal of Developmental & Behavioral Pediatrics*, *38*(2), 129–134.