NIH
HEAL
INITIATIVE

CONNECTIONS

Partnering to Accelerate Research into Action

#NIHhealInitiative

NIH HEAL Initiative and Helping to End Addiction Long-term are service marks of the U.S. Department of Health and Human Services.

NIH National Institutes of Health
HEAL Initiative

A Two-Part Series: Inclusive Language, Imagery, and Storytelling for Addiction and Pain Researcher Teams

- Real-world case examples for communicating with respect to stakeholders across the HEAL addiction and pain research spectrum.
- Actionable resources to reduce stigma and make research communications more engaging and impactful.
- Opportunities to partner with HEAL Connections to support inclusive language, imagery, and communications product development.

In consideration of the distinct challenges addiction and pain research teams face, the series includes two linked sessions:

Focus on Addiction
JULY 27 | 1 P.M. ET

Focus on Pain
AUGUST 31 | 1 P.M. ET

Find recordings, slides,
and resources at:
bit.ly/HEALConnectionsSharingSessions

HEAL CONNECTIONS
SHARING SESSION

Inclusive Language, Imagery, and Storytelling for Addiction and Pain Researcher Teams

---

Part 2: Focus on Pain

TODAY'S AGENDA

1:10 to 1:25 p.m.
Incorporating the Perspectives of Those with Lived Experience into the Research Process — and the Importance to Pain Research with Janelle Letzen

1:25 to 1:50 p.m.
Flash talks on pain, stigma, and inclusive communication with Kate Nicholson, Joanna Hobson, Emily Wakefield, Soumitri Sil, and Kerri Cavanaugh

1:50 to 2:25 p.m.
Panel discussion, polling questions, audience Q&A

2:25 to 2:30 p.m.
Closing remarks, reminders, housekeeping

HEAL CONNECTIONS
SHARING SESSION

Inclusive Language, Imagery, and Storytelling for Addiction and Pain Researcher Teams

---

Part 2: Focus on Pain

August 31 | 1PM ET

Part 1 of this series focused on Inclusive Language, Imagery, and Storytelling for Addiction Research Teams. It took place on July 27.

Janelle Letzen, Ph.D.,
Health Science Policy Analyst, NINDS

Kerri Cavanaugh, M.D.,
Associate Professor of Medicine, Vanderbilt University Medical Center

Joanna Hobson,
Ph.D. Candidate, University of Alabama at Birmingham

Kate Nicholson, J.D.,
Founder and Executive Director, National Pain Advocacy Center

Soumitri Sil, Ph.D.,
Associate Professor of Pediatrics, Emory University School of Medicine

Emily Wakefield, Psy.D.,
Psychologist, University of Connecticut School of Medicine

What You Will Learn

1 Real-world case examples for communicating with respect to stakeholders from those who have researched pain stigma and its impact on people with lived experience.

2 Explore actionable resources to engaged people with lived experience, reduce stigma, and make research communications more engaging and impactful.

3 Hear about opportunities to partner with HEAL Connections to support the use of inclusive language, imagery, and communications product development.

The Importance of Including People with Lived Experience of Pain in Research

Janelle Letzen, Ph.D.

Health Science Policy Analyst,
National Institute of Neurological Disorders and Stroke

Person- and Community-Centered Pain Research

- Pain is a **subjective** and often **invisible** experience
  - Invalidation, stigma
  - Compounded for those with marginalized identities
- People with lived experience of pain are **experience experts**
  - Person who directly experiences pain
  - Caregivers
  - Community leaders
- Engaging people from populations that are marginalized can **improve health equity**
- **Engagement is a core value of HEAL research**

HEAL Initiative Engagement Efforts

NIH HEAL Initiative

Diana Morales

Nora Hathan

Parisa Parsafar

NINDS, Office of Pain Policy & Planning

Andrew Siddons

Janelle Letzen

NIDA, Services Research Branch

Marcy Fitz-Randolph

Coordinates and carries out action plans for:

HEAL Community Partners Committee (HCPC)

Advises on:

Engagement Working Group

~20 NIH staff across institutes that support engagement priorities within HEAL and collaborate as a community of practice

HEAL Engagement Definition

- Effectively involving people with lived experience throughout the research process so that findings can be useful for real people in real communities

- **Who to engage:**
  - *Primary* — people who directly experience pain, their caregivers, community leaders
  - *Secondary* — other relevant collaborators (e.g., health care providers, policymakers)

- **When to engage:**
  - Any point in the lifecycle of a research project that involves a decision
  - Think beyond recruitment/retention efforts
  - The sooner, the more effective
  - Across the translational pain research spectrum

When to Engage?

Develop the Research Concept

Conversations where the general idea for the project is developed

Design the Research Plan

Stage when the research methods and study design are determined

Recruit and Retain Participants

Development of a plan and materials to advertise the study and keep participants enrolled in the study through the end

Monitor the Research Project

Ensure that the research project is moving forward as hoped and in a safe and ethical way

Analyze Data and Interpret Results

Analyze the collected data and draw on other sources of information to understand and explain the results

Disseminate Study Information

Communicate the study's results to communities, including people with lived experience of pain

Why is engagement important?

- The end goal of HEAL research is to **improve the lives** of those living with pain and/or OUD
- Effective **engagement improves**:
  - Precision of science
  - Meaningfulness of findings for people within affected communities
  - Likelihood of community knowledge and uptake of research findings
  - Health equity
  - Reduces stigma

Effective Engagement

- Requires open dialogue
- Shares power
- Is collaborative and mutually beneficial
- Means communities feel their input is valued and acted on
  - Avoiding tokenism
- Aligns with community needs, cultural values, and preferences for how people offer feedback
- Can be measured

HEAL's engagement resources:
https://heal.nih.gov/resources/engagement

In Today’s Sharing Session

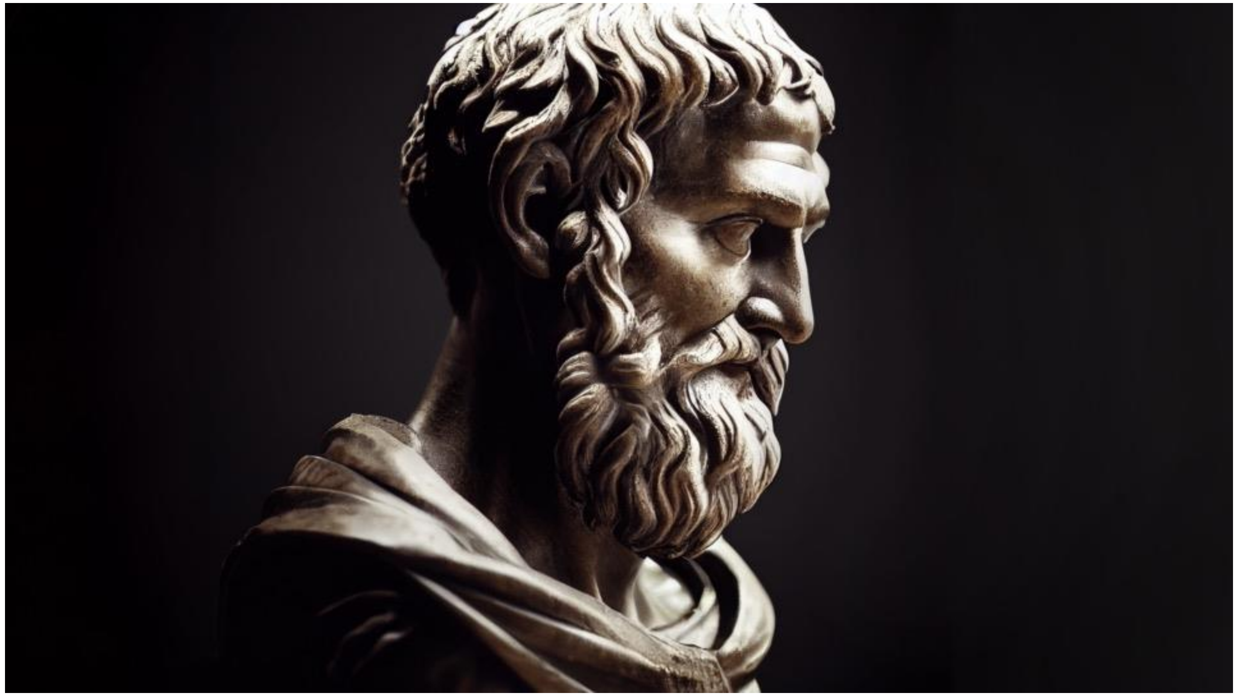
- Pain Stigma
  — *Kate Nicholson, JD*
- Stigma & Discrimination: The Roots of Pain & Substance Use Disparities
  — *Joanna Hobson*
- Pain-Related Stigma in Adolescents with Chronic Pain
  — *Emily Wakefield, PsyD*
- Addressing Stigma through Community Engagement and Cultural Adaptation in Pediatric Sickle Cell Disease
  — *Soumitri Sil, PhD, ABPP*
- Action items to Eliminate Stigma
  — *Kerri Cavanaugh, MD, MHS*

Pain Stigma

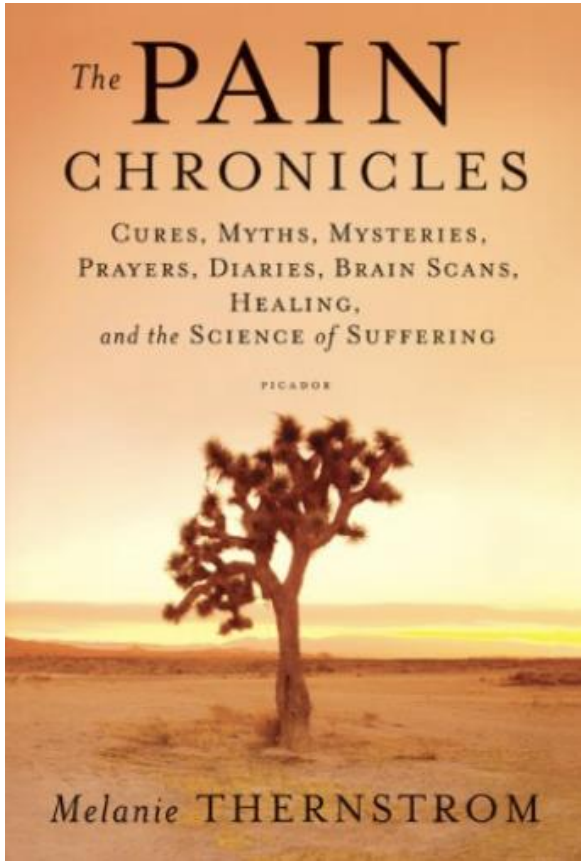
Kate M. Nicholson, JD

(no conflicts)

Historic Ideas



Aristotle. Pain is pre-ordained, deserved.
"*Poena.*" Latin meaning punishment/penalty.



The PAIN CHRONICLES

Cures, Myths, Mysteries, Prayers, Diaries, Brain Scans, Healing, and the Science of Suffering

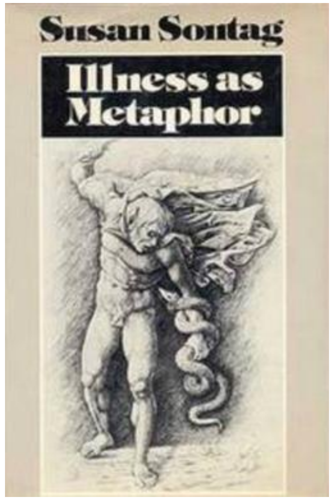
Picador

Melanie THERNSTROM

Nonwestern traditions.
Religious ideas re: pain and purpose (stigmata).

Modern Ideas

- **Objectivism:** Invisible nature of pain often frustrates core knowledge framework of medicine, which focuses on identifying pathology.
- **Somatization:** “Faking it” to get something. Railway spine (Goldberg). Today: drugs, benefits.
- **Metaphor:** In diseases poorly understood in their time, ambiguity is resolved with stigmatizing metaphors.


