



“How do you define Resilience?”

Examining the Psychological Resilience of Black Adults Living with Sickle Cell Disease (SCD)

¹Corinne April Conn, MPH, ²Melissa Creary PhD, ³Vence L. Bonham, J.D.

¹ University of California San Francisco School of Medicine ² University of Michigan ³Social and Behavioral Research Branch, National Human Genome Research Institute, National Institutes of Health

Background

- Sickle cell disease (SCD) is caused by a single point mutation in the sixth codon of the β -globin gene, resulting in abnormal hemoglobin β -globin subunits. The mutation produces red blood cells that are sickle-shaped and impaired in their function.¹
- Resilience research attempts to better understand its effects and its potential to improve patient health outcomes, particularly in chronic disease.²
- Adults with SCD in the U.S. develop their resilience in relation to their chronic genetic condition contextualized by multiple stigmatized identities.³
- A recent literature review of the term “psychological resilience” revealed the discrepancies in terminology and the limited ability to compare research results in this field.⁴
- Validated measures of resilience have not been used to study an adult population living with SCD
- **Research Question:** Examine the psychological resilience of adults living with SCD through a mixed methodological approach

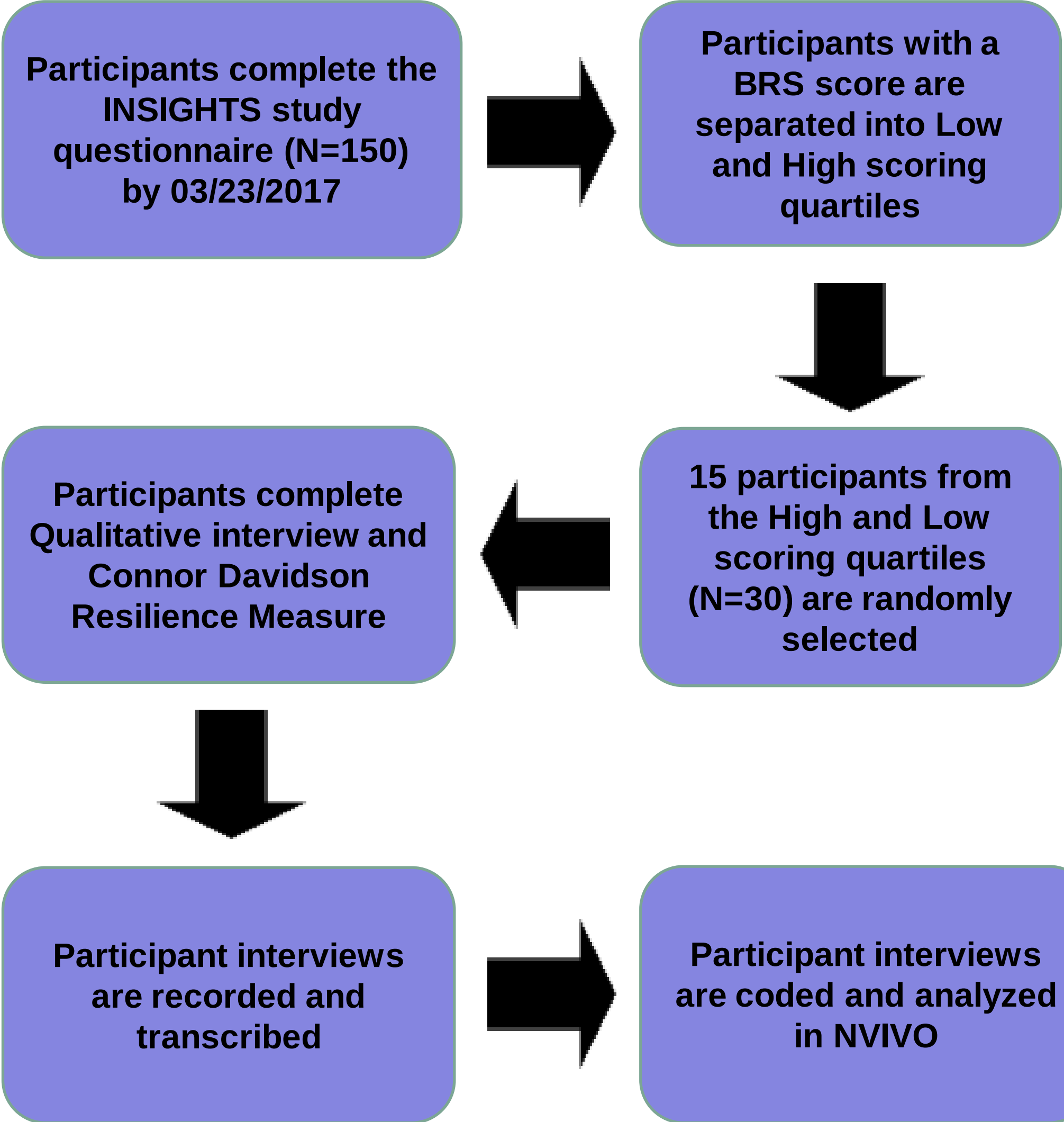
- The Brief Resilience Scale (BRS) is made up of six statements, three of which focus on a temporal component being important to one's resilience. It defines resilience as “the ability to bounce back after stress”⁵

