

Identification of gaps in care for patients with chronic pain through the establishment of a state-wide pain registry in Maine - PainRegistryforME

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Disclosure



The presenters have nothing to disclose with regard to commercial relationships.

Learning objectives



1. Explain why chronic pain is a public health problem in Maine.
2. Describe the co-morbidities associated with chronic pain in Mainers.
3. Identify factors within social determinants of health (SDOH) that may affect Mainers' pain experience.
4. Discuss major challenges for Mainers to receive adequate pain care and potential interventions.

Outline

- Background
- Study design – PainRegistryforME
- Results
- Summary
- Acknowledgements



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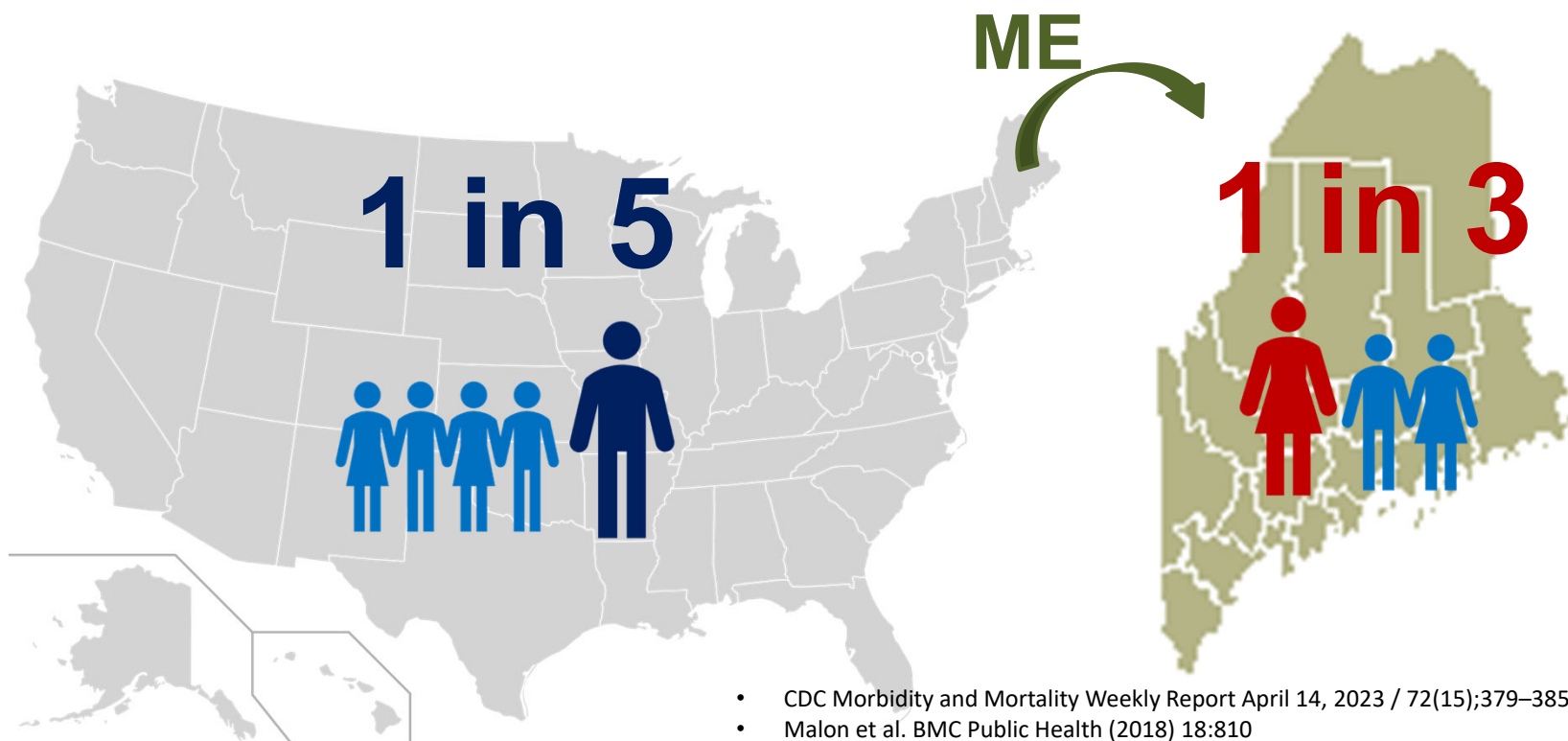
Chronic pain is a public health concern in the US and in **Maine**



