Layers of Invisibility: Chronic Pain, Disability, and Aging Across Identities

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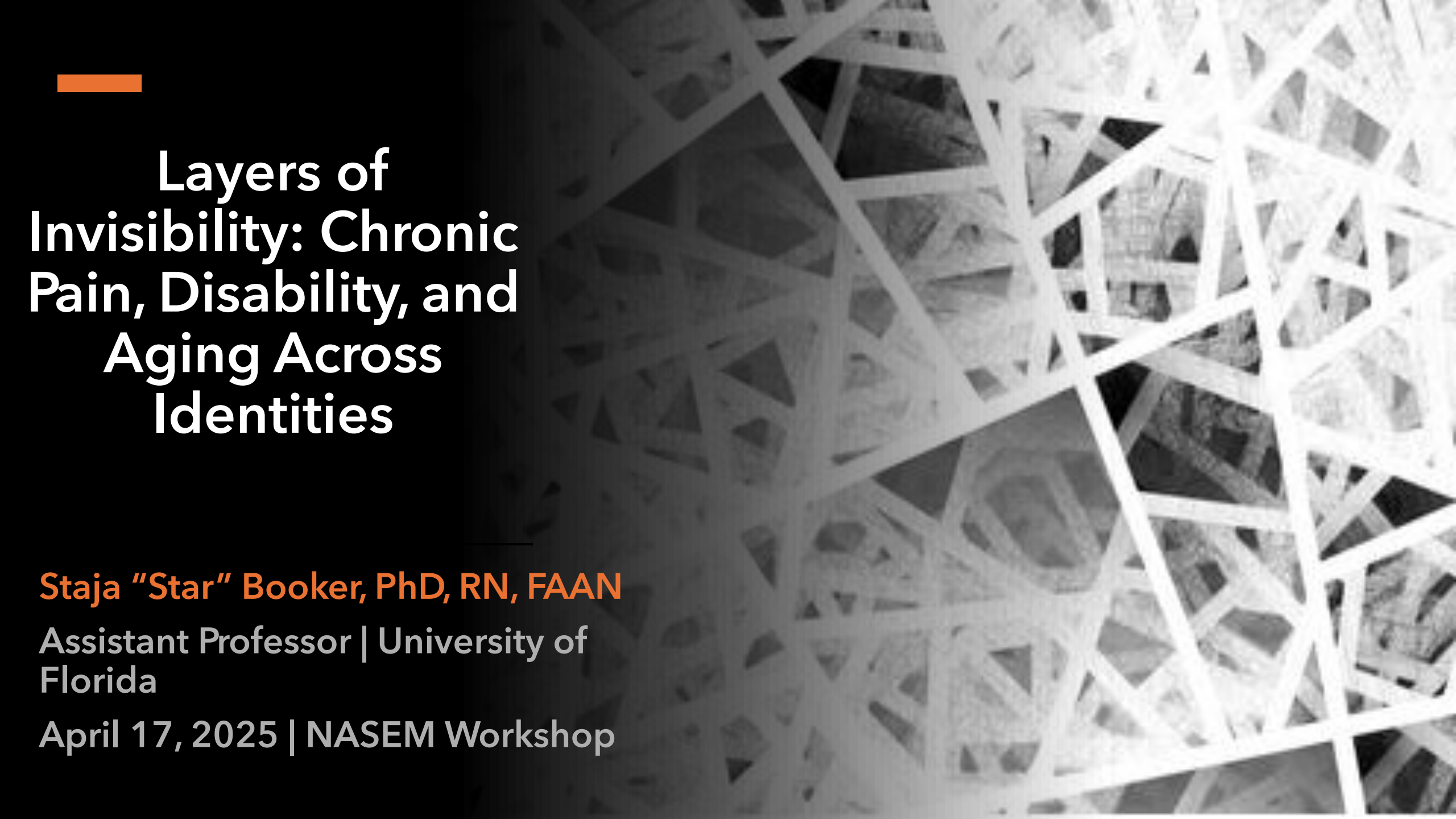


SCIENCE OF PAIN IN AGING

Experience of Chronic Pain (Osteoarthritis/MSK Conditions)