Susan Sontag
Illness as Metaphor

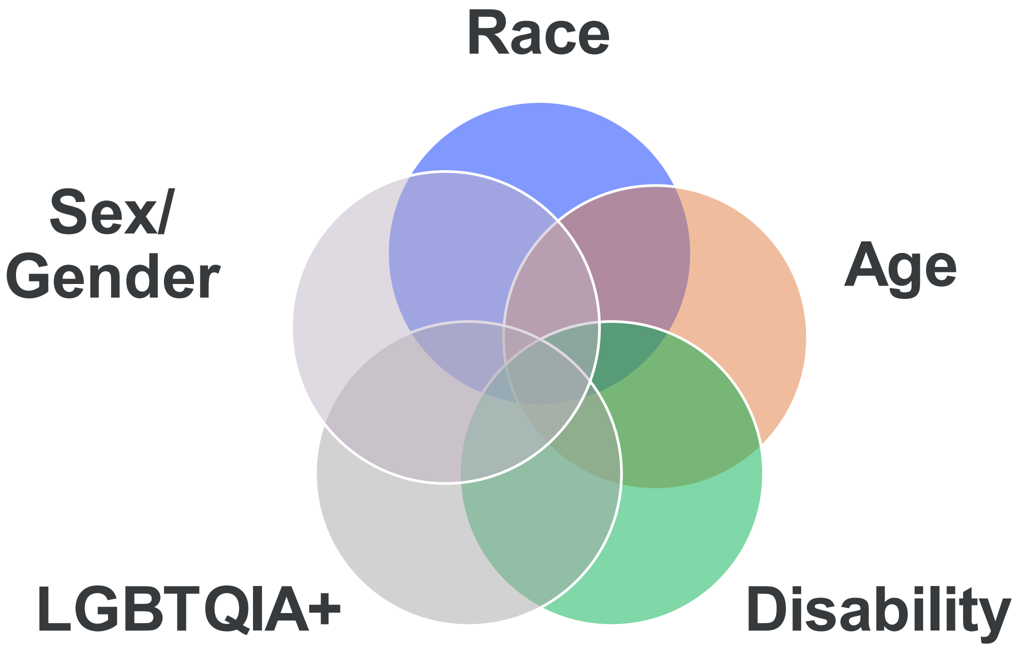
Stigma & Power

- **Stigma is structural**, so stigma and power are intimately connected.
- **Provider/patient hierarchy** (Foucault's *Birth of the Clinic*).
- Social hierarchy: **disadvantaged groups are more likely to be stigmatized**.

Bias & Injustice

- **Racial Bias:** Providers rate the pain of Black and Brown persons as being less severe; Black and Brown persons receive less medication even at the end of life (race medicine; drug policy).
- **Gender/Gender Identity Bias:** Women are more often dismissed or disbelieved (hysteria).
- **Testimonial Injustice:** Being disbelieved based on your identity. (Fricker)

Intersectionality: The Compounding of Disadvantage



When we focus on categories like race, we often **mythologize a universal experience**. (Crenshaw).

Those who fall outside familiar prisms **become invisible**.

Example: Pain disparately affects older people. Well established racial bias. Little research on pain in aging Black men.

Real Pain Story: Quána Madison

- Preventive surgeries: hysterectomy, oophorectomy & double mastectomy.
- Severe post-surgical complications: vaginal cuff tear & necrosis.
- Persistent post-surgical pain.
- Sought help at ER. Was wrongly cast as "drug seeking" for reporting pain.
- Identifies as Black, queer, disabled, female.

Why does stigma matter?

Stigma is often considered a social determinant of health and even a cause factor in disease.

Stigma can be a barrier to care. Who wants to seek healthcare if you will be dismissed or disbelieved?

Stigma and bias connect to the well-established inequities and disparities we see with pain.

Why include People with Lived Experience (PWLE)?

”Nothing about us without us.” Clarion call of the disability rights movement.

The idea that research and policies should engage those most affected.

We all exist in siloes that limit perspective. PWLE may have a perspective on their disease you haven’t considered.

Example: People without disabilities rate the quality of life of people with disabilities differently than disabled people do.

Pain is the chief cause of disability. Quality of life is a core domain.

How to Include PWLE

- **Recruit broadly**: not just re: condition but race, gender, gender identity, age, disability, income, etc. PWLE are not interchangeable.
- **Be transparent** about how a person's input will be used (ethics: privacy)
- **Manage expectations** for trial benefit vs. benefit for personal care (ethics: vulnerability)
- **Use culturally competent** and **accessible materials**.
- **Be respectful**, including offering compensation where appropriate.

Stigma & Discrimination: The Roots of Pain & Substance Use Disparities

Joanna Hobson

UAB COLLEGE OF ARTS AND SCIENCES
The University of Alabama at Birmingham

UAB COLLEGE OF ARTS AND SCIENCES
The University of Alabama at Birmingham

No Conflicts of Interest to Disclose

Views are my own ☺

Disparities & Inequities

- **Stigma — Belief**
  - Negative beliefs
- **Stigmatization — Behavior**
  - Discredit, invalidate
- **Discrimination — Behavior**
  - Differential treatment
- **Intersectionality — Framework**
  - e.g. Race, gender, sexual orientation

Neurobiology of Pain 12 (2022) 100101

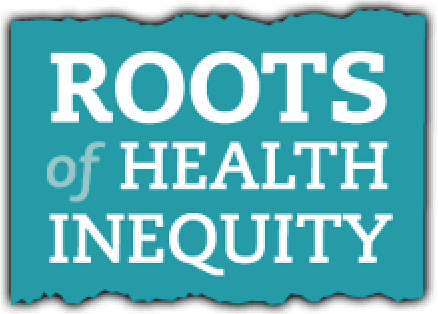
Contents lists available at ScienceDirect

Neurobiology of Pain

journal homepage: www.sciencedirect.com/journal/neurobiology-of-pain

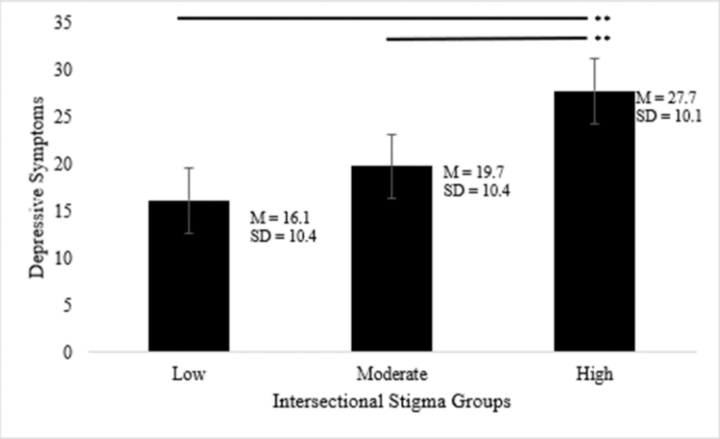
The neurobiology of social stress resulting from Racism: Implications for pain disparities among racialized minorities

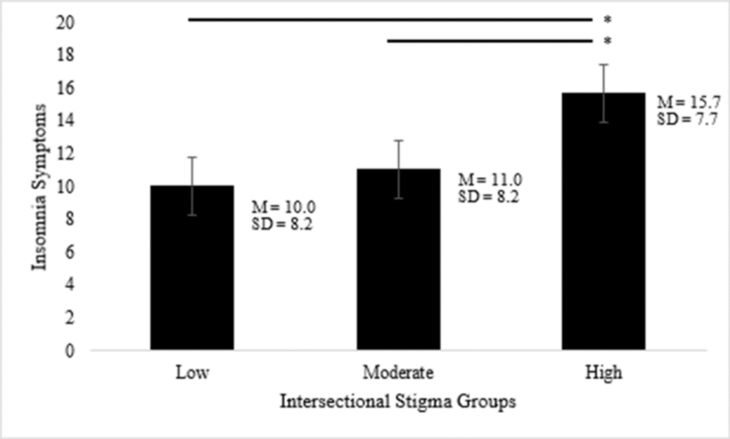
Joanna M. Hobson [a,*], Myles D. Moody [b], Robert E. Sorge [a,c], Burel R. Goodin [a,c]

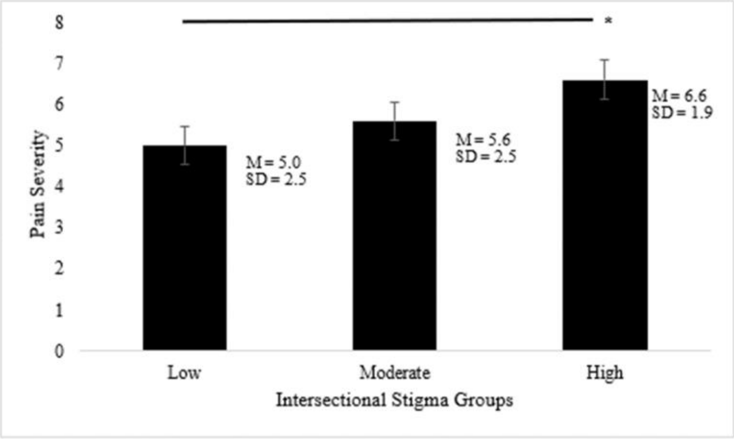


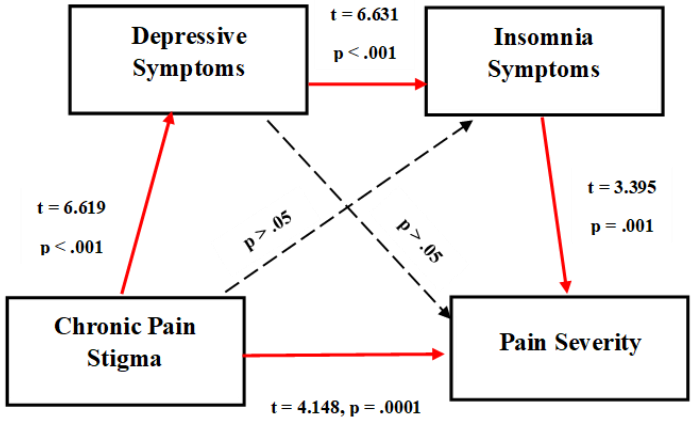
Intersectional HIV and Chronic Pain Stigma: Implications for Mood, Sleep, and Pain Severity

Joanna M. Hobson, BS[1], Shannon R. Gilstrap, BS[1],
Michael A. Owens, PhD[2], Gabrielle F. Gloston, MS[1],
Michael D. Ho[1], Jenna M. Gathright[1], Hannah F. Dotson, BS[1],
Dyan M. White, BS[1], Shameka L. Cody, PhD, AGNP-C[3],
S. Justin Thomas, PhD[1], and Burel R. Goodin, PhD[1]









Depressive Symptoms

Insomnia Symptoms

Chronic Pain Stigma

Pain Severity

t = 6.631 p < .001

t = 6.619 p < .001

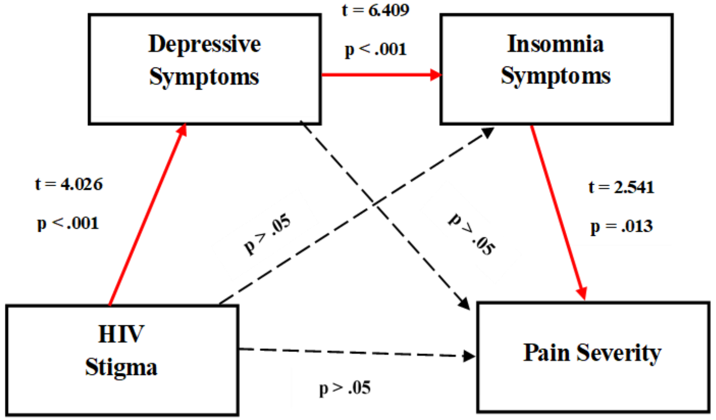
t = 3.395 p = .001

p > .05

p > .05

t = 4.148, p = .0001

(Indirect Effect = .8017, 95% Confidence Interval = .3667 to 1.4978)