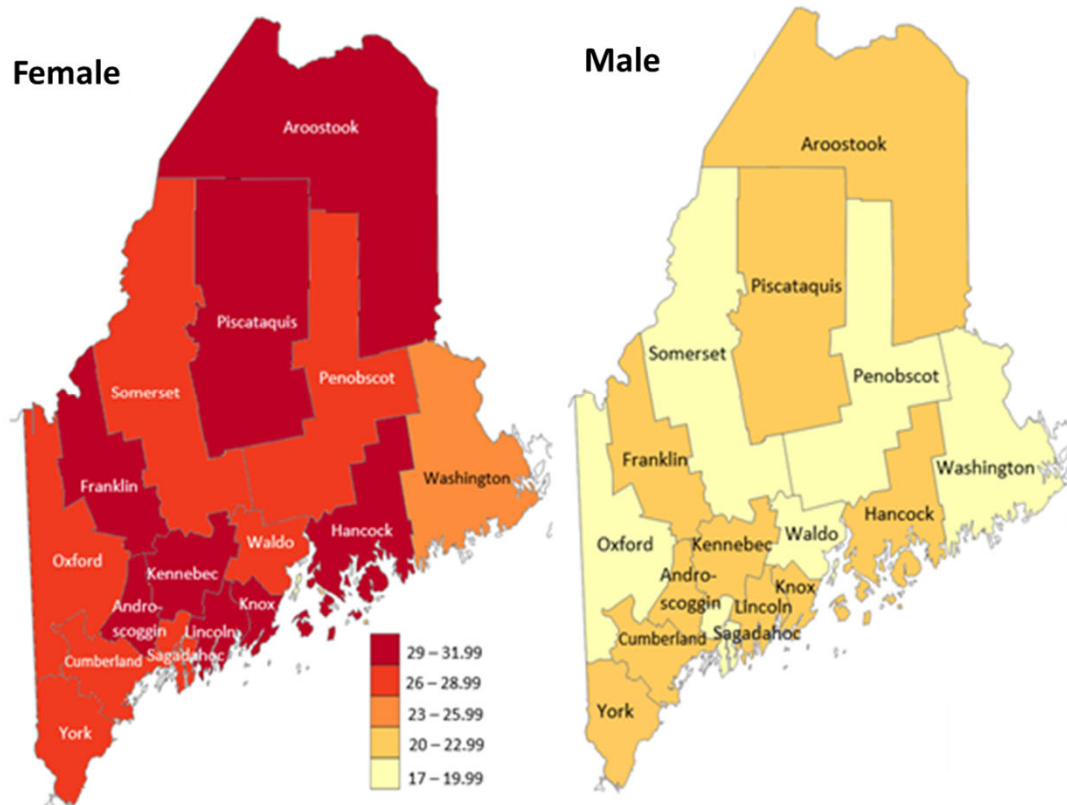
\$600 BILLION
**CHRONIC
PAIN**

**Heart Disease
Diabetes
Cancer**

Institute of Medicine 2011. <https://doi.org/10.17226/13172>.



- CDC Morbidity and Mortality Weekly Report April 14, 2023 / 72(15);379–385
- Malon et al. BMC Public Health (2018) 18:810
- Modified from <https://pngimg.com/image/46482> and <https://digital.newberry.org/ahcb/pages/Maine.html>



The burden of chronic pain is significantly **higher in females** at all age groups (>10 years old) and across all counties.

Malon et al. BMC Public Health (2018) 18:810

Multiple factors contribute to chronic pain, a **bio-psycho-social** condition

Biologically female
Advanced age
Non-Hispanic or Latino
Veteran

Lower income
unemployment
Lower education level
Non-metropolitan living



Depression
Anxiety
Catastrophizing
Adverse childhood experiences

Smoking
Inadequate nutrition
Lack of physical activity

- <https://extension.usu.edu/heart/research/exercise-and-chronic-pain>
- https://wwwn.cdc.gov/NHISDataQueryTool/SHS_adult/index.html
- Mills et al. British J. of Anaesthesia. (2019) 123(2):e273-e283
- Karran et al. Pain. (2020) 161(11):2476-2493

Mainers face more challenges of chronic pain

Ranks **first** for:
% of persons ≥ 65 years
% of White alone

Veteran: 7.2%
Poverty: 10.8%
No health insurance: 8.4%
Disability (in <65 years): 11.5%

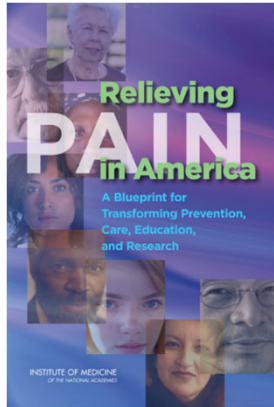


Rural state
Lack of public transportation

Lack of providers that
specialize in pain management
or are racially and culturally
diverse

- <https://www.census.gov/quickfacts>
- <https://www.aamc.org/media/58216/download>
- Modified from <https://digital.newberry.org/ahcb/pages/Maine.html>

Actions...