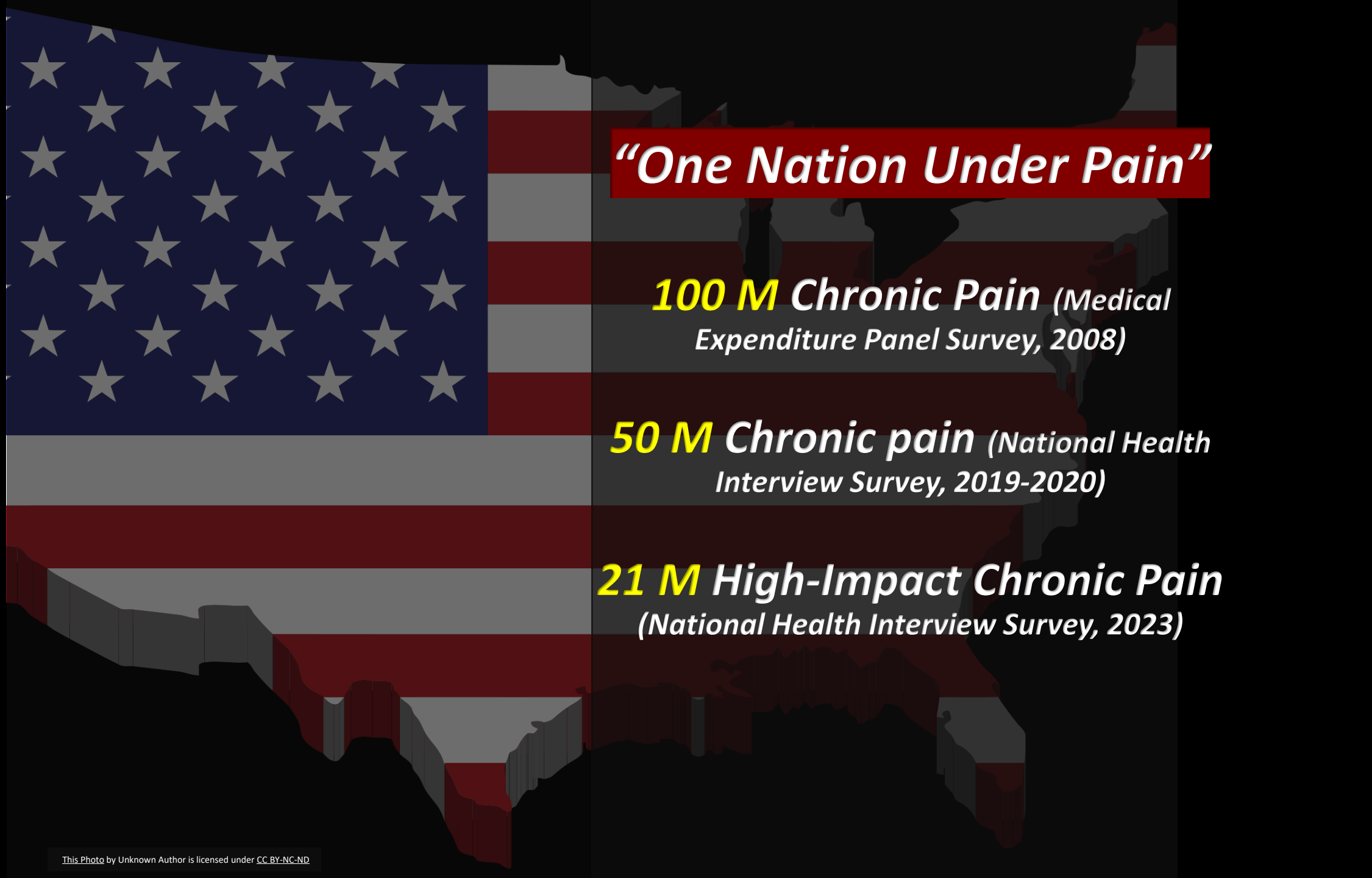
Models	Mechanisms	Measurement	Management
Lived Experience	Biopsychosocial Factors	Standards and Strategies	SM Differences and Preferences

Movement-Evoked Pain

Movement-evoked pain + Physical function limitations + Impaired mobility = DISABILITY TRINITY