Depressive Symptoms

Insomnia Symptoms

HIV Stigma

Pain Severity

t = 6.409 p < .001

t = 4.026 p < .001

t = 2.541 p = .013

p > .05

p > .05

p > .05

(Indirect Effect = .0272, 95% Confidence Interval = .0073 to .0634)

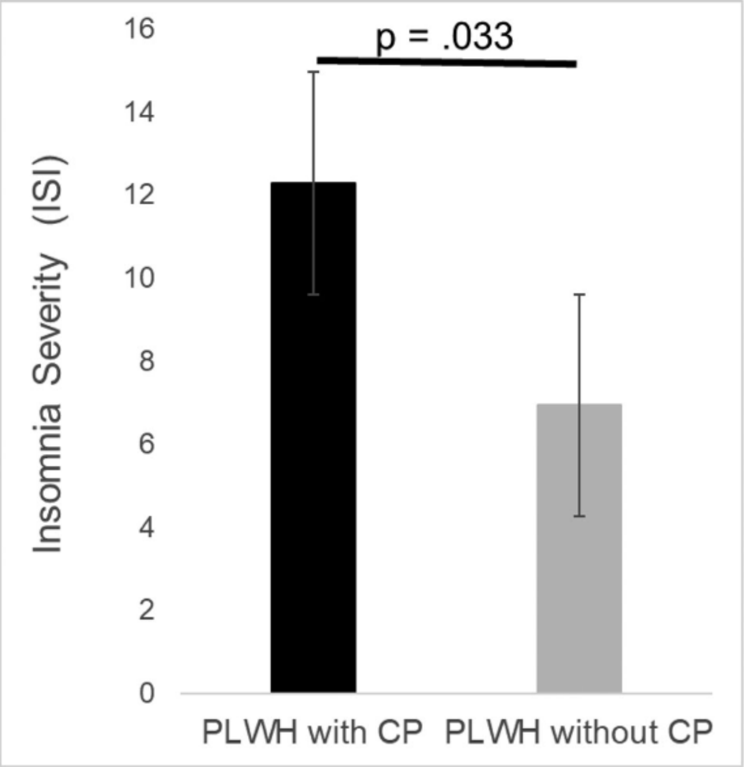
Joanna Hobson,
UAB

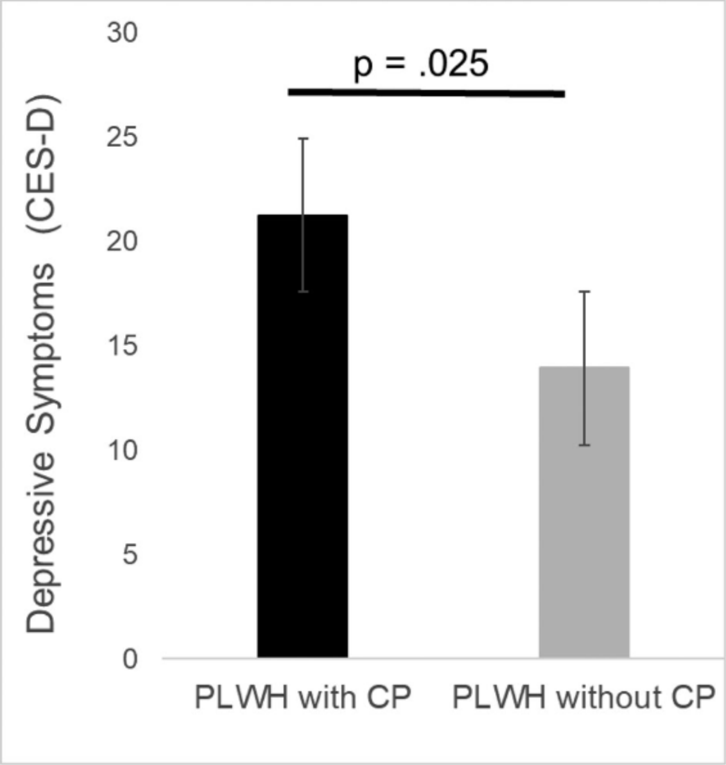
N = 82, 74% Black/African American, 67% Male, 90% Below Poverty Line

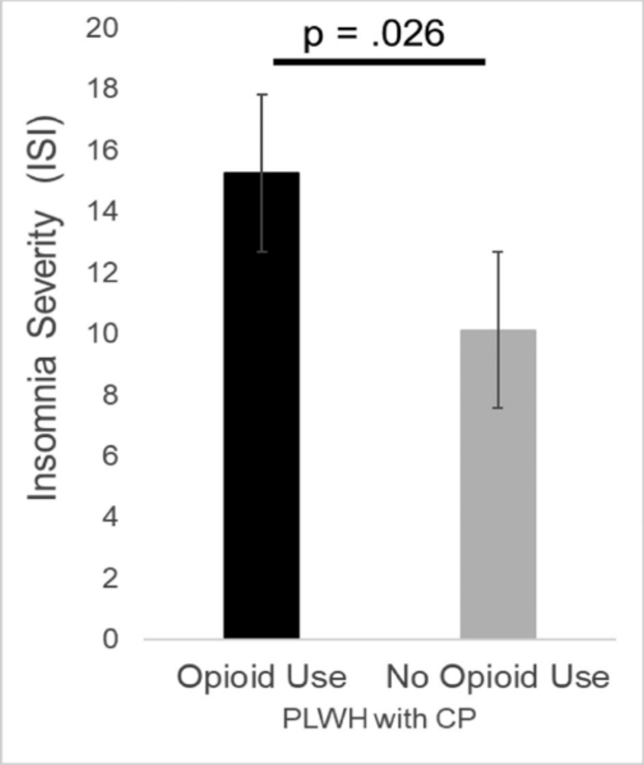
Insomnia severity and depressive symptoms in people living with HIV and chronic pain: associations with opioid use

Shameka L. Cody[a], Joanna M. Hobson[b], Shannon R. Gilstrap[b], Gabrielle F. Gloston[b], Kevin R. Riggs[c], S. Justin Thomas[d] and Burel R. Goodin[b,e]

[a]Capstone College of Nursing, The University of Alabama, Tuscaloosa, AL, USA; [b]Department of Psychology, University of Alabama at Birmingham, Birmingham, AL, USA; [c]Division of Preventive Medicine, University of Alabama in Birmingham School of Medicine, Birmingham, AL, USA; [d]Department of Psychiatry & Behavioral Neurobiology, University of Alabama at Birmingham, Birmingham, AL, USA; [e]Center for Addiction & Pain Prevention & Intervention (CAPPI), University of Alabama at Birmingham, Birmingham, AL, USA







Do’s and Don’ts

✓ DO

- ✓ Encourage your audience
- ✓ Be patient
- ✓ Lead by example
- ✓ Use supportive words (substance use disorder, disability, etc.)

× DON’T

- × Apply too much pressure
- × Use non-inclusive language (drug addict, junky, dirty, laced, etc.)
- × Ostracize the individual and/or group
- × Tell them to “be strong”

This is what a scientist looks like.

Acknowledgements

Pain-Related Stigma in Adolescents with Chronic Pain

Emily Wakefield, Psy.D.

Assistant Professor of Pediatrics
University of Connecticut School of Medicine
Pediatric Psychologist
Divisions of Pain and Palliative Medicine

Acknowledgements

- No financial disclosures
- This research is supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases of the National Institutes of Health under award number 1K23AR073934-01A1 and the Goldfarb Pain and Palliative Medicine Fund.

Chronic Pain Prevalence in Childhood

- 11-38% of children and adolescents have chronic pain
- Headache with most prevalence
- Rates are on the rise

King et al., 2011

The Problem with Pain

Pain Invisibility

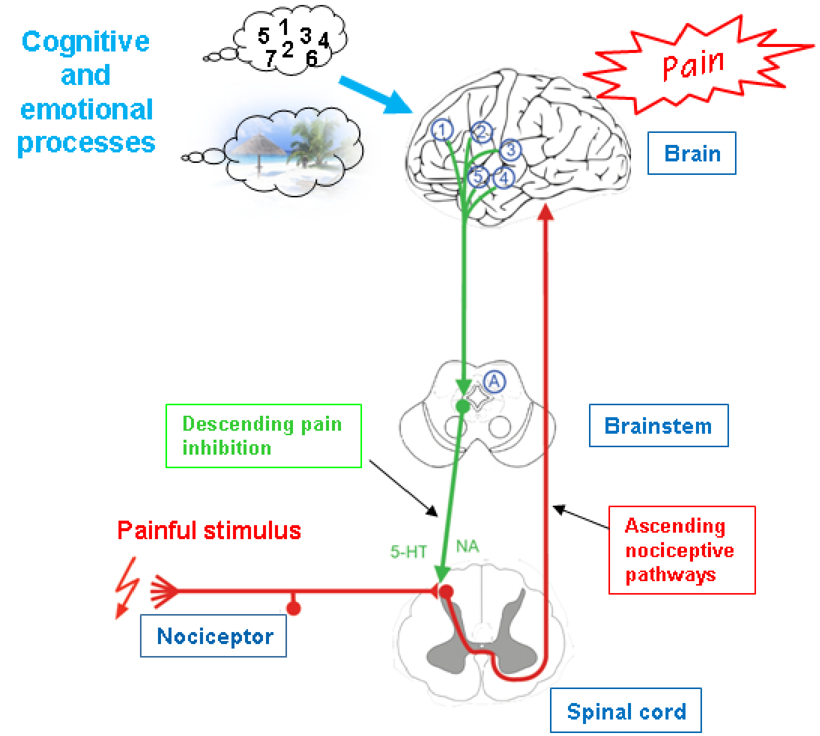


Figure: A. Kreusch/S. Kraft

Pain Experience

Pain is expressed via individual report

!!!!

Pain is Subject to Observer Bias

The interaction between pain patient and observer is ambiguous

????

Pain-Related Stigma Characteristics

Pain Dismissal

Initially, when doctors, they would just say: “Oh, it’s nothing. It’ll go away. There’s nothing wrong with you.”

Faking or Exaggerating

They would always just yell at me and say, like: “Sit down. You need to get to class. Stop faking it.”