- **LACK** of consistent data on pain
- **EMPHASES** on POPULATION RESEARCH and increased capacity to gather pain-related information
- **NEEDS** for establishing national registries, databases & research networks
- **NO** pain registry in Maine



Institute of Medicine 2011. <https://doi.org/10.17226/13172>
<https://www.iprcc.nih.gov/node/5/national-pain-strategy-report>

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PainRegistryforME

1. Instrument: **Anonymous survey** administered via REDCap
2. Participants: **Adults** (≥ 18 years) who suffer from **persistent or recurrent pain** and live in Maine for all or part of the year
3. Recruitment: **Flyer** with survey link and QR code

Survey Link:



Email: PainRegistryforME@une.edu

Web link: <https://www.une.edu/research/center-pain-research/maine-pain-registry>

PainRegistryforME

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VOLUNTEERS NEEDED!

Do you or does someone you know suffer from PAIN? If so, you may be able to contribute to a research project that seeks to establish a state-wide pain registry in Maine. We are currently looking for people who suffer from pain who are willing to fill out a survey.



TOPARTICIPATE OR FMI

Scan the QR code or go to
[redacted]
to access the survey.

Potential participants can also email to Dr. Ling Cao,
PainRegistryforME@une.edu FMI.

You are eligible for this research project, if you:

- are at least 18 years old;
- are a Maine resident or currently living in Maine;
- suffer from persistent or recurrent pain, with or without an official diagnosis of chronic pain. (Persistent or recurrent pain is pain experienced most of the days or everyday)

You will be asked about the following

- Basic information about yourself;
- Your pain and its impact on your life;
- How your pain is managed;
- Your economic status, education, food security, physical environment.
- The study will also ask your permission to contact you to complete these surveys again in the future.

The first 500 respondents of the Pain Registry are eligible to receive a \$25 gift card after completing the survey for the first time. After that, participants may enter a gift card drawing.

This project has been approved by the Institutional Review Board (IRB) at both MaineHealth and University of New England.



MaineHealth



INNOVATION FOR A HEALTHIER PLANET

PainRegistryforME



4. Survey questions:
 - 1) Basic demographics
 - 2) Pain characteristics
 - 3) Pain management
 - 4) Social determinants of health - *Manchanda, Rishi and Gottlieb, Laura (2015). Upstream Risks Screening Tool and Guide V2.6.*
5. Data analysis: Interim analysis with **first 100 participants**

PainRegistryforME - Pain Characteristics

PROMIS (NIH PROMIS-29+2 Profile/Battery v2.1 (PROPr; total: 31 questions)

- ✓ Physical function (4)
- ✓ Anxiety (4)
- ✓ Depression (4)
- ✓ Fatigue (4)
- ✓ Sleep disturbance (4)
- ✓ Ability to participate in activities (4)
- ✓ Pain interference (4)
- ✓ Cognitive function (2)
- ✓ Rate pain on scale of 0-10 (1)

Hypothesis

Social determinants of health (such as racial/ethnicity groups, education, income, housing environment, etc.) significantly affect the **characteristics of pain** (such as daily functions and psychological conditions) and its **management** (such as opioid usage, and types of and access to primary providers).



MaineHealth



NIGMS [U54GM115516 (PI, Rosen)]

Outline

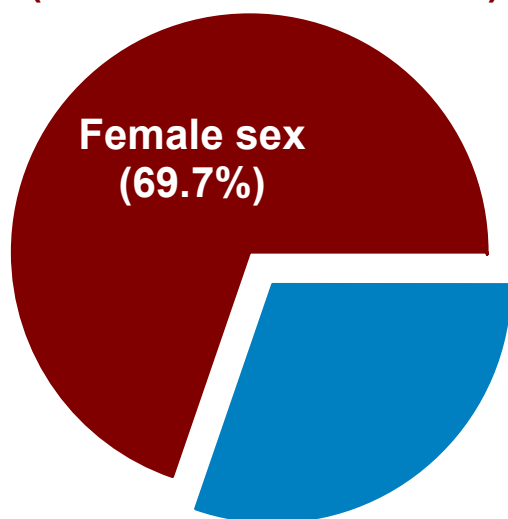
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Results - Demographics