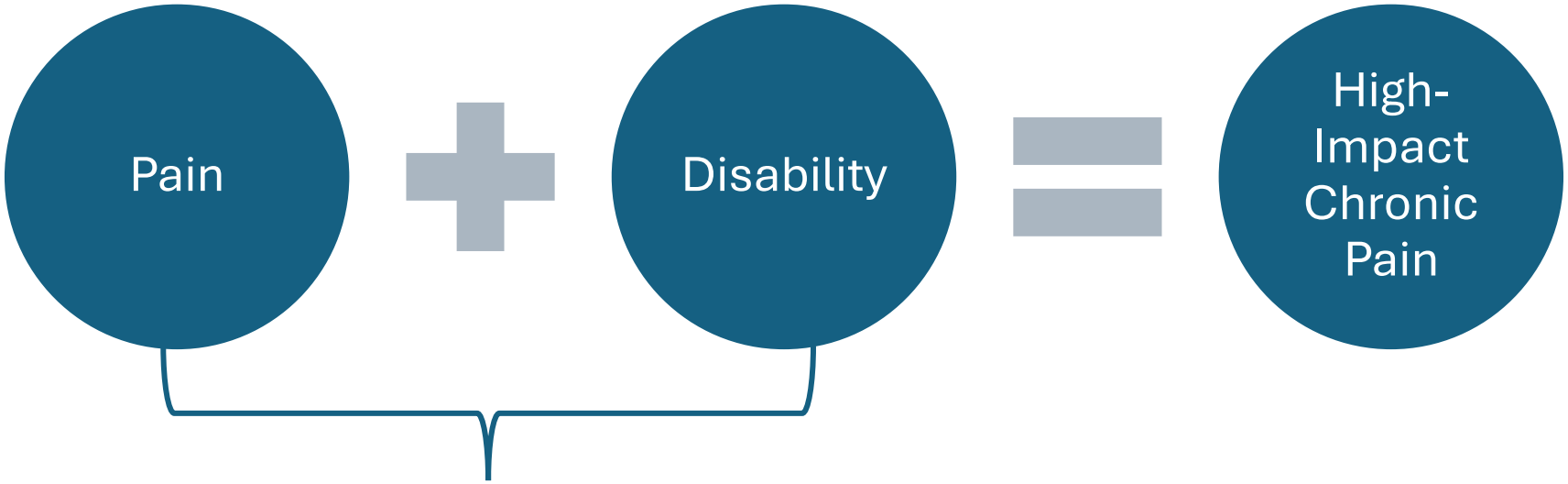
Food for Thought

- Chronic Pain as a singular syndrome >> **Multisystem Chronic Disease**
- Pain in Chronic Pain is not a sx >> **Disease State**
  - *Evaluating the intensity and persistence of your symptoms*
- Disability as the Outcome >> **Process (trajectory) of disablement**
  - Proactive approaches to determining people at high risk for disability; ICD-10 Chronic Pain Codes
- Other impacts: **cognition, contribution to frailty and mortality**
  - *Impact on daily activities and need for assistive devices*
  - *Medically equal*
- Management of chronic pain (diagnosis, treatments, etc.) >> **Timeliness of a disability determination is part of pain management**
  - *Medically determinable impairment*



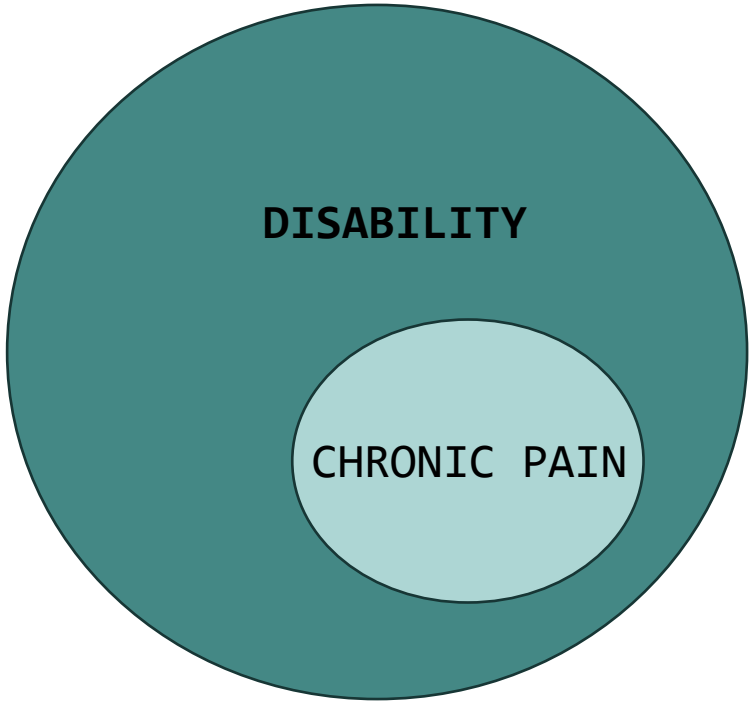
High-Impact Chronic Pain

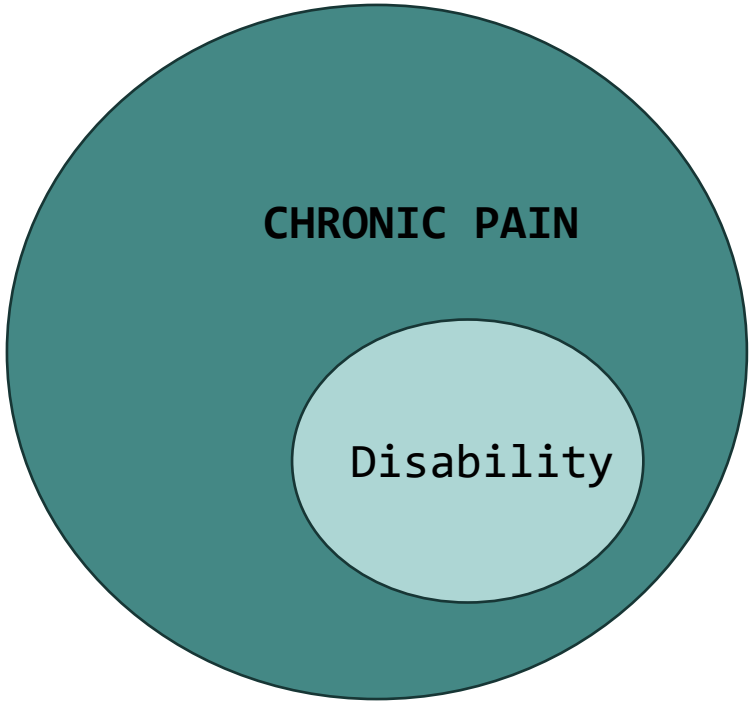
A type of chronic pain that significantly restricts a person's daily activities and ability to function



Pain-related disability refers to the limitation of daily activities due to chronic pain, even with treatment or medication, leading to a loss of capability in effectively integrating physical and/or psychosocial functions.

Current Perceptions of Pain x Disability





We expect older adults to be both disabled and in pain. Normalized pain in certain groups and invalidated pain in other groups.

PAIN

/pān/

An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.

