

THE STIGMA OF MIGRAINE

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DISCLOSURE INFORMATION

CONSULTANT/SPEAKER

- Allergan – MINDs Advisory Board (11/2019 – 12/2020)
- Biohaven
 - Advisory Board (01/2020 – 12/2020);
 - Speakers Bureau (07/2019 – 07/2020)
- Eli Lilly and Company – Advisory Board (01/2020 – 12/2020)
- Teva – Advisory Board (01/2020 – 01/2021)
- Theranica – Consultant (01/2019 – 12/2019)

OTHER

- Past President for the Alliance for Headache Disorders Advocacy (AHDA)
- Advising Physician for the Coalition for Headache and Migraine Patients (CHAMP)
- President for Miles for Migraine

RESEARCH

- Amgen 08/2015 - present
- Cumberland 06/2011 - present
- Eli Lilly 10/2016 - present
- Novartis 07/2016 - present
- PCORI 03/2017 - present
- Satsuma 09/2020 - present
- Scion 01/2017 - present
- Teva 01/2017 - present
- Zosano 01/2018 - present

HOW DOES MIGRAINE RANK IN THE WORLD?

Disability (YLD)

1. Low back pain
2. Migraine
3. Age related hearing loss

**MIGRAINE IS
#2**

9. Neck pain
10. Falls
11. COPD
12. Endo/metab/blood/immune
13. Other gynecological
14. Schizophrenia
15. Ischemic stroke

Impact (Death+YLD)

1. Ischemic heart disease
2. Lower respiratory infection
3. Diarrheal diseases

**MIGRAINE IS
#14**

9. Ischemic stroke
10. Neonatal encephalopathy
11. Malaria
12. Lung cancer
13. Drug susceptible TB
14. Migraine
15. Other musculoskeletal

A CONVERSATION DRIVES IT HOME

A respected colleague said to me –

“I’m glad you do headache. I don’t like treating those patients”

BLAMING = STIGMA

“Stigma is an established construct in the social sciences that describes an attribute, trait or disorder that is deeply discrediting and may elicit some form of community sanction. “

Goffman E. Stigma: notes on the management of spoiled identity. New York: Simon and Schuster, 1963:

A WAY TO LOOK AT STIGMA

**PUBLIC
STIGMA**

**STRUCTURAL
STIGMA**

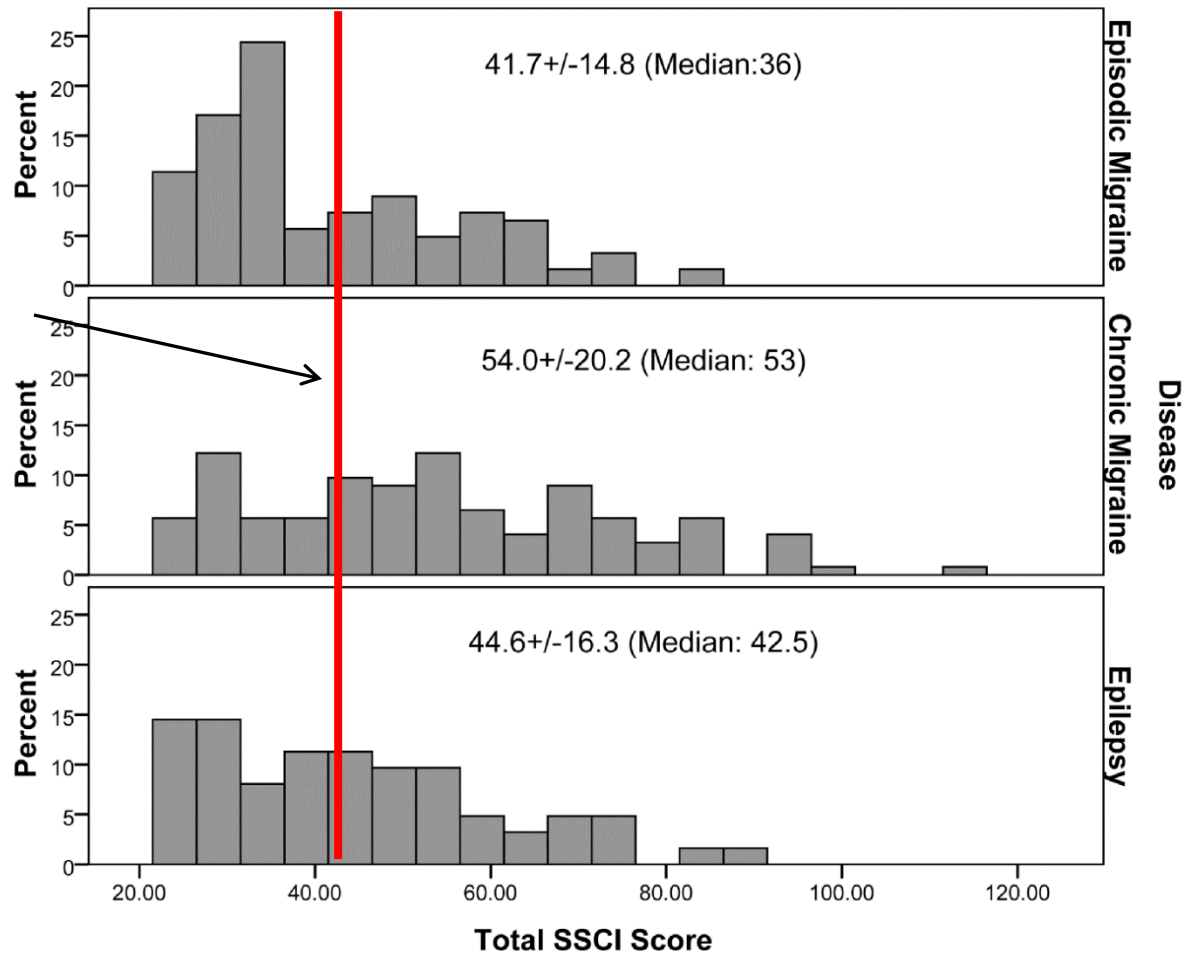


Self stigma process

**SELF
STIGMA**

I STUDIED STIGMA IN MY PATIENTS

Mean, panel of diverse neurological diseases



Young WB, Park JE, Tian IX, Kempner J (2013) The Stigma of Migraine. PLoS ONE 8(1)

RESULTS

- **Stigma: CM > EM or Ep**
 - Ability to work ↔ stigma
 - Ability to work was worse form CM than Em or Ep
- **Physical component score ↔ stigma**
- **Mental component score ↔ stigma**
 - But is this the result of the stigma?
- **Regression model**
 - Chronic migraine and Epilepsy equally stigmatized
 - Episodic migraine less so

WHAT CORRELATES WITH BEING A STIGMATIZER (MOST TO LEAST)