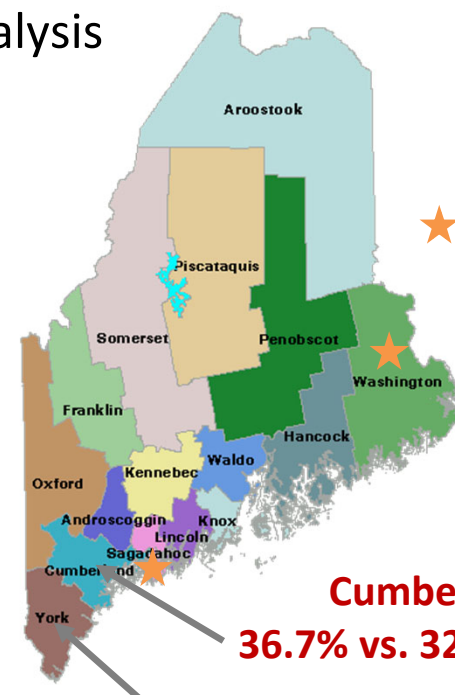
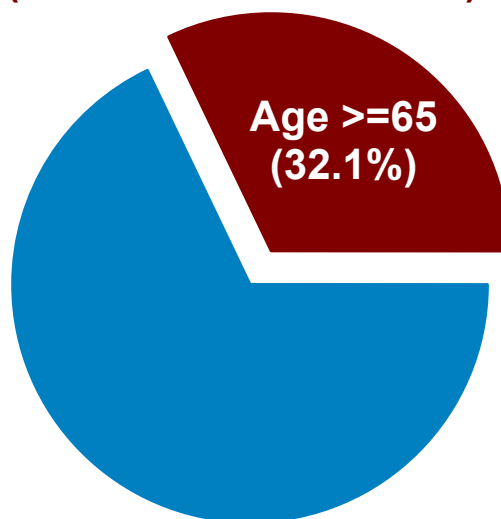
Data from 109 participants are eligible for the interim analysis

Female sex
(69.7% vs. 50.7% in ME)



<https://www.maine.gov/sos/kids/about/maps>

Age >=65
(32.1% vs. 22.5% in ME)



★ No respondents
Sagadahoc
Washington

Cumberland
36.7% vs. 32.1% in ME

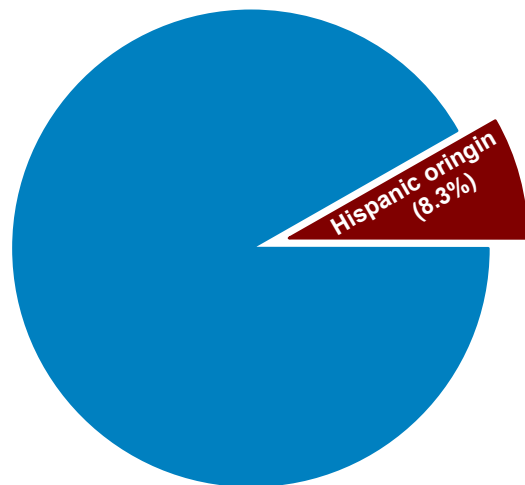
York 22.2% vs. 15.7% in ME

Results - Demographics

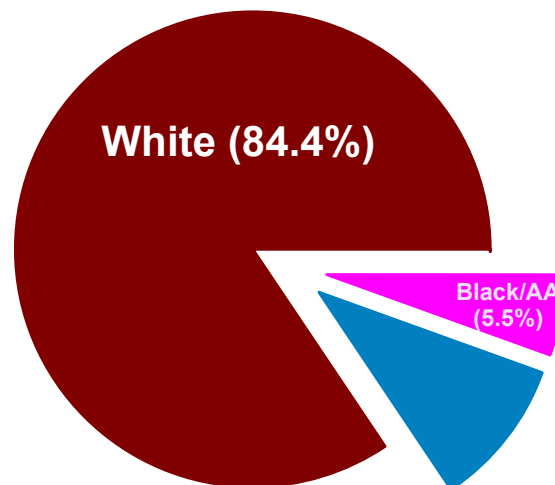
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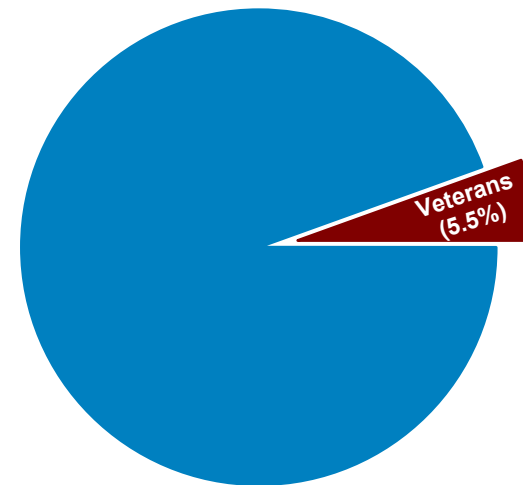
Hispanic oringin
(8.3% vs. 2.0% in ME)