References

¹ Kato, G.J., et al., *Sickle cell disease*. Nature Reviews Disease Primers, 2018. 4: p. 18010.
² Campion, J., et al., *European Psychiatric Association (EPA) guidance on prevention of mental disorders*. Eur Psychiatry, 2012. 27(2): p. 68-80.
³ Creary, M. (2021). Bounded Justice and the Limits of Health Equity. *Journal of Law, Medicine & Ethics*, 49(2), 241-256. doi:10.1017/jme.2021.34
⁴ Sisto A, Vicinanza F, Campanozzi LL, Ricci G, Tartaglioni D, Tambone V. Towards a Transversal Definition of Psychological Resilience: A Literature Review. *Medicina (Kaunas)*. 2019 Nov 16;55(11):745. doi: 10.3390/medicina55110745. PMID: 31744109; PMCID: PMC6915594.
⁵ Smith BW, Dalen J, Wiggins K, Tooley E, Christopher P, Bernard J. The brief resilience scale: assessing the ability to bounce back. *Int J Behav Med*. 2008;15(3):194-200. doi: 10.1080/10705500802222972. PMID: 18696313.
⁶ Ehrich J, Mornane A, Power T. Psychometric Validation of the 10-item Connor-Davidson Resilience Scale. *J Appl Meas*. 2017;18(2):122-136. PMID: 28961149.