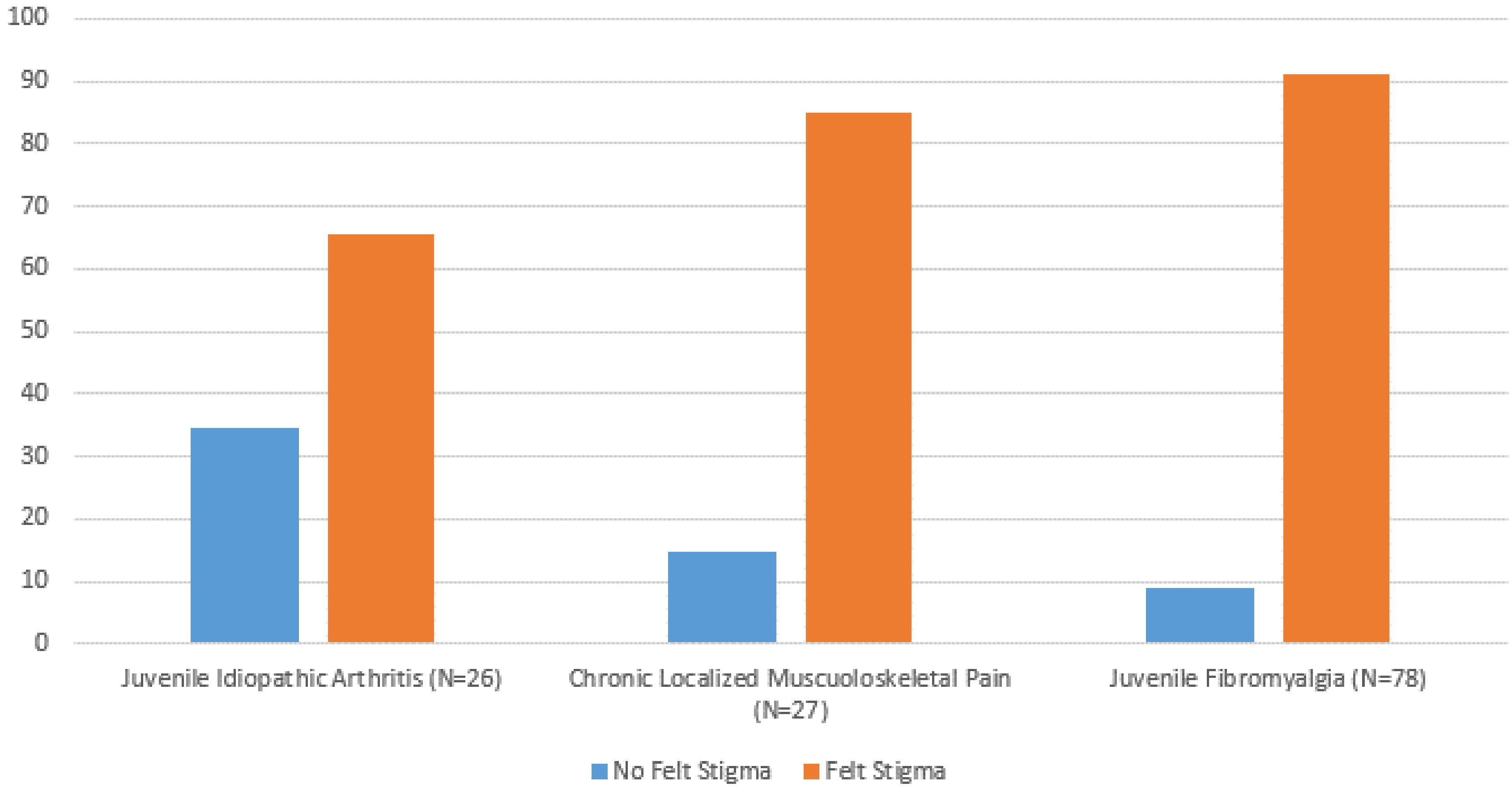
Mental Health Stigma

I have had some say: “Maybe she just needs a psychiatrist.”

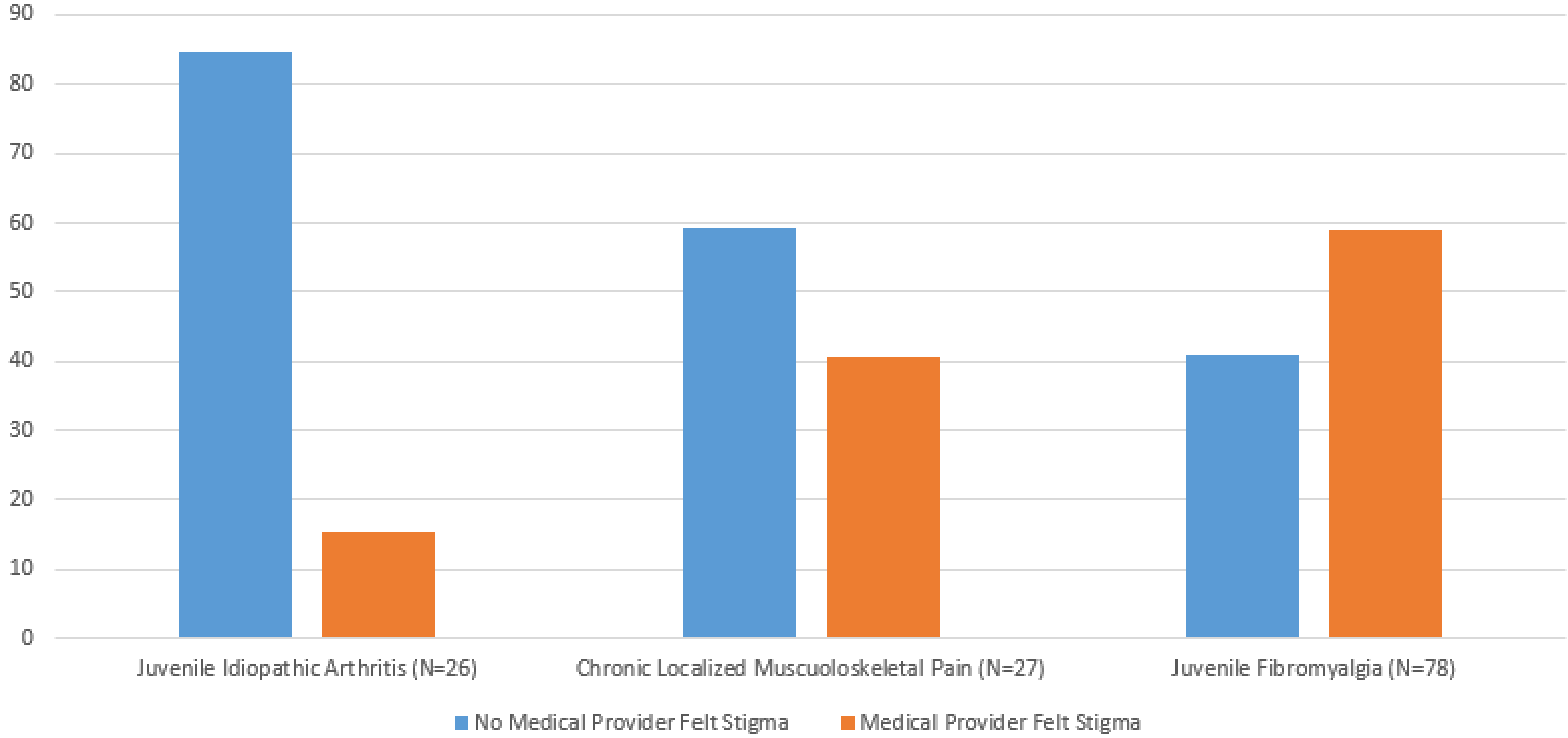
Wakefield et al., 2022

Preliminary Prevalence of Pain-Related Stigma

Percent of Pain-Related Stigma Across Disease Groups



Percentage of Felt Stigma from Medical Providers Across Disease Groups



Potential Impact on Recruitment

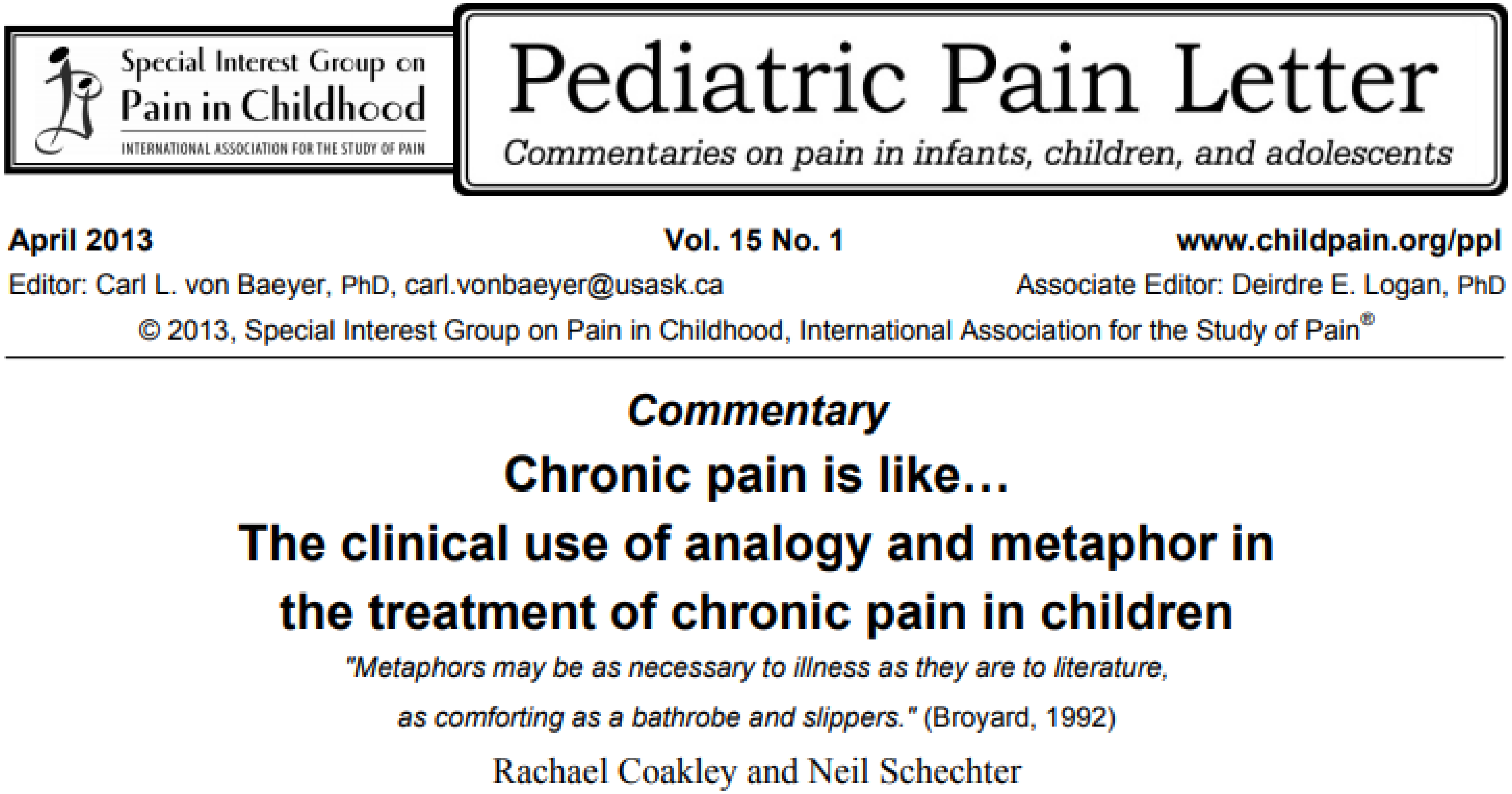
PARENT OF ADOLESCENT WITH CHRONIC PAIN:

"What will my child benefit from? Something for years she was told it's all in her head? She no longer trusts doctors due to them dismissing her pain. Until you feel her pain and other kids with her type of pain, you will never understand. A stupid gift card is even more lousy. Don't reach out to me again. You can say PT and therapy will help, but it doesn't. Again we are lost in understanding juvenile fibromyalgia that we renamed to chronic pain syndrome. You have all these doctors that have these degrees, but without personal experience, you lack understanding."

Next Steps

- Increase awareness of how pain-related stigma may influence outcomes and recruitment efforts in pediatric chronic pain populations
- Patient and parent advocates can help with study design and recruitment practices
- Language matters
    - Person-first language
    - Biopsychosocial language
    - Consider metaphors to describe chronic pain for children

Pediatric Chronic Pain Resource



Special Interest Group on Pain in Childhood
INTERNATIONAL ASSOCIATION FOR THE STUDY OF PAIN

Pediatric Pain Letter
Commentaries on pain in infants, children, and adolescents

April 2013 **Vol. 15 No. 1** **www.childpain.org/ppl**
Editor: Carl L. von Baeyer, PhD, carl.vonbaeyer@usask.ca Associate Editor: Deirdre E. Logan, PhD
© 2013, Special Interest Group on Pain in Childhood, International Association for the Study of Pain®

Commentary

Chronic pain is like…
The clinical use of analogy and metaphor in the treatment of chronic pain in children

"Metaphors may be as necessary to illness as they are to literature,
as comforting as a bathrobe and slippers." (Broyard, 1992)

Rachael Coakley and Neil Schechter

http://ppl.childpain.org/issues/v15n1_2013/v15n1_coakley.pdf

References

- Coakley, R., & Schechter, N. (2013). Chronic pain is like… The clinical use of analogy and metaphor in the treatment of chronic pain in children. *Pediatric Pain Letter*, *15*(1), 1–8. www.childpain.org/pplKing, S., Chambers, C. T., Huguet, A., MacNevin, R. C., McGrath, P. J.,

- Parker, L., & MacDonald, A. J. (2011). The epidemiology of chronic pain in children and adolescents revisited: A systematic review. *Pain*, *152*(12), 2729–2738. https://doi.org/10.1016/j.pain.2011.07.016

- Wakefield, E.O., Belamkar, V., Litt, M.D., Puhl, R., & Zempsky, W. (2022). "There's nothing wrong with you": Pain-related stigma in adolescents with chronic pain. *Journal of Pediatric Psychology, 47*(4), 456-468. https://doi.org/10.1093/jpepsy/jsab122

- Wakefield, E. O., Belamkar, V., Sandoval, A., Puhl, R. M., Edelheit, B., Zempsky, W. T., Rodrigues, H. A., & Litt, M. D. (2023). Does diagnostic certainty matter?: Pain-related stigma in adolescents with juvenile idiopathic arthritis. *Journal of Pediatric Psychology*, *2023*, 1–11. https://doi.org/10.1093/JPEPSY/JSAC092

Contact Information:
ewakefield@connecticutchildrens.org
@EmilyOWakefield

Addressing Stigma Through Community Engagement and Cultural Adaptation in Pediatric Sickle Cell Disease

Soumitri Sil, PhD, ABPP

Associate Professor of Pediatrics, Emory University School of Medicine
Director, Pediatric Psychology Clinic, Aflac Cancer and Blood Disorders Center
Pediatric Psychologist, Children's Healthcare of Atlanta

Sickle Cell Disease (SCD)

Genetic blood disorders affecting approximately **100,000 people in U.S**.