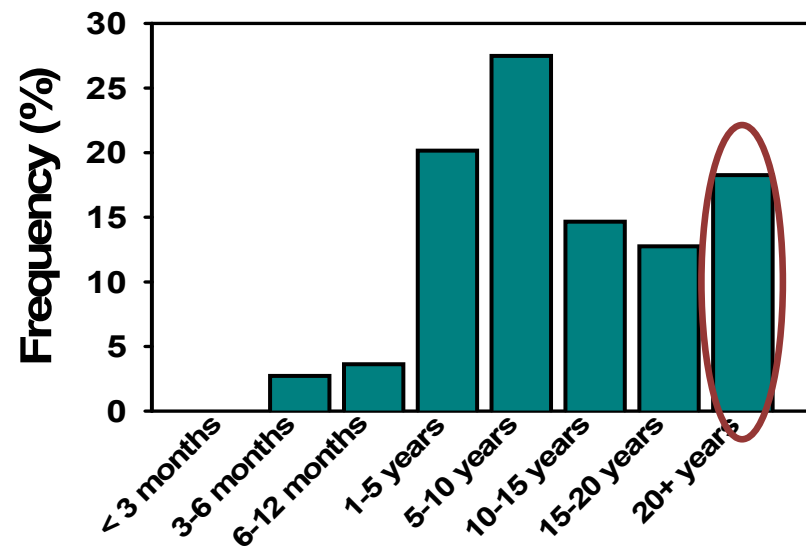
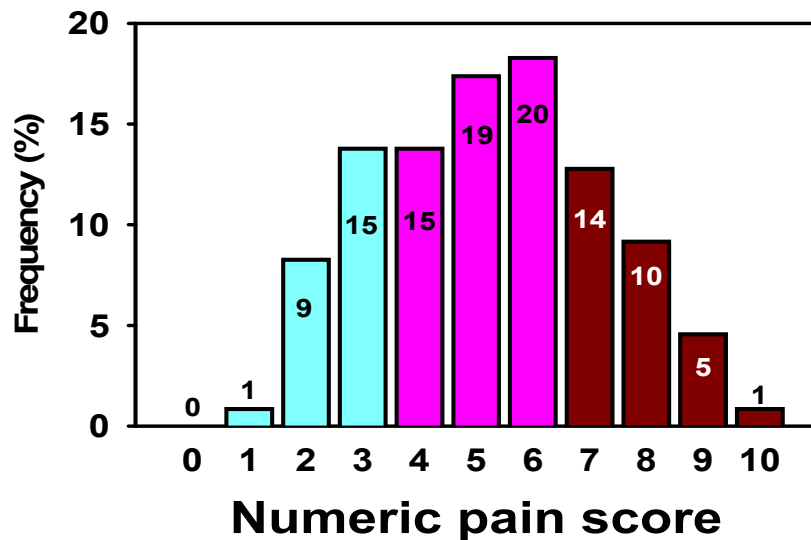
White (84.4% vs. 93.9% in ME)
Black/African American
(5.5% vs. 2.0% in ME)



Veterans
(5.5% vs. 7.2% in ME)