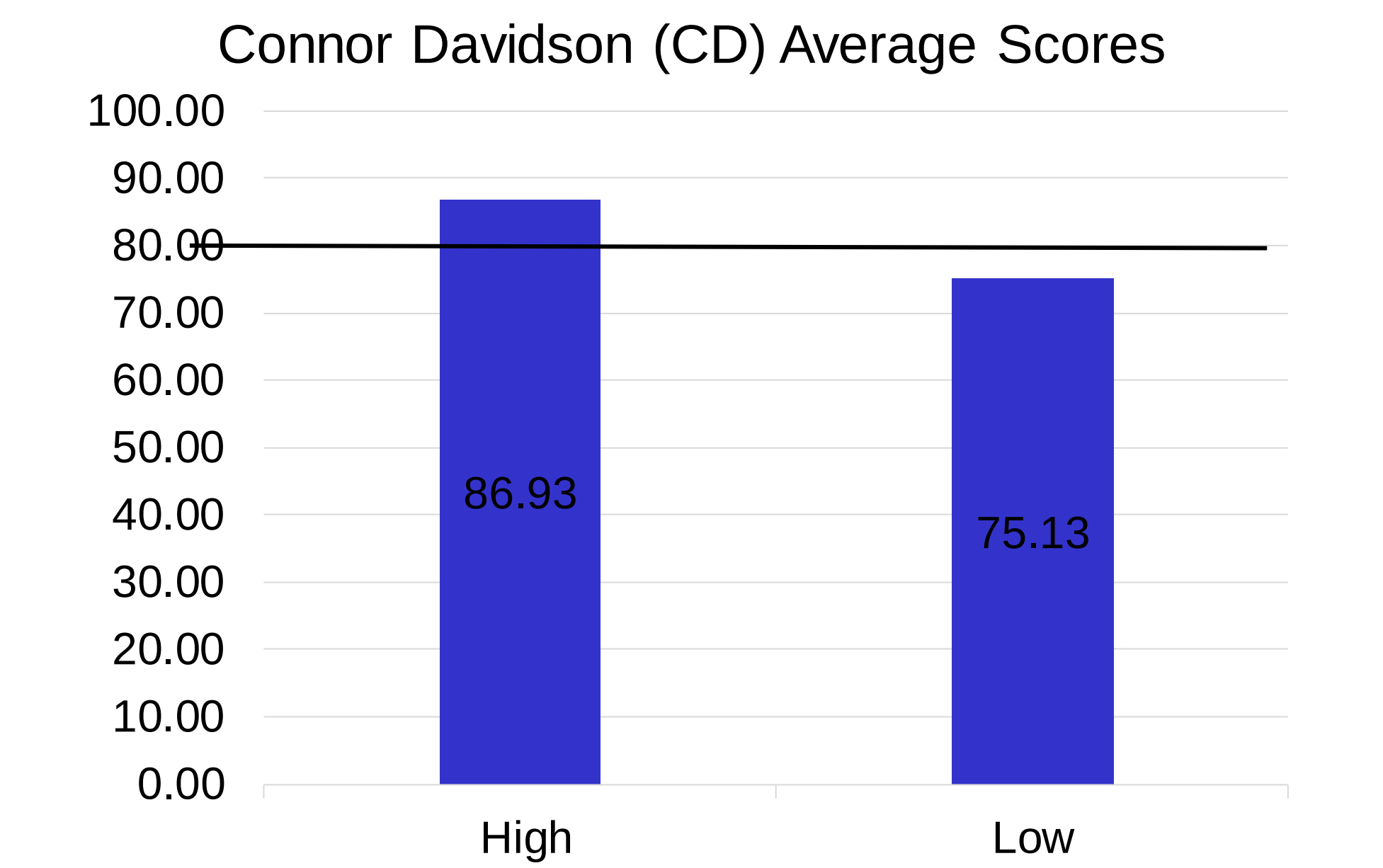
Methodology



Demographics

Demographic	Low BRS Group, N=15	High BRS Group, N=15
Sex: Female	9	8
Average Age	39	46
Hispanic or Latino	2	1
SCD Type: HbSS	14	13