INVISIBLE

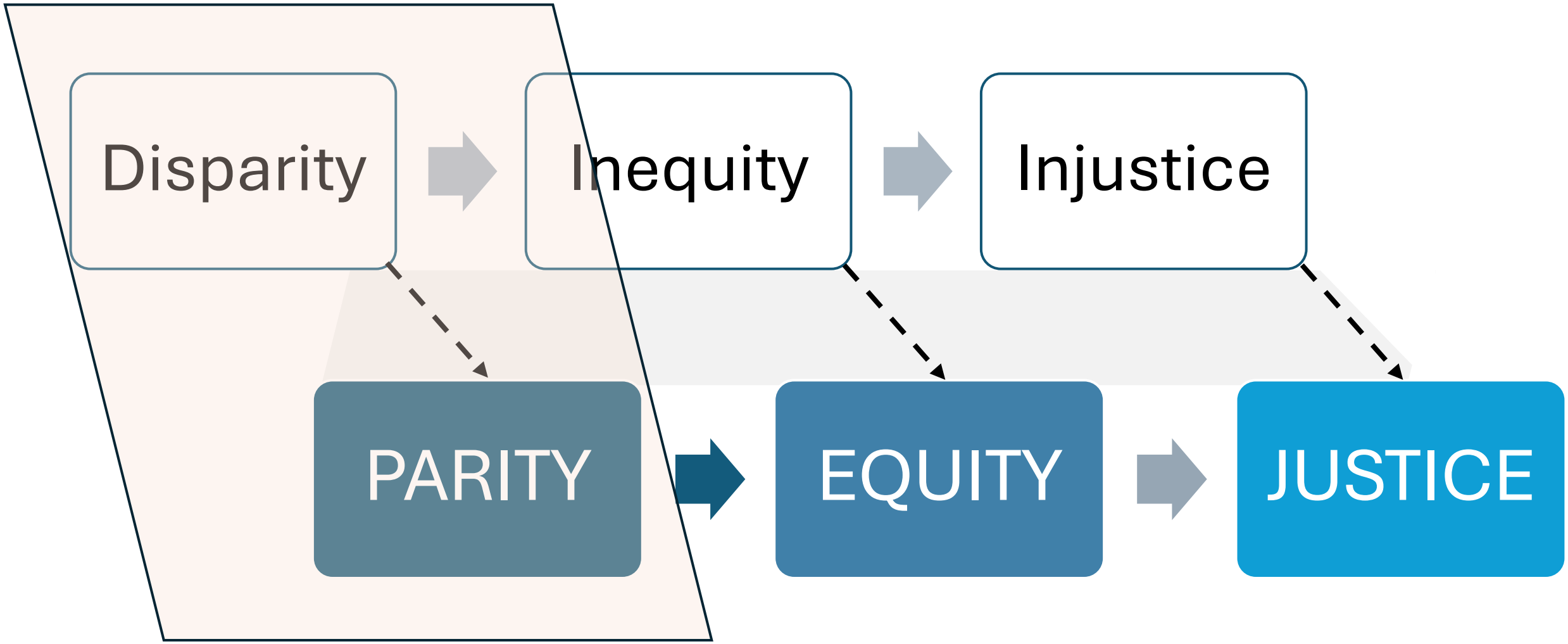
Universal

Inevitable

Variable

Incurable

DISABLING


Disparity
Inequity
Injustice
PARITY
EQUITY
JUSTICE

Social determinants happen at different "levels"

Major contributors to pain disparities

- Person living with pain
- People they interact with
- Where they get their care
- Where they live
- Policies and general beliefs in their broader society