MALE

NON-WHITE

YOUNGER

NOT DIAGNOSED WITH MIGRAINE

FEAR OF PAIN

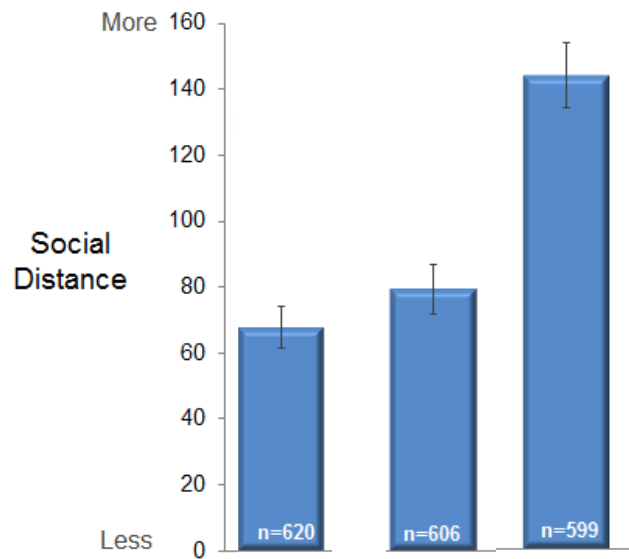
NOT EXPRESSING EMPATHY

REDUCED FEAR OF MIGRAINE

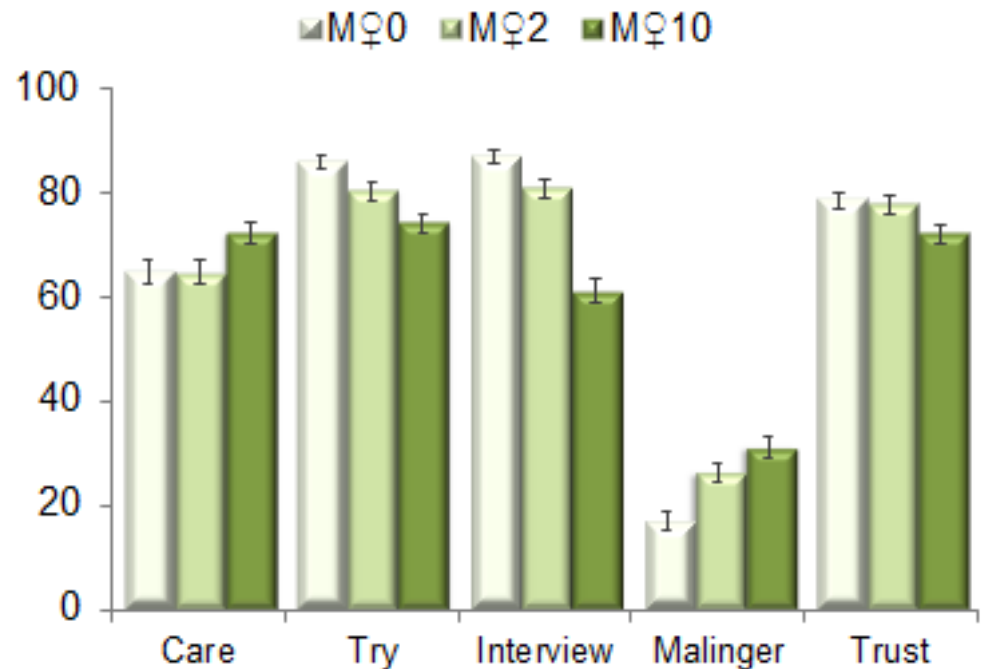
LOWER INCOME

Shapiro, et al Headache 2019

MIGRAINE STIGMA: VARIES BY WORKPLACE RELIABILITY



Condition	M	M	M
Gender	♀	♀	♀
Workdays lost	0	2	10



Shapiro, R.E., et. Al. J Headache and Pain 2014;15(Suppl 1):E36.

OVERCOME SURVEY

BELIEFS OF PERSONS WITHOUT MIGRAINE

- **1/3: easily treated or due to a person's unhealthy behavior**
- **3/10: use migraine disease to gain attention or get out of their commitments**
- **Those who know multiple people with migraine tend to hold more negative attitudes towards people with the disease**
 - **may be explained by family, friend, and coworker burden and impact felt by people without migraine**

STIGMA IN OUR LANGUAGE

HOW TO FIX IT

SAY THIS	DON'T SAY THIS
Disease, Condition (sometimes)	Illness, Disorder, Condition (mostly)
Migraine	Migraines
Migraine	Migraine headache
Person with migraine	Migraineur
Person with migraine	Migraine sufferer
Person with migraine	Migraine personality, migraine-type person
Rebound headache or medication adaptation headache	Medication overuse headache

Young WB et al. Naming migraine and those who have it. *Headache*. 2012;(52(2):283-291.

Coalition For Headache and Migraine Patients (CHAMP). Headache & Migraine Disease Language & Image Guide 2018/19; CHAMP website. Published November 2018. Accessed February 27, 2019.