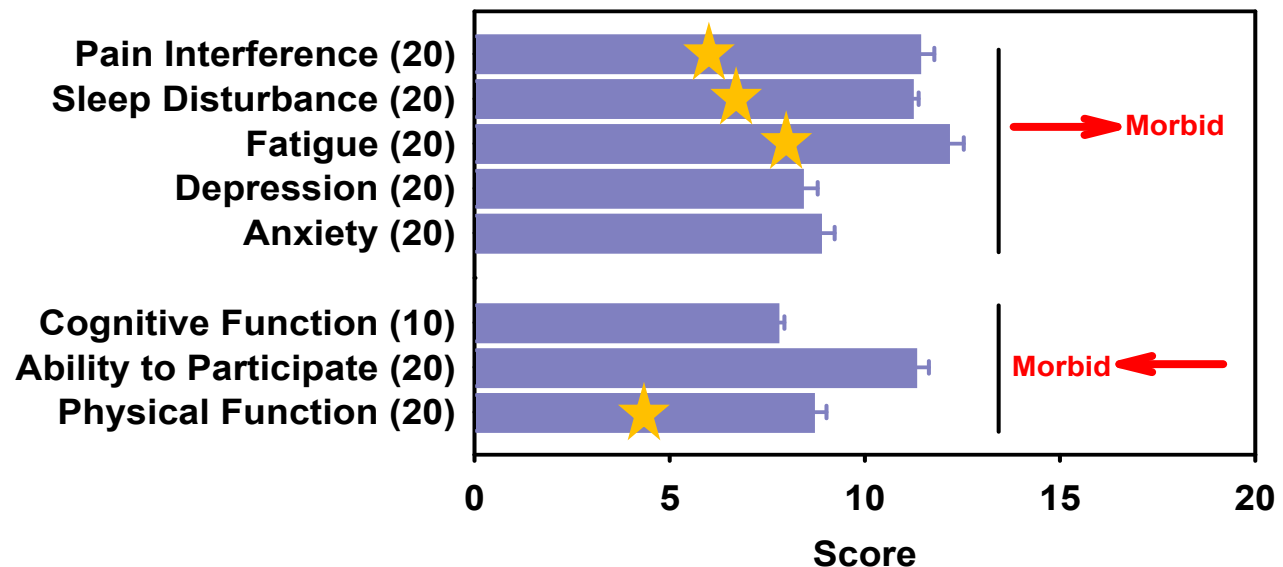
Results – Pain characteristics



- Most participants suffers from moderate to severe pain (Mean±SD: 5.25 ± 2.01).
- The majority of participants had pain ≥ 1 year, and ~20% had pain ≥ 20 years.
- The longest suffering time reported was **52 years!**

Results – Pain characteristics

- Pain location: **Low back (46.8%)** > Shoulder(s) (28.4%) > Neck (27.5%).
- Precipitating events: **Trauma/injury (35.8%)** > Chronic non-cancer illness (25.7%)
- Pain co-morbidities:



Results – Pain management

- Q: “Who is primarily responsible for helping you manage your pain?”
“Myself” (51.4%) > “Primary care physician” (12.8%) > “Pain specialist” (10.1%)
- On average, individuals have used 5.5 ± 3.0 (range 1-13) different approaches to manage their pain
- Pain management approaches:
 - ✓ Physical therapy (67.0%)
 - ✓ Non-opioid medications (65.1%) (only (25.7%) used opioid medications)
 - ✓ Exercise program (55.0%)
 - ✓ Massage therapy (51.4%)
 - ✓ ...
 - ✓ Osteopathic manipulative treatment (36.7%)

Results - Pain management

Q: “Major problems faced that prevent pain care access”

- Treatment cost is too high (25.7%)
- Lack of flexible work schedule (17.4%)
- The type(s) of provider I need are not available in my area (11.0%)
- Long distance to travel to provider(s) (9.2%)

There is significant **frustration regarding lack of treatment options**

tired of **guess work** and being poked
and prodded and made to **feel crazy**

No one has been able
to diagnose or treat

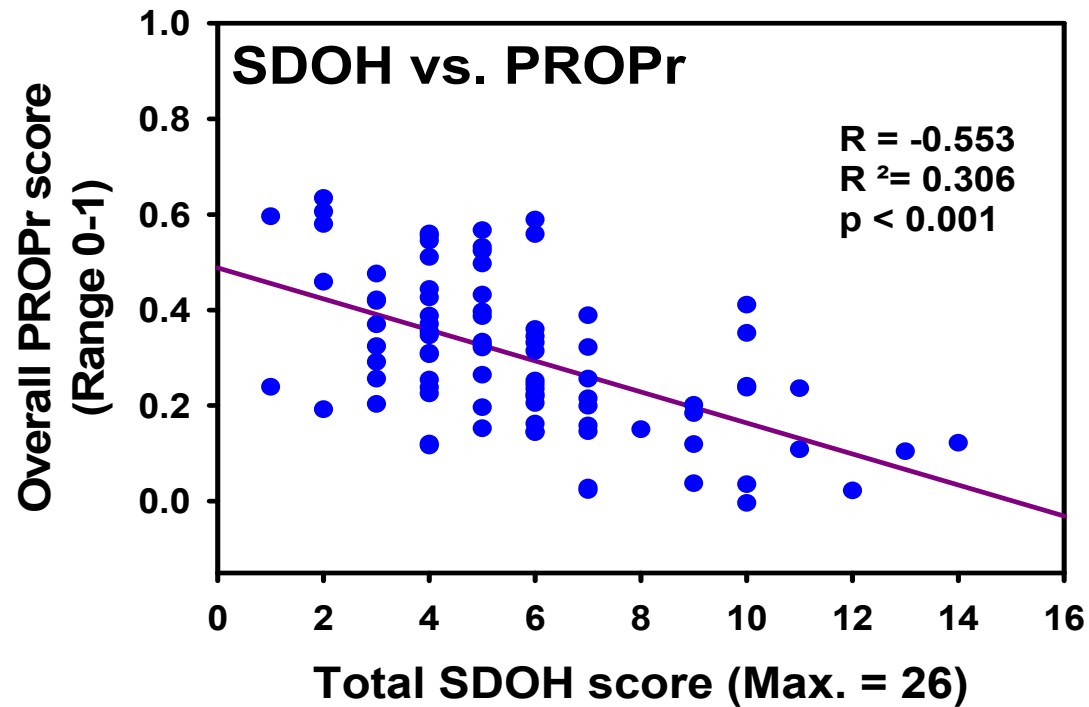
they say there is **nothing else they can do**
and I just **have to live with constant pain**