Where pain interventions and research usually happen

Provider bias and/or lack of knowledge

Pain services only offered in certain neighborhoods/areas

UPSTREAM — DETERMINANTS OF HEALTH DISPARITIES

MIDSTREAM — DETERMINANTS OF HEALTHCARE EQUITY

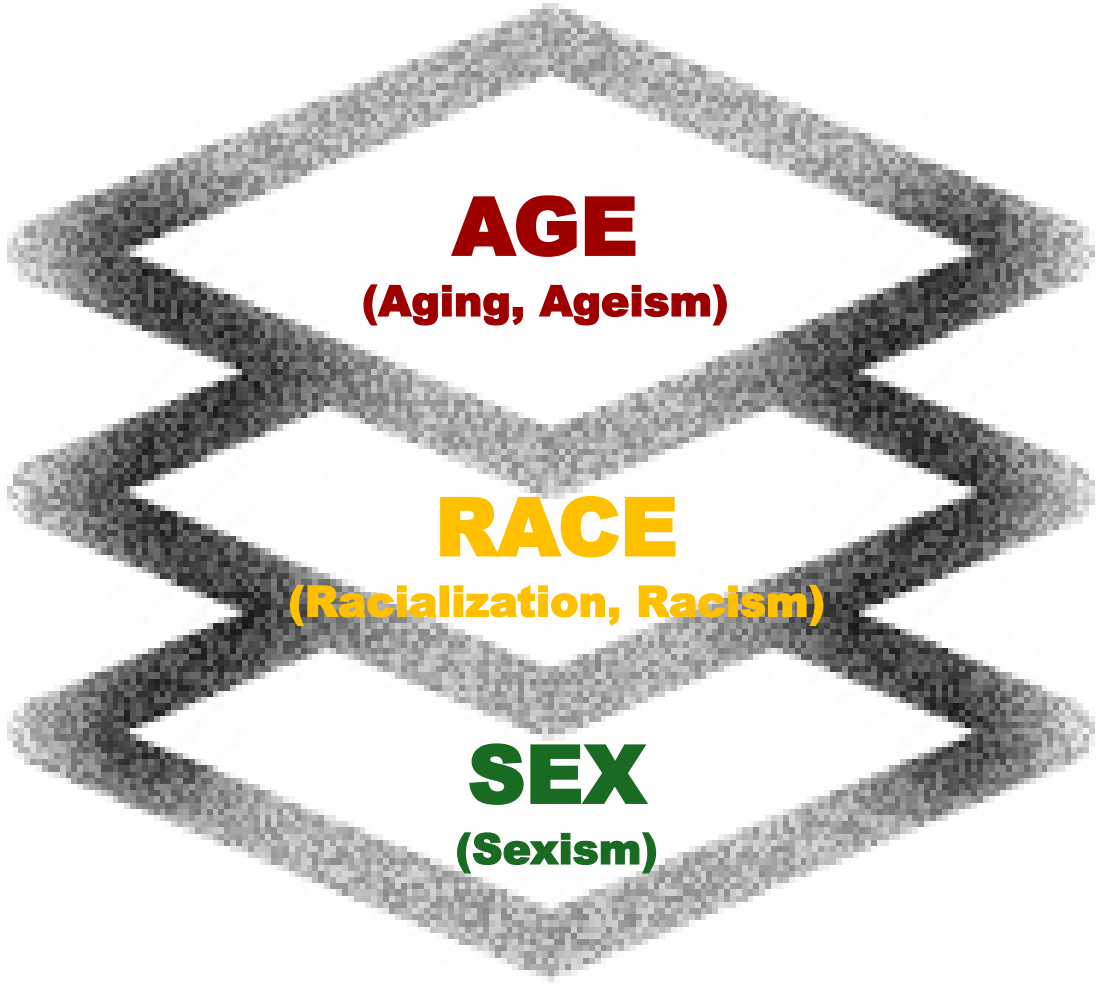
DOWNSTREAM — DETERMINANTS OF HEALTH OUTCOMES

Slide modified from NIH HEAL Initiative workshop. (March 12-13, 2024). *Advancing Health Equity in Pain Management: Community Engagement, Multi-level Interventions, & Research Collaborations.* Presented by Janelle Letzen, PhD and Cheryse Sankar, I

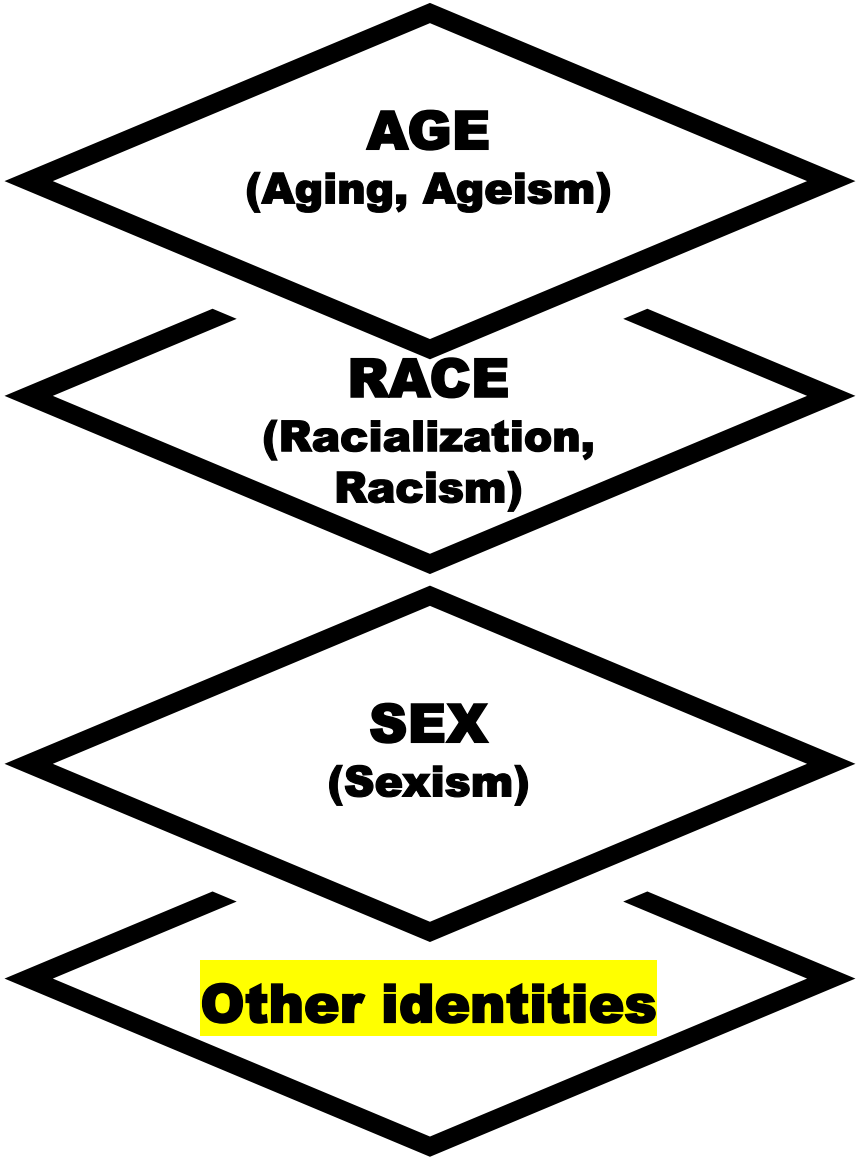
Intersectionality aka "Layers of Identity"

Disability and chronic diseases occur earlier in the life-course (age 45+) especially in the context OA.