Single **most common inheritable** disease **worldwide**

Highest prevalence among individuals of **African ancestry**

1 in 500 Black Americans have SCD

NHLBI Expert Panel Report, 2014

SCD Pain Across Lifespan

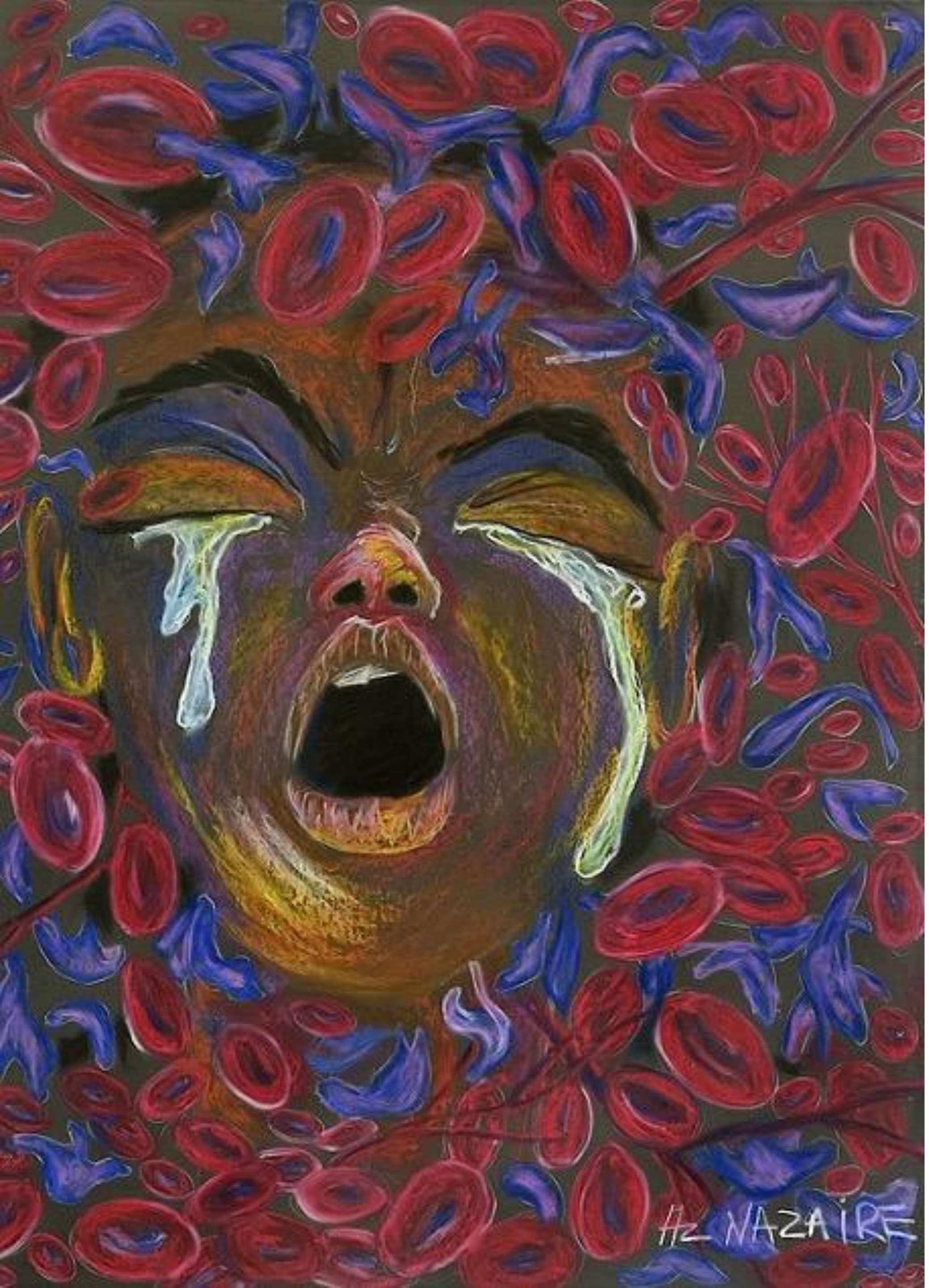
Minimal pain, acute pain often presents as dactylitis

Acute, intermittent pain, mostly **managed at home** with some ED visits and hospitalizations

Pain frequency increases, length of hospital stay increases, **emergence of chronic pain (15-20%) and co-morbidities**

Higher prevalence of **chronic daily pain (30-40%) and comorbidities** contributing to chronic pain

AAPT: Analgesic, Anesthetic, and Addiction Clinical Trial Translational Innovations Opportunities and Networks and American Pain Society Pain Taxonomy; Dampier et al 2017; Field et al 2018; Smith et al 2008; Sil et al 2016



Racial Bias & Stigma in SCD

- **Provider bias** and **stigmatizing language** leads to the **underassessment** and **under-management** of pain in Black Americans
- **Direct and indirect consequences of stigma on social, psychological, and physiological health** in SCD
- Directly relate to **inequity of resources** for **patients with SCD**.

Booker, 2016; Brousseau et al., 2009; Wakefield et al 2017; Bulgin et al 2018; Goddu et al 2018

Stigmatizing Language in Research

Patients with SCD are…

- Difficult
- Hard to reach
- Non-adherent
- From chaotic family backgrounds
- Mistrusting of doctors and research

"My teacher thinks **I'M FAKING IT** and **doesn't let me** go to the nurse."

12 Y Male with SCD

NIH HEAL INITIATIVE | CONNECTIONS
Partnering to Accelerate Research into Action

"It's like, they [providers] ask me **how bad my pain is**, "It's like, they [providers] ask me how bad my pain is, and maybe because I'm playing videogames and not screaming or actin' crazy, **they don't believe** I'm hurting.

> "It's like, they [providers] ask me how bad my pain is, and maybe because I'm playing videogames and not screaming or actin' crazy, they don't believe I'm hurting. There are definitely those people that think I'm **just coming to get drugs**."
>
> —*16 Y Male with SCD*

NIH
HEAL
INITIATIVE

CONNECTIONS
Partnering to Accelerate Research into Action

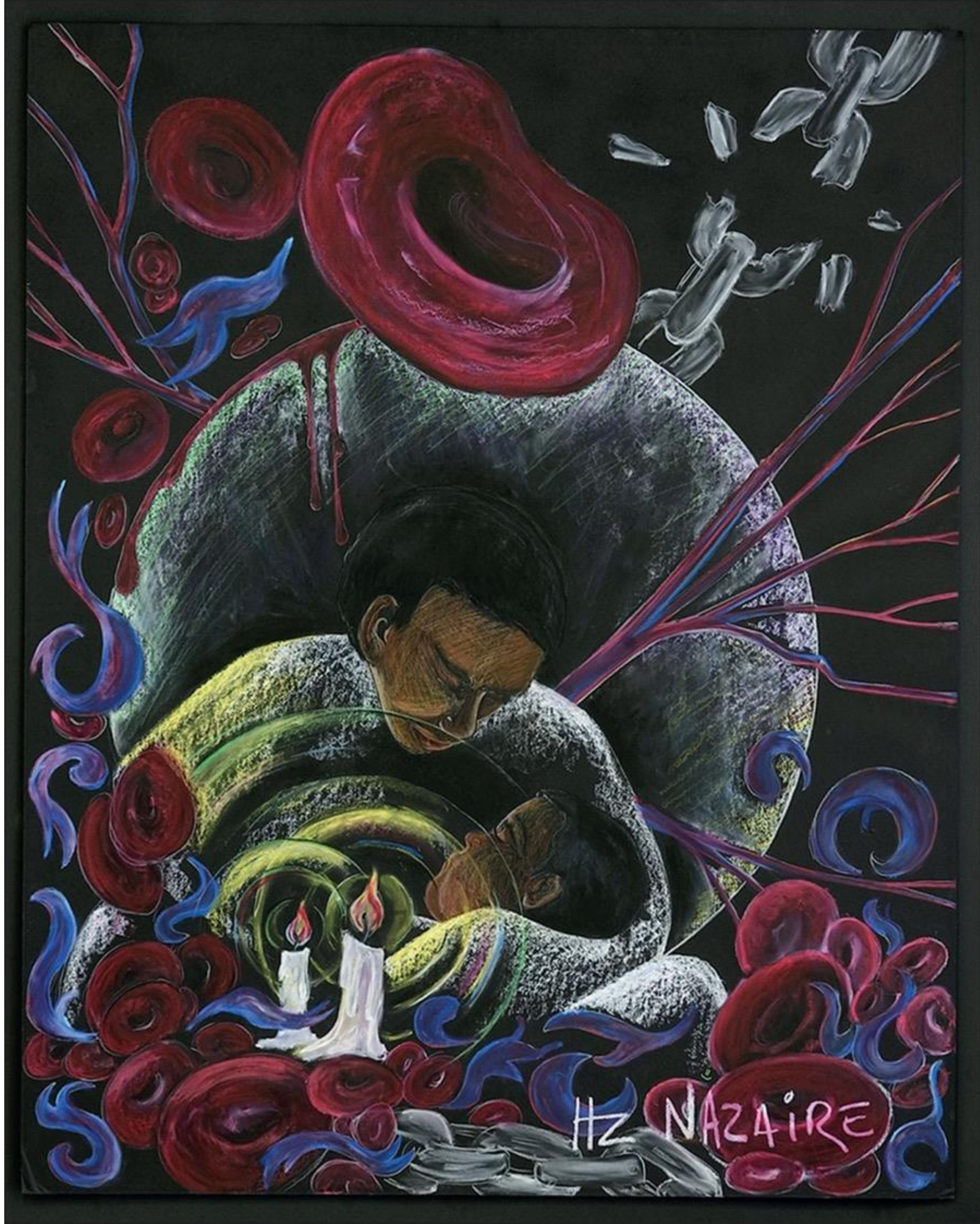
“People **can’t see** sickle cell, because like, you can’t see it on the outside. So they **don’t believe me** when I’m in pain.”

—14 Y Female with SCD

Anti-Racism Research Framework

- Consider how our traditional approaches may not fit their needs by **reframing study design**.
- Patients and families often want to participate but are **not aware** of options.
- Build **engagement with stakeholder** partnership to extend our reach and make an impact.