**STIGMA HAS
CONSEQUENCES**

Migraine Claimants Scorecard: Initial Allowance and Participation Rates

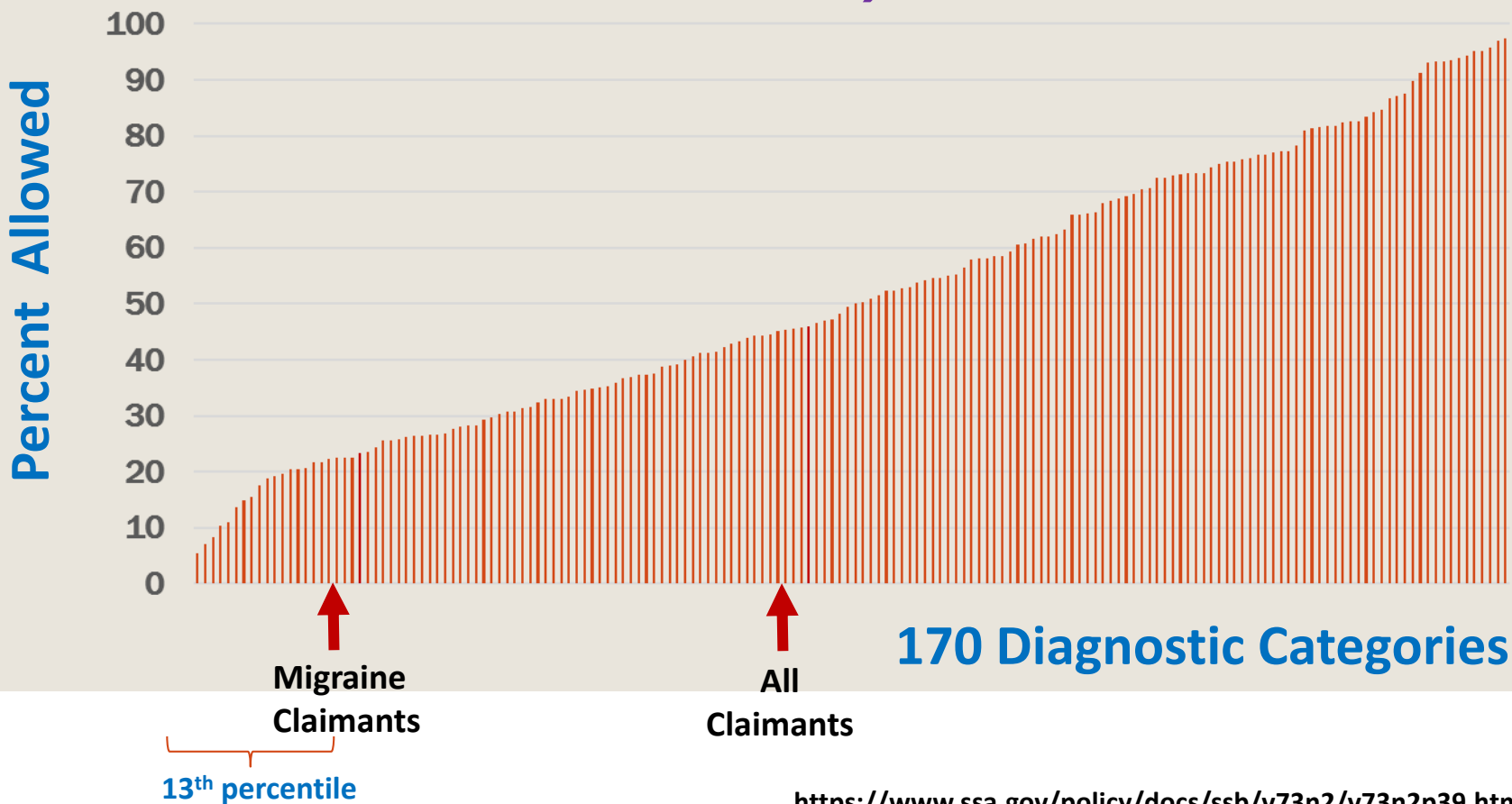
	Initial Allowance Rate (SSDI, 1997-2004) Workers 18 - 65 years	Initial Allowance Rate (SSDI / SSI, 2009)	Percent of All SSDI Claimants (1997-2004)	Percent of US YLDs (2000)
Migraine Claimants	23%	17%	0.3%	5.57%
All Claimants	46%	38%	18.6 fold disparity	

<https://www.ssa.gov/policy/docs/ssb/v73n2/v73n2p39.html#tableA1>
<https://www.ssa.gov/policy/docs/workingpapers/wp113.html>
<https://vizhub.healthdata.org/gbd-compare/>

STRUCTURAL STIGMA

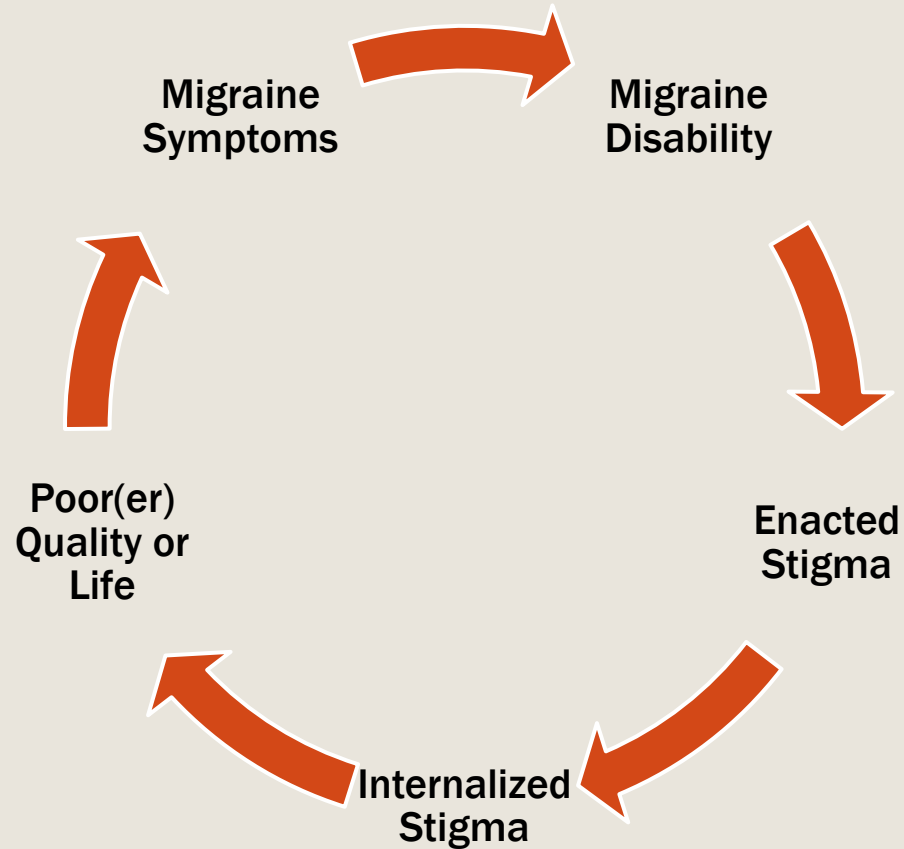
STRUCTURAL STIGMA

SSDI INITIAL ALLOWANCE RATES (1997-2004)



<https://www.ssa.gov/policy/docs/ssb/v73n2/v73n2p39.html#tableA1>

STIGMA WORSENS PAIN



Rao, D et al Qual Life Res (2009) 18:585–595

Discrimination hurts: The effect of discrimination on the development of chronic pain *Social Science & Medicine* 204 (2018) 1–8 Brown, T et al

MY LEARNINGS FROM THE SHUT THE DOOR ON MIGRAINE STIGMA SYMPOSIUM

- Number one: Disclosure
- Empathy should be nurtured
- Disability is key
- “Brain Disease” will fail
- New frames can harm
- Framing must be studied
- Patients have to lead
- Actions are needed for
 - Structural Stigma
 - Interpersonal (enacted) stigma
 - Internalized stigma