- What happens when you experience bias in pain care due to these layers? How does that impact progression to disability and determination of disability?
- What happens when a system that wasn't designed for people on the "margins" have the same rules applied by that biased system?
- What happens when objective medical evidence is not available because of diagnostic biases?



Black Americans with Osteoarthritis



Visible: older age risk factor and predictor of chronic pain
Invisible: *signs and experiencing sx at earlier ages, such as 35/40 especially in people who identify as Black*

Visible: OA more severe
Invisible: *disabling or less painful in certain races*

Visible: women
Invisible: *women (of color) more likely to have pain dismissed and sx attributed to other causes*

Race/Ethnicity Moderates the Association Between Psychosocial Resilience and Movement-Evoked Pain in Knee Osteoarthritis

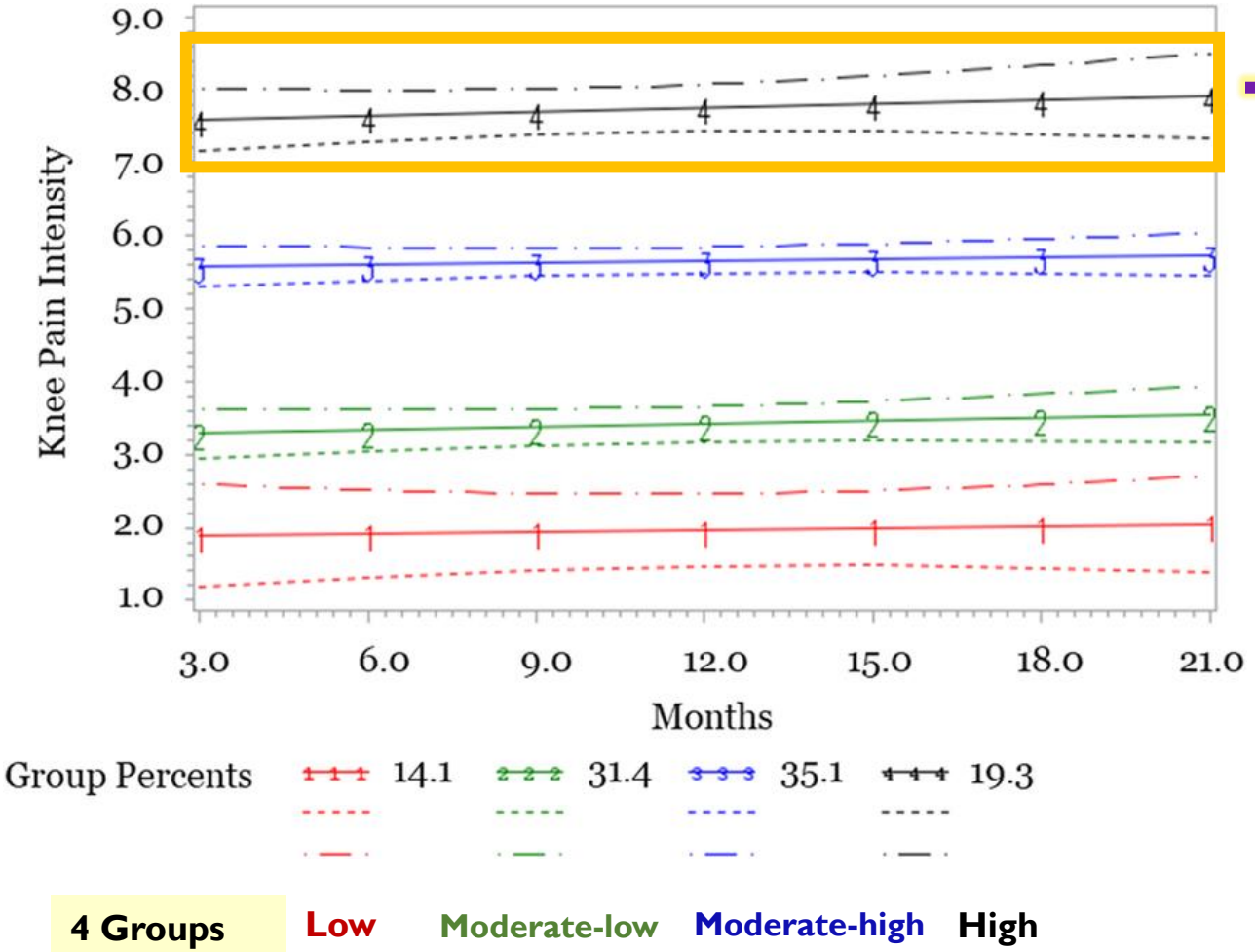
(Bartley et al., 2019)

Table 4. Descriptive and inferential statistics for measures of pain and function

	Unadjusted				Adjusted			
	NHB N = 105	NHW N = 96	Comparison		NHB N = 105	NHW N = 96	Comparison	
	M (SD)	M (SD)	F	η_p^2	M (SD)	M (SD)	F	η_p^2
GCPS pain (0-100)	66.6(20.3)	43.5(20.1)	61.77**	0.25	63.4(20.4)	47.1(20.1)	29.03**	0.14
GCPS disability (0-100)	57.0(27.7)	36.6(29.6)	23.99**	0.11	52.9(28.3)	40.5(29.6)	7.84**	0.04
SPPB function (0-12)	9.1(1.8)	9.7(1.5)	6.26*	0.03	9.2(1.8)	9.6(1.5)	1.85	0.01
SPPB pain (0-100)	29.6(29.2)	14.0(17.9)	19.08**	0.09	29.0(29.5)	16.2(18.0)	10.93**	0.06

Note. *$P < 0.05$, **$P < 0.01$. Adjusted models controlled for age, income, education, marital status, employment, body mass index, and study site. Abbreviation: NHB, non-Hispanic black; NHW, non-Hispanic white; GCPS, Graded Chronic Pain Scale; SPPB, Short Physical Performance Battery.

TRAJECTORIES OF KNEE PAIN



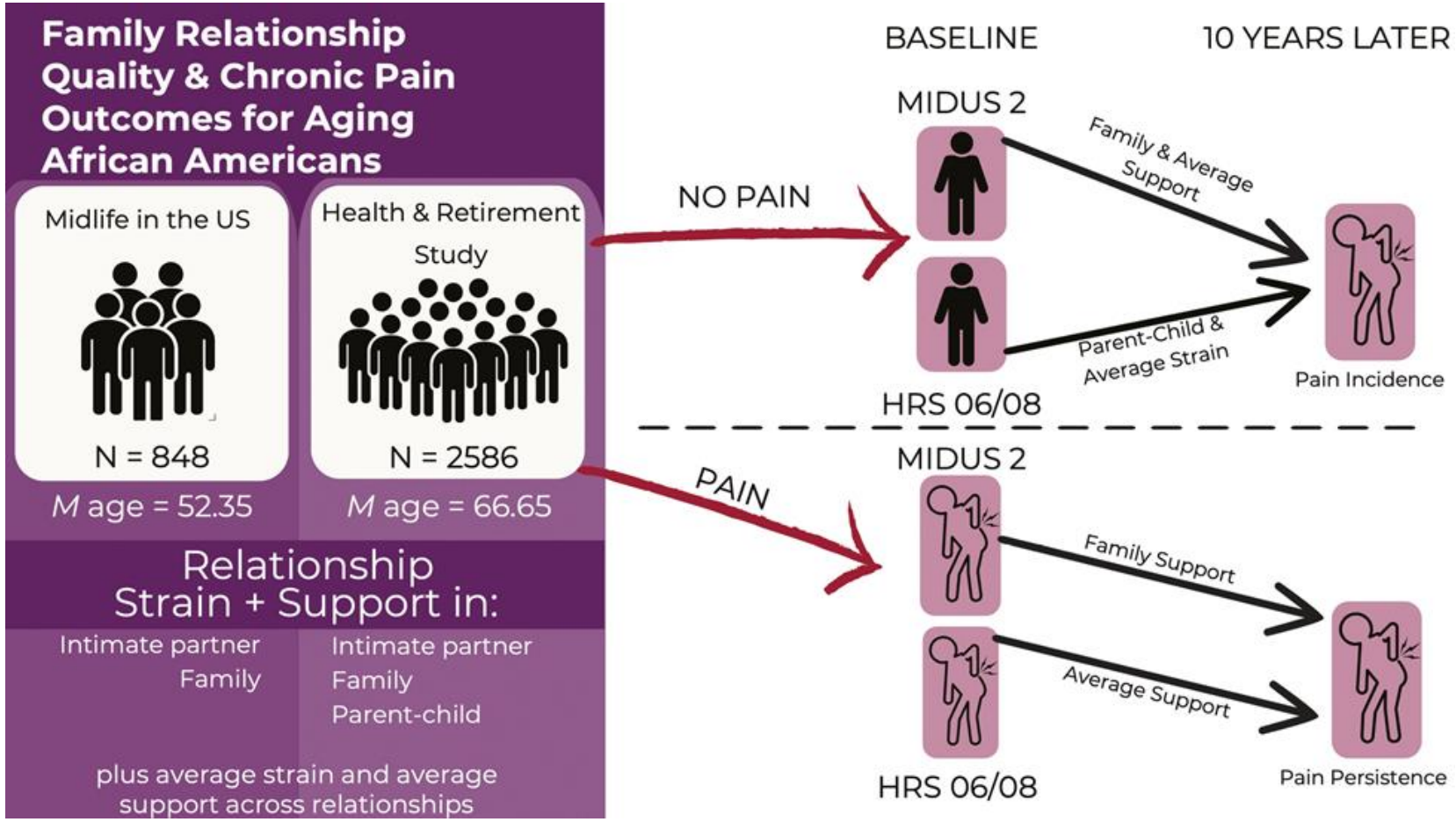
younger, less educated, lower income, and **non-Hispanic Black participants with OA had a greater representation in the highest pain trajectory group**.