Fisher et al 2011; Morais et al 2022; Letzen et al 2022; Hood et al 2022; Strong et al 2023



Community Engagement Continuum

Increasing Level of Community Involvement, Impact, Trust, and Communication

OUTREACH

Communication flows unidirectional, to inform

CONSULT

Communication to community and then back, answer seeking

INVOLVE

Communication flows bidirectional, participatory

COLLABORATE

Communication flows bidirectional, develop partnerships

SHARED LEADERSHIP

Decision making at community level

CTSA Community Engagement Key Function Committee Task Force Report, 2011; Key et al 2019

Cultural Adaptation (The How)

Design and Adapt with Implementation in mind

Focus on Reach from the beginning

Take an Equity Lens

Increase Satisfaction, Effectiveness, Sustainability of treatment

Baumann & Cabassa 2020; Cabassa & Baumann 2013; Glasgow et al 1999; 2001; Lyon et al 2014; Santisteban et al 2013

Acknowledgements

Patients, Families, and Advisory Boards

Children's Healthcare of Atlanta, Aflac Cancer and Blood Disorders Center

Land

On native land
of the Muscogee
Creek people

Mentors and Study Team

Carlton Dampier, MD
Lindsey Cohen, PhD
Marianne Celano, PhD
Vivien Sheehan, MD, PhD
Nitya Bakshi, MBBS
Alison Manikowski, PsyD
Mallory Schneider, PhD
Kerri Woodward, PhD
Yelena Johnson, PhD
Lauren Quast, PHD

Katyria Thornton
Nwanna Ifendu
Shawn Reece
Lauren Trotter
Sharon Shih, MA
Caitlin Shneider, MA

Funding

NIH National Heart, Lung, and Blood Institute

NIH National Center for Complementary and Integrative Health

NIH National Institutes of Health *Division of Loan Repayment*

NIH National Center for Advancing Translational Sciences

Thank you!

Soumitri Sil, PhD, ABPP

✉ soumitri.sil@emory.edu

@SoumitriSilPhD

VANDERBILT UNIVERSITY
MEDICAL CENTER

Action Items to Eliminate Stigma

Communication Techniques for Research & Chronic Pain

Kerri L. Cavanaugh, MD, MHS

Associate Professor of Medicine
Director, Vanderbilt Center for Effective Health Communication
Vanderbilt University Medical Center, Nashville, Tennessee

Acknowledgments

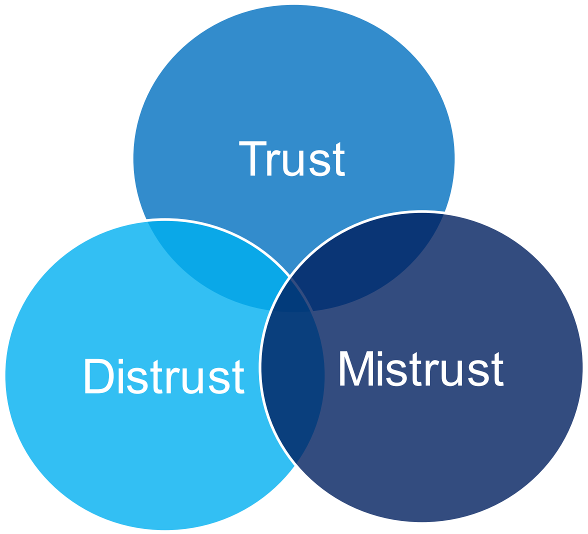
- No financial disclosures
- Dr. Cavanaugh is supported by the NIH NIDDK award U01DK123821, a recruitment center for the Hemodialysis Pain Reduction Effort (HOPE) Trial

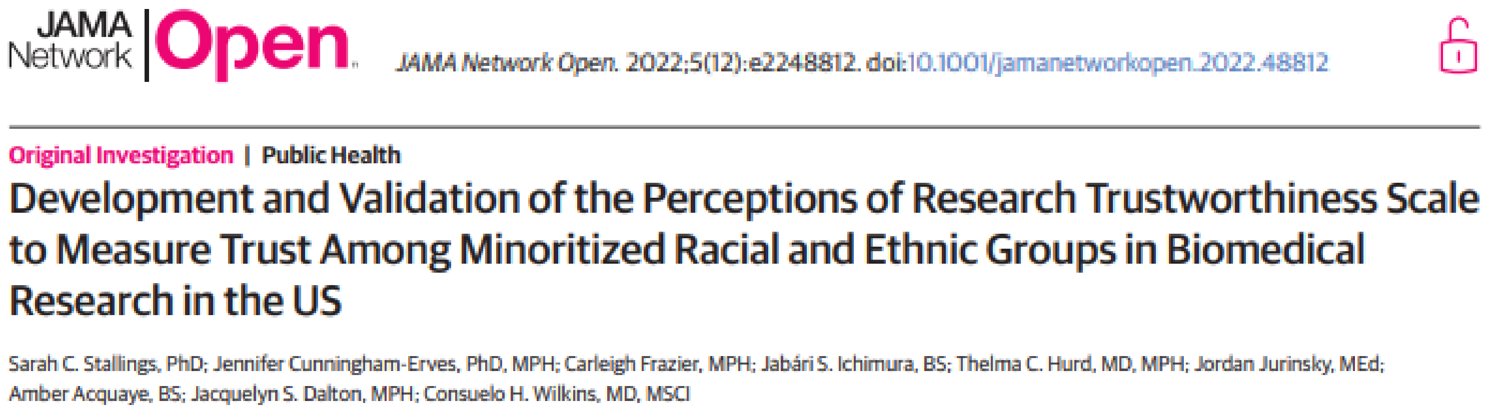
Foundational

- Stigma and stigmatizing experiences are profuse at **multiple levels**
- Stigma is a barrier to care and to **participation in research**
- Stigma **can be addressed** through program priorities to understand and eliminate stigma through training, procedures and policies

Trust

- Organizational trust
- Research trustworthiness





JAMA Network | Open. JAMA Network Open. 2022;5(12):e2248812. doi:10.1001/jamanetworkopen.2022.48812

Original Investigation | Public Health

Development and Validation of the Perceptions of Research Trustworthiness Scale to Measure Trust Among Minoritized Racial and Ethnic Groups in Biomedical Research in the US

Sarah C. Stallings, PhD; Jennifer Cunningham-Erves, PhD, MPH; Carleigh Frazier, MPH; Jabári S. Ichimura, BS; Thelma C. Hurd, MD, MPH; Jordan Jurinsky, MEd; Amber Acquaye, BS; Jacquelyn S. Dalton, MPH; Consuelo H. Wilkins, MD, MSCI

- 18-Item survey, Trust and Distrust
- Developed in partnership with minoritized racial & ethnic communities
- Conceptual framework informed by literature, theory, focus groups
- Trust dimensions added:
  - Secrecy
  - Fairness
  - Community benefit
  - Privacy

Griffith DM, et al. Am J Prev Med 2021; 60(3):442-445

Trustworthiness — Assessment

Items with significant mean differences by race and ethnicity

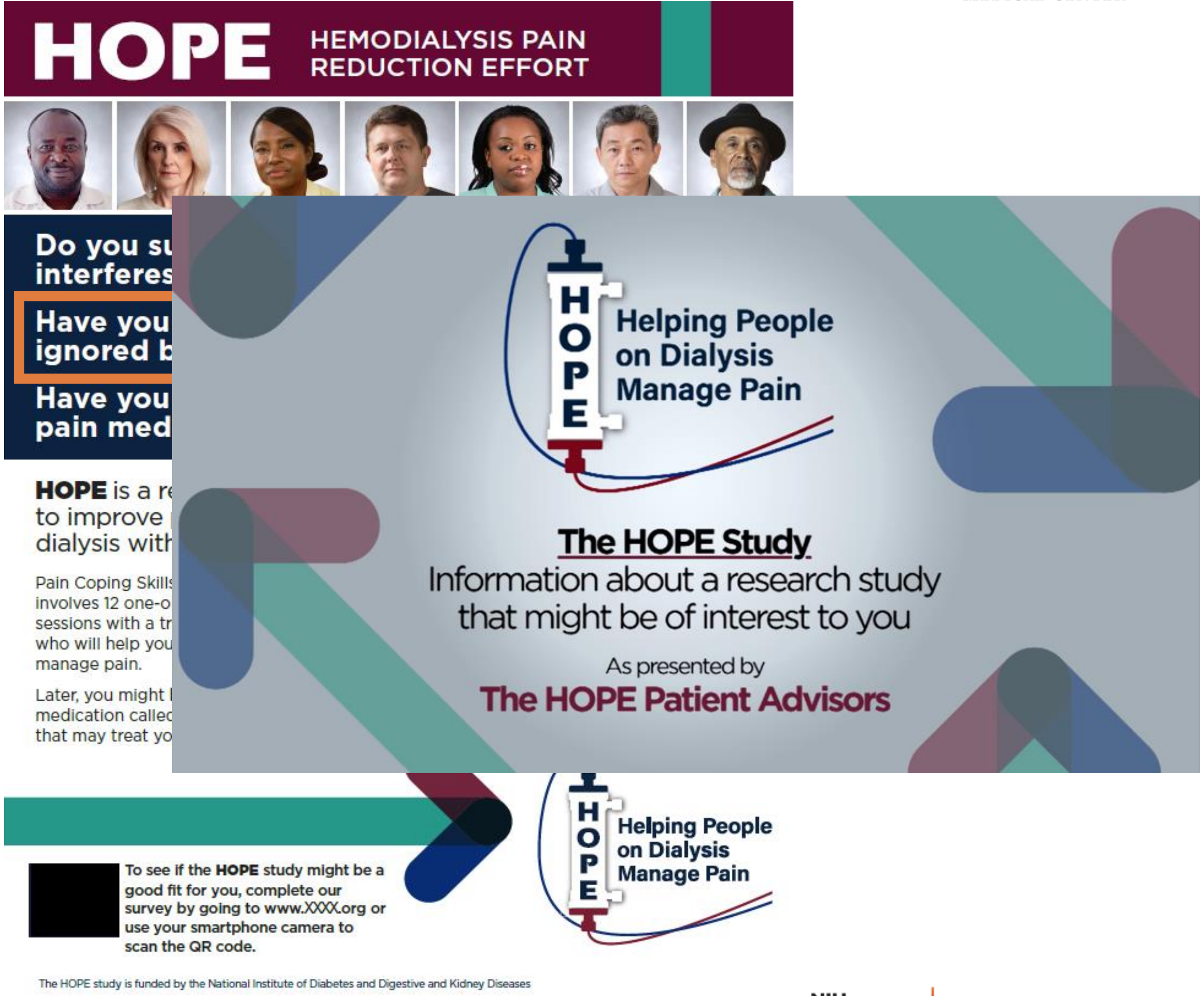
Trust	Distrust
Medical researchers tell people everything they need to know about being in a research study	Medical research is secretly designed to give diseases to minority groups
Medical researchers would never give someone something that would hurt them, just to study how it works in people	Medical researchers would lie to people to convince them to be in a research study
Participation in medical research benefits society	Medical researchers will share my personal info with anybody else they want to, even if I don't tell them they can do that
Medical researchers only do research on people who know it is happening	**With input from patient participant advisors:** Anonymous survey of community Research program evaluation and planning Buy-in and investment of leadership: strategic plan
My physician would not ask me to be in a medical research study if [they] thought it would hurt me	

JAMA Network Open. 2022;5(12):e2248812. doi:10.1001/jamanetworkopen.2022.48812

Validation & Belief

- **Acknowledgment**
- **Avoid**
  - Disbelief
    - Discounting
    - Lack of understanding
  - Judgment
- **Dialogue**
  - What matters most
  - Acknowledge beliefs, difficulties and social contexts
  - Involve participants

www.hopehdtrial.org



HOPE HEMODIALYSIS PAIN REDUCTION EFFORT

Do you su
interferes

Have you
ignored b

Have you
pain med

HOPE is a re
to improve
dialysis with

Pain Coping Skills
involves 12 one-o
sessions with a tr
who will help you
manage pain.

Later, you might
medication called
that may treat yo

[redacted] To see if the **HOPE** study might be a good fit for you, complete our survey by going to www.XXXX.org or use your smartphone camera to scan the QR code.