Resilience Measure Results



Health Disparities Unit

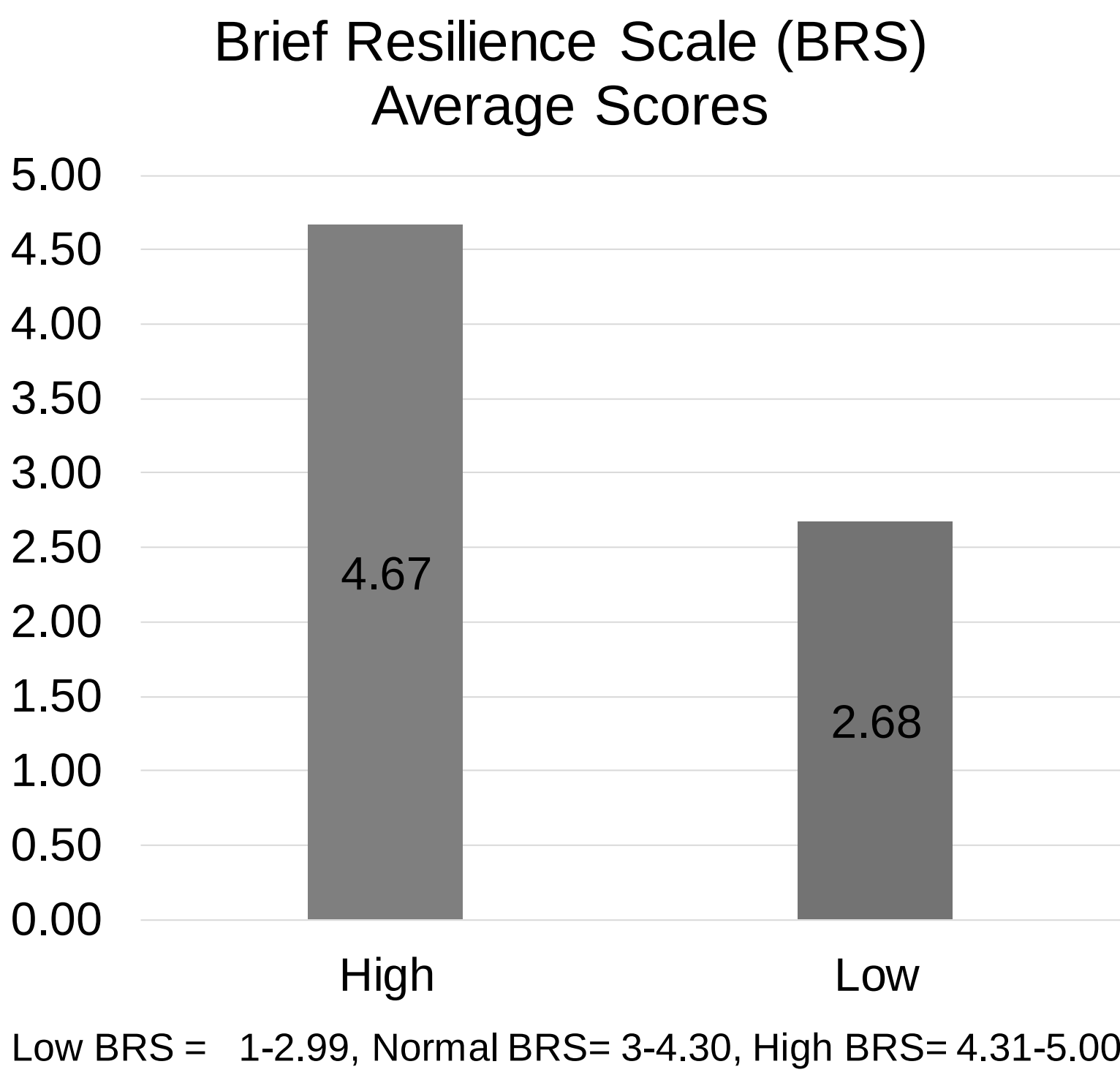


Figure 1 & 2 . Bar graph presenting average scores for both the BRS and CD measures for the Low and High BRS groups. The High BRS scoring group scored above the mean CD score for the US general population (80), while the Low BRS scoring group scored above the mean score for Primary care patients, Psychiatric outpatients, and patients with Generalized Anxiety.⁶

*CD scale range is 0-100, BRS scale range is 0-5

Qualitative Results: “How do you define Resilience?”

Theme 1: “Not Giving Up”

Resilience is just **basically not giving up...** Everybody goes through ups and downs. Just never giving up, even when it looks as though there's literally nothing that you can do to fix the situation or make it better. – *High BRS*

“Not giving up” means that an individual continues to *try* for themselves when confronted with stress or a pain crises

I understand resilience as -- I consider it the same as **perseverance**. It's the ability to be fearless in -- to an extent -- and not really know it. I think that that is -- it's fearlessness without the awareness of being fearless. – *Low BRS*

Theme 2: “Moving Forward”

I feel like your resilience is your bounce-back. **Sometimes, you get kicked down and it takes a little longer. Sometimes, the hurt hurts a little longer, and you stay down a little longer. But you must get back up.** – *High BRS*

“Moving Forward” means that an individual understands that they will return, eventually, to a more positive state of being than they currently find themselves

Even though I'm down, **I'm keeping a frame or keeping a structure to move on or to carry on to find that light at the end** or to get out of that darkness that I'm in, to grow into something. – *Low BRS*

Theme 3: “How one Deals”

For me, resilience is if I will go about dealing with day to day problems.. It's **how you handle the issues. How you stop fighting. How you make it better.**– *High BRS*

“How one deals” means that an individual focuses on the *process* used to manage stress or pain

I define resilience as -- to me it's **how will you deal with pains and struggles; how will you cope with the storms.**– *Low BRS*

Discussion

- All 30 participants consider themselves to be resilience individuals
- Scores from the CD show this cohort to be as resilient as the general U.S. population
- Resilience is described as a dynamic process sub-divided into three themes:
 1. **Not giving up** = also conceptualized as persevering, not quitting, being unstoppable
 2. **Moving forward** = conceptualized as individuals returning to a more positive state of being, finding the light, or bringing themselves “up after being down”
 3. **How one deals** = also conceptualized as the manner that one endures, and that individuals choose to cope to lessen stress or pain

Next Steps

- Further research needed to assess whether BRS, CD, or other resiliency scales are associated with measures of SCD severity or quality of life
- There is utility in developing a new psychological assessment tool for this population utilizing definitions shared by our participants as mental health resources can be directed to fostering resilience
- Resilience research conducted in communities with genetic diseases should consider a longitudinal mixed methodological approach