Table 3 Sample Characteristics by Pain Trajectory Group

	Low (*n* = 22)	Moderate-Low (*n* = 57)	Moderate-High (*n* = 78)	High (*n* = 31)	p
Age, mean year ± SD	63.7 ± 7.0	59.3 ± 8.8	56.8 ± 6.5	54.3 ± 6.7	< 0.001
Gender, %					0.054
Female	72.7%	66.7%	52.6%	77.4%	
Male	27.3%	33.3%	47.45	22.6%	
Ethnicity/Race, %					< 0.001
Non-Hispanic Black	0%	40.4%	65.4%	74.2%	
Non-Hispanic White	100%	59.6%	34.6%	25.8%	

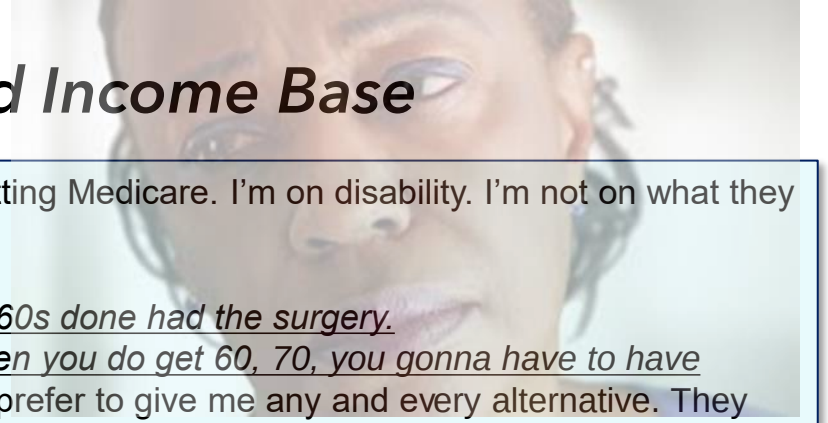
[Johnson, Vasilopoulos, Booker, et al., 2021]

TRAJECTORIES OF PAIN IN OLDER BLACKS AND IMPACT OF FAMILY SUPPORT OR STRAIN



Family relationships and support are important in understanding the development and chronicity of pain in Black older adults.

Jeanette's Experience: Intersection of Race, Place, and Income Base



See, like me. I'm actually drawin' disability. Basically my full disability almost. And that's how I ended up getting Medicare. I'm on disability. I'm not on what they call it SSI. The only way you get SSI is that you haven't worked the amount of years to earn disability.

See, I'm just 50. *They don't wanna give me surgery, because of my age, and I've seen people that in their 60s done had the surgery. ….He said, "Now when you get about 70, that's different." He said, "But at your age right now," he say, "when you do get 60, 70, you gonna have to have another one."* He said, "Because it's not a guarantee to it." I'm like, "Okay, then.' That's why they said they prefer to give me any and every alternative. They prefer to give me a kneescope once a year, every other year, instead of givin' me knee surgery.

Oh, **you just got arthritis here** and gave me some inflammatory pills and sent me
on out the door and said, '**No, you're too young for surgery**' ***…OH, YOU BE ALL RIGHT***…
I literally had to go in there the same way. **In tears.**
All that he did was took x-rays and, okay. Here. **Take these pain pills and go home.**
That's it. That's all they [doctors] do.

Now he [doctor] tried to get me gel. He tried to get me MRIs. He tried to get me knee braces. Medicaid wouldn't pay for nothin'. If you can't afford it, you just outta luck. They sent me information about the knee braces. I told 'em. I said, "I got Medicare. Don't start til September." "Oh, well. Call us back," and hang up the phone. Medicaid sure isn't gonna help you. [Laughter] I'm just being honest.

That's why we as Black people do not go to the doctor, because of the way they get treated when they go. EVEN IF IT'S IN THE EMERGENCY ROOMS, THEY LOOK AT YOU THE SAME WAY, cuz when I was sick with that pain up under my arm. *I went three times! Oh take some ibuprofen and go home.* ***THEY ACTUALLY THINK ONLY BLACK [PEOPLE] COME IN HERE FOR PAIN MEDICINE. They need to get outta that mentality****.*

Said, "Well, tell her to come into the walk-in clinic." I was like, "Well, I just be dang." [Laughter] Reason why I say that, ***there was this White lady come in****. This white family. Woman was—I don't even know if she had insurance or not.* ***OH, THEY GOT HER OFF. RUSHED HER OFF QUICK! SHOOT. I JUST NODDED MY HEAD. I SAID, "OKAY."*** And the other thing about it, if it depends on what kind of insurance you got. A lot of times if we do have insurance, like you said, it's not necessarily the right insurance, or we don't have insurance, whereas White people, they have Medicare plus somethin' else. But they had better resources as far as doctor-wise than we did. Just that, even to this day. Some of 'em still got better resources to doctors than we do. **Prejudice is still prejudice.** Prejudice to me is not [just] a color….If it was a choice [between] this Black man and this White man, White man more likely gonna go first before the Black man does, if your bank account don't look right or your insurance. That's why you see a lot of us goin' through it worser than you do the Whites. (Booker et al., 2021)

Pain Affirming Care (PAC)

(Booker & Okolie, 2024)

- Prognosis
- Timeliness of disability determination
- Timeliness of workers’ compensation

“Effective pain management is a moral imperative, a professional responsibility, and the duty of people in the healing professions”

[National Academy of Sciences, Engineering, and Medicine (Formerly Institute of Medicine) 2010, Box S-1].

Human Right

Civil Right

Patient’s Right

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UF

Faculty Enhancement Opportunity

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Thank You!