HOPE Helping People on Dialysis Manage Pain

The HOPE study is funded by the National Institute of Diabetes and Digestive and Kidney Diseases

HOPE Helping People on Dialysis Manage Pain

The HOPE Study

Information about a research study that might be of interest to you

As presented by

The HOPE Patient Advisors

VANDERBILT UNIVERSITY MEDICAL CENTER

NIH HEAL INITIATIVE | CONNECTIONS Partnering to Accelerate Research into Action

Language matters.

JAMA Network Open. JAMA Network Open. 2022;5(1):e2144967. doi:10.1001/jamanetworkopen.2021.44967

Original Investigation | Health Policy

Examination of Stigmatizing Language in the Electronic Health Record

Gracie Himmelstein, MD; David Bates, MD, MS; Li Zhou, MD, PhD

Examples of Stigmatizing Words and Phrases		
Narcotic(s)	Failure/Fails/Failed	Habit
Drug seeking	Refused/Refuse/ Refuses	Fake
Malingering	Unwilling	Drug seeking
Secondary gain	Unmotivated	Difficult patient
Abuse/Abuser	Uncontrolled	Belligerent
Compliance/Compliant	User	Combative
Adherence/Adherent	Substance abuse	Cheat/cheating

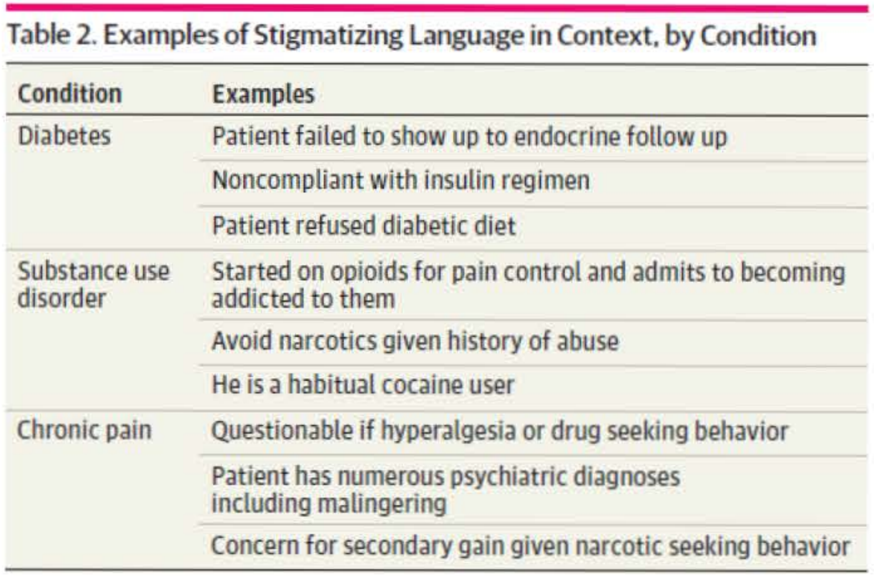


Table 2. Examples of Stigmatizing Language in Context, by Condition

Condition	Examples
Diabetes	Patient failed to show up to endocrine follow up
	Noncompliant with insulin regimen
	Patient refused diabetic diet
Substance use disorder	Started on opioids for pain control and admits to becoming addicted to them
	Avoid narcotics given history of abuse
	He is a habitual cocaine user
Chronic pain	Questionable if hyperalgesia or drug seeking behavior
	Patient has numerous psychiatric diagnoses including malingering
	Concern for secondary gain given narcotic seeking behavior

Language indicating disbelief

Training — Health/Research Communication

- **Listening and empathy**
  - Being listened to and encouraged, feeling understood
  - Skills and behaviors can be taught, but may vary over time
- **Strategies for training:**
  - Role-playing, low-fidelity simulation, reflective writing, pseudo-hospitalizations
  - Non-verbal communication account 2X more than verbal communication differences

❖ Eye Contact

❖ Body Orientation

❖ Trunk Lean

❖ Physical Distance

Lajante et al. PLoS ONE 18(8):e02897893, Aug 14, 2023

Operational Considerations

- **Continuity** of participant-researcher relationships
- **Time** — allow for more time in each interaction
- **Setting** — privacy

https://www.nih.gov/health-information/nih-clinical-research-trials-you/researchers-trial-sites

Action Steps Summary

- Assessment of trust in research as organizational/community strategy
- Validation of the experience of chronic pain with an emphasis on interactions that convey belief
- Program training at multiple levels (group/team; organizational)
  - Language
  - Listening and empathy
- Structuring of protocols and procedures to:
  - Result in continuity of research personnel who interact with study participants
  - From the start allow for the required time for effective communication

What will be the action that you will take?

Questions?

If you have any questions for the presenters, please let us know via **Chat.**

Which patient has chronic low back pain?

https://radiopaedia.org/cases/disc-extrusion-l5s1

Patient 1

https://radiopaedia.org/cases/normal-lumbar-spine-mri-3-t

Patient 2

Medically Unexplained Low Back Pain (“non-specific”)

- Associations between back pain symptoms and diagnostic imaging (e.g., CT, MRI) results are consistently weak
  - Up to 85% of patients with low back pain cannot be given a precise pathoanatomical diagnosis using these methods (Deyo RA, Weinstein JN, N Engl J Med, 2001)
  - Even when anatomic abnormalities are detected, the significance is unclear, since disc herniation is found in high percentages of asymptomatic individuals (Brinjiki W et al, AJNR Am J Neuroradiol, 2015)

- Can lead to negative social interactions with friends, family, and healthcare providers

American Pain Society

RESEARCH
EDUCATION
TREATMENT
ADVOCACY

PUBLISHED BY ELSEVIER

The Journal of Pain, Vol 13, No 12 (December), 2012: pp 1198-1205
Available online at www.jpain.org and www.sciencedirect.com

We Discount the Pain of Others When Pain Has No Medical Explanation

Lies De Ruddere,[*] Liesbet Goubert,[*] Tine Vervoort,[*] Kenneth Martin Prkachin,[†] and Geert Crombez[*]

[*] *Department of Experimental-Clinical and Health Psychology, Ghent University, Ghent, Belgium.*
[†] *Department of Psychology, University of Northern British Columbia, Prince George, British Columbia, Canada.*

IASP

PAIN® 154 (2013) 669–676

PAIN®

www.elsevier.com/locate/pain

Discounting pain in the absence of medical evidence is explained by negative evaluation of the patient

Lies De Ruddere[a,*], Liesbet Goubert[a], Michaël Stevens[b], Amanda C. de C. Williams[c], Geert Crombez[a]

[a] *Department of Experimental-Clinical and Health Psychology, Ghent University, Ghent, Belgium*
[b] *Department of Experimental Psychology, Ghent University, Ghent, Belgium*
[c] *Research Department of Clinical, Educational and Health Psychology, University College London, London, UK*

American Pain Society

RESEARCH
EDUCATION
TREATMENT
ADVOCACY

PUBLISHED BY ELSEVIER

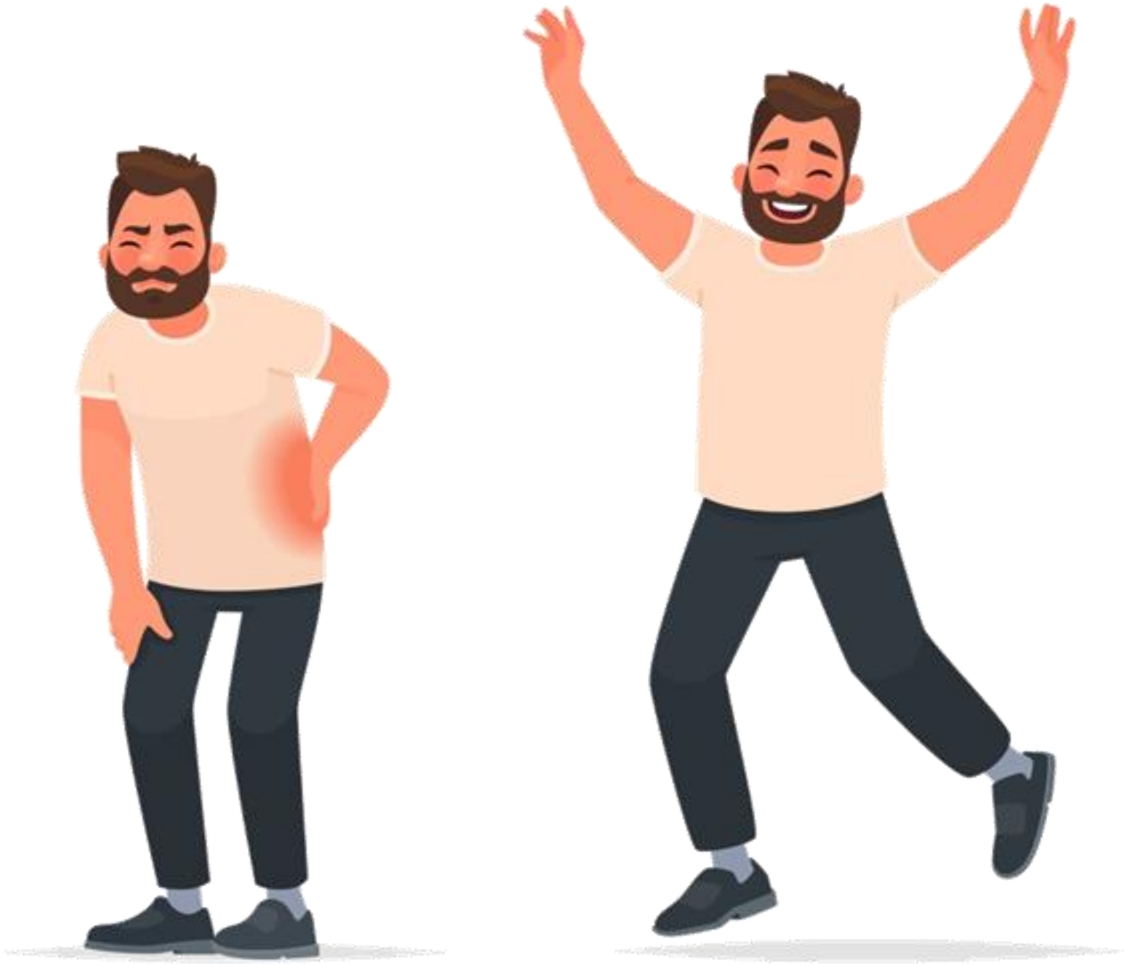
The Journal of Pain, Vol 17, No 9 (September), 2016: pp 1028-1035
Available online at www.jpain.org and www.sciencedirect.com

Patients Are Socially Excluded When Their Pain Has No Medical Explanation

CrossMark

Lies De Ruddere, Martinus Bosmans, Geert Crombez, and Liesbet Goubert
Department of Experimental-Clinical and Health Psychology, Ghent University, Ghent, Belgium.

Does this look like chronic low back pain?



Polling Question:

What topics are you most interested in exploring in future HEAL Connections sharing sessions?