The treatments **do not**
work well enough if at all

Results – SDOH

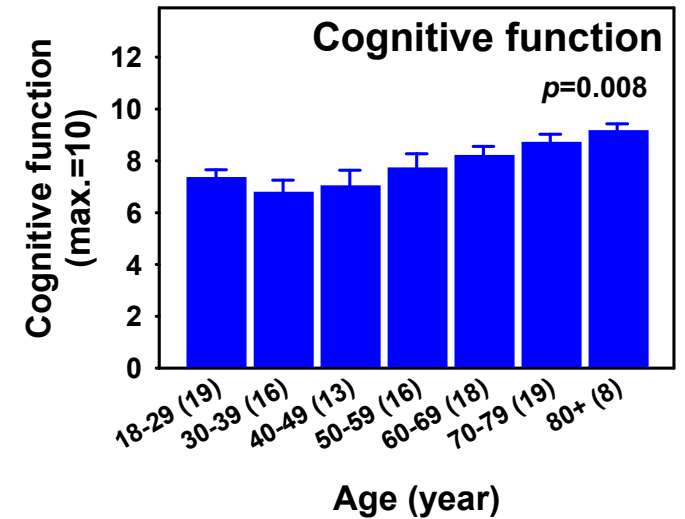
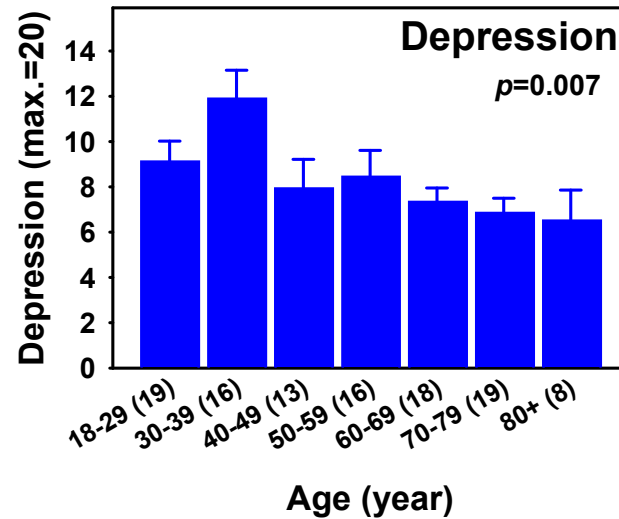
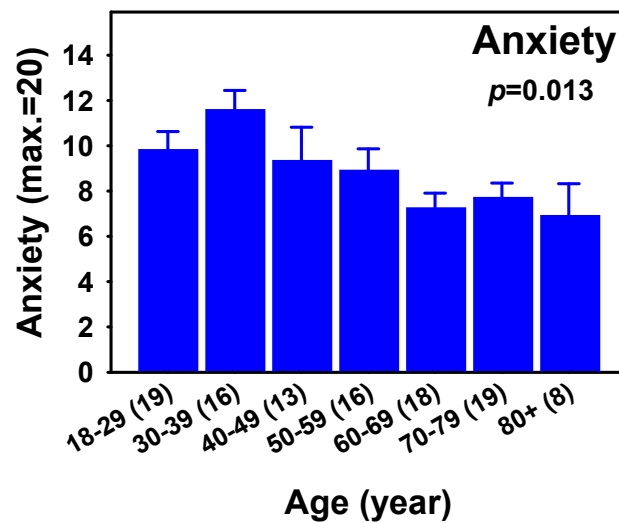
- **Well educated:** Bachelor's degree (45.0%) + Master's or Doctoral degrees (21.2%)
- **Employed full-time (40.4%)** or retired and volunteering (9.2%)
- **All had medical insurance** and half (51.4%) had private insurance
- Majority **had no concerns about housing, transportation, paying for basic needs, or neighborhood safety**
- Most **communicate with family or friends** at least once a week
- ❖ **Overall, the participant pool has less risky SDOH factors**