- Crafting impactful, policy-focused communications
- Understanding the theory of dissemination
- Producing plain-language materials
- Building your research elevator pitch
- Engaging patients in research design, delivery, and dissemination

The Next Step: Join Us for Office Hours

A Deeper Exploration of our Sharing Session topic with HEAL Connections

ABOUT OFFICE HOURS

- Consult with your peers and our in-house team of communications experts, receiving input specific to your research project
- Incorporate the inclusive imagery and language best practices we shared today into your specific dissemination efforts

REGISTER TODAY!

http://bit.ly/InclusiveLanguageOfficeHours

TOPIC

Inclusive Language, Imagery, and Storytelling for Addiction and Pain Research Teams

Burel Goodin
Professor of Anesthesiology
Washington University
School of Medicine

Jess Hulsey
CEO and Founder
Addiction Policy Forum

Colin Miller
Community Liaison
UNC Street Drug
Analysis Lab

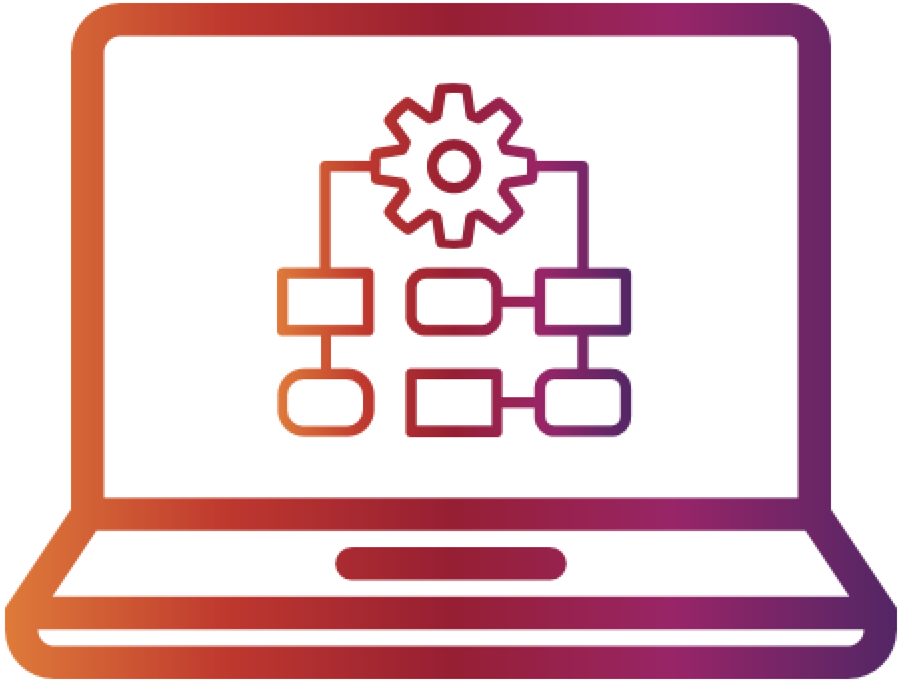
Kerry Stenke
Graphic Designer
Duke Clinical
Research Institute

MONDAY, SEPTEMBER 18
12:00 P.M. ET to 1:00 P.M. ET

NIH HEAL INITIATIVE | CONNECTIONS
Partnering to Accelerate Research into Action

Stay tuned for post-event follow-up emails with:

- Registration for Office Hours
- HEAL Connections Sharing Session webpage featuring recommended resources
- Evaluation survey



Meeting Evaluation

To help design, contribute to, and improve our programming, please complete the evaluation survey at **bit.ly/HCSharingSession3Eval**

Appendix

Additional Slides from Janelle Letzen’s presentation

How is engagement currently used in HEAL?

Most common areas of engagement:
Participant recruitment and retention, outreach materials

Least common areas of engagement:
Study concept/aims/design and dissemination of results

Funding sources:
40% said costs for engagement are covered either in full or part from NIH grants

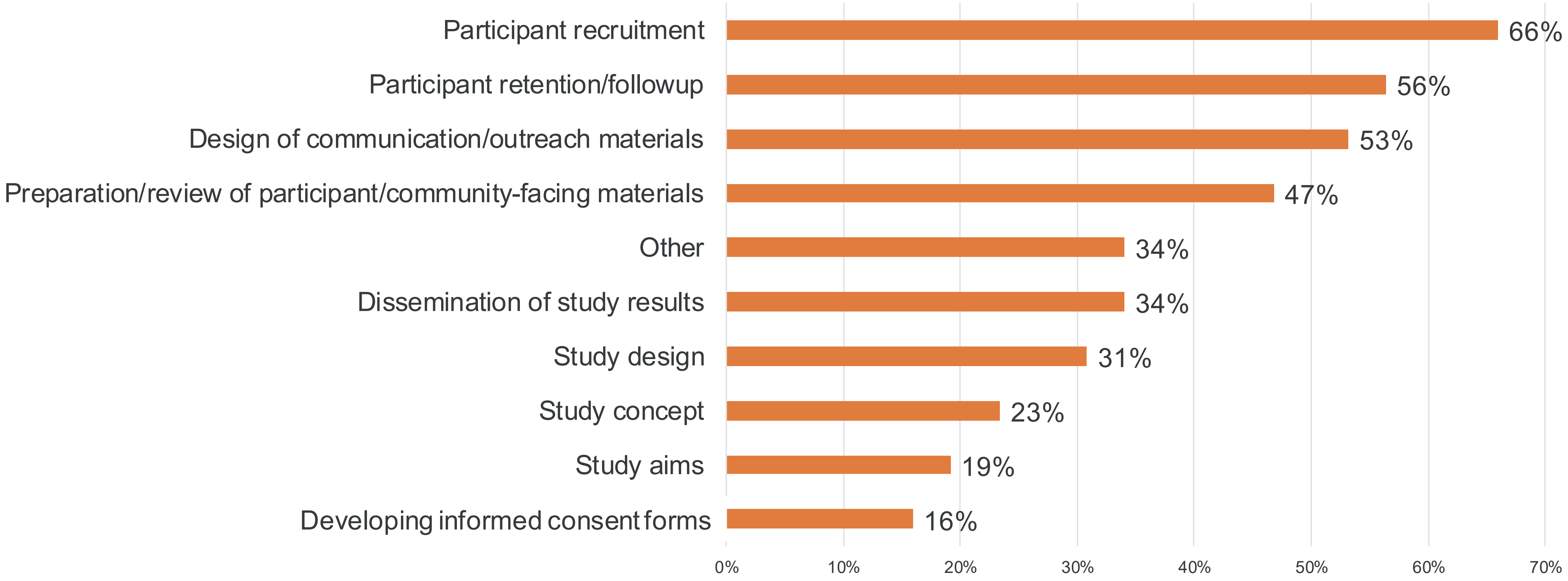
Reasons for lack of engagement:
Studies with no or very few human participants

How do researchers find partners?
- Community organizations
- Past research participants
- Hospital/university community advisory panels

When/how are partners engaged?
- As needed vs. regular basis
- Individuals vs. group

Common challenges:
- Retention of marginalized populations
  - Takes time to re-build trust
- Developing sustained partnerships
- Funding

How is engagement currently used in HEAL?



How is engagement currently used in HEAL?

- **Planning for engagement:**
  - Start early in the research process
  - Hire adequate staff to manage the workload associated with engagement
  - Institutions need to play a bigger role
  - Guidance on engagement is needed

- **Effective engagement is most likely when:**
  - It is treated as a core step in the research process
  - Feedback from people with lived experience is integrated at every level
  - Institutions provide investment and support

HEAL's engagement resources:
https://heal.nih.gov/resources/engagement

Additional Slides from Soumitri Sil’s presentation

Cultural Adaptations

Surface

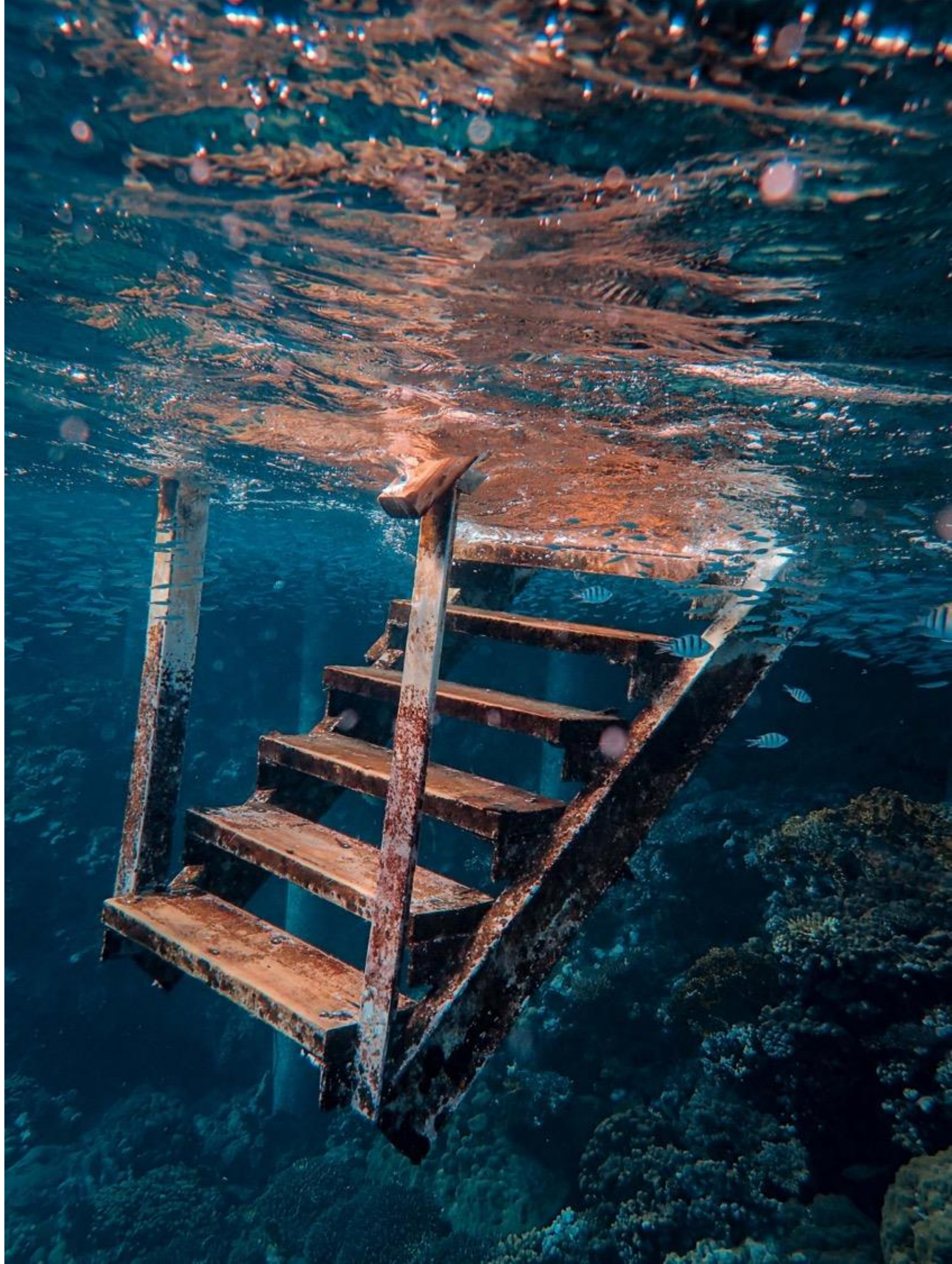
Language, pictures, reading level

Deep

Cultural values, norms, traditions, history

Beliefs about illness, treatment, stigma, bias

Resnicow et al, 1999; Chu & Leino, 2017



Cultural Adaptation (The How)

- Design and Adapt with Implementation in mind
- Focus on Reach from the beginning
- Take an Equity Lens
- Increase Satisfaction, Effectiveness, Sustainability of treatment

Baumann & Cabassa 2020; Cabassa & Baumann 2013; Glasgow et al 1999; 2001; Lyon et al 2014; Santisteban et al 2013

Stakeholder Partnership

Engage stakeholders to identify their unique needs related to pain condition

Inform intervention **adaptation**

- Clinically meaningful outcomes
- Address treatment barriers and facilitators
- Enhance feasibility, acceptability, and implementation

Advisory Board Meetings

Recruitment materials

Integrated relevant language and lived experiences

Partner and advise on treatment handouts, relevance, refinement, and engagement process

Clarify their treatment preferences.

RE-AIM	Parent and Adolescent Feedback
Reach	• Learn about program from **trusted medical staff**
Efficacy	• **Parents want to learn** coping skills • Children: School and social engagement • Teens: Preparing for “real-life”
Adoption	• Use **patient/family language** and testimonials
Implementation	• **Flexibility** in scheduling and treatment delivery • Colorful handouts with visual images • Use **relevant examples** common in SCD • All content may not be needed for every family
Maintenance	• **Support and social connection** with other patients/families with SCD

Cultural Adaptation

Support **equity** in healthcare

Enhance treatment **engagement** and **satisfaction**

Optimize **efficacy** of interventions

Partnership

Build trust with under-represented groups

Inform **patient-centered** assessments

Enhance **impact** and communication