Results - SDOH vs. Pain domains



Higher risk in SDOH
correlates to worse
satisfaction by
individuals with
chronic pain

Results - Age vs. Pain domains



Results - Sex vs. Pain domains



Gender identity	# of respondents (%)
Female	73 (67.0)
Male	29 (26.6)
Transgender	3 (2.8)
Non-binary	1 (0.9)
Prefer not to answer	1 (0.9)
No response	2 (1.8)

Biological sex	# of respondents (%)
Female	76 (69.7)
Male	30 (27.5)
Prefer not to answer	1 (0.9)
No response	2 (1.8)

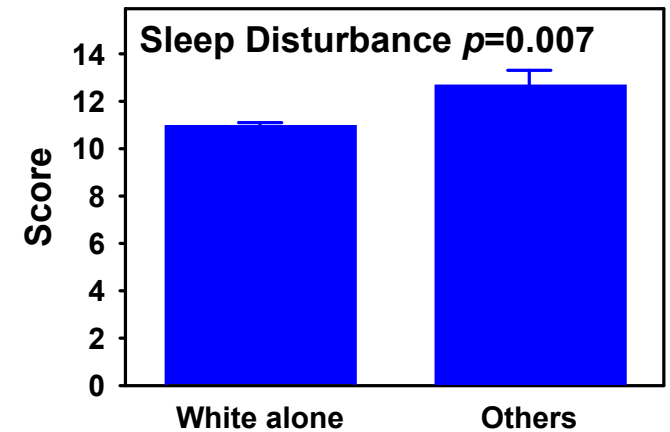
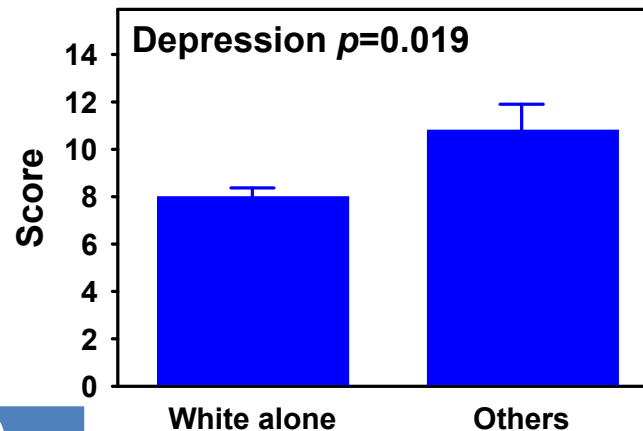
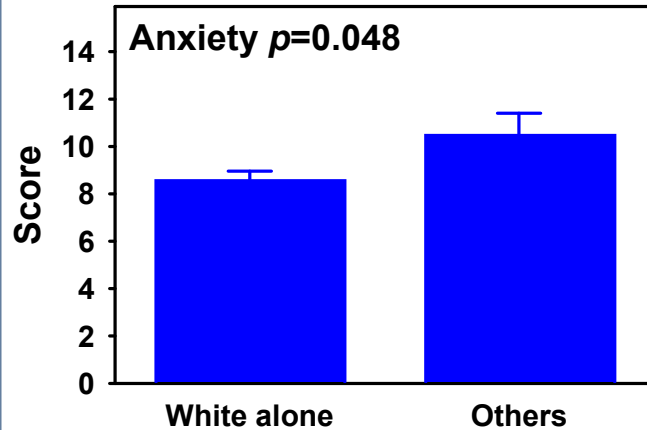
No significant correlations between sex and individual pain domain measures was found.

Results - Veteran Status vs. Pain domains

Veteran Status	# of respondents (%)
Yes	6 (5.5)
No	100 (91.7)
Prefer not to answer	0 (0.0)
No response	3 (2.8)

No significant correlations between Veteran Status and individual pain domain measures was found.

Results - Race vs. Pain domains



Race	# of Respondents (%)
White Alone	92 (84.4)
Others	17 [3 mixed w/White] (15.6)

Results - County of residence vs. Pain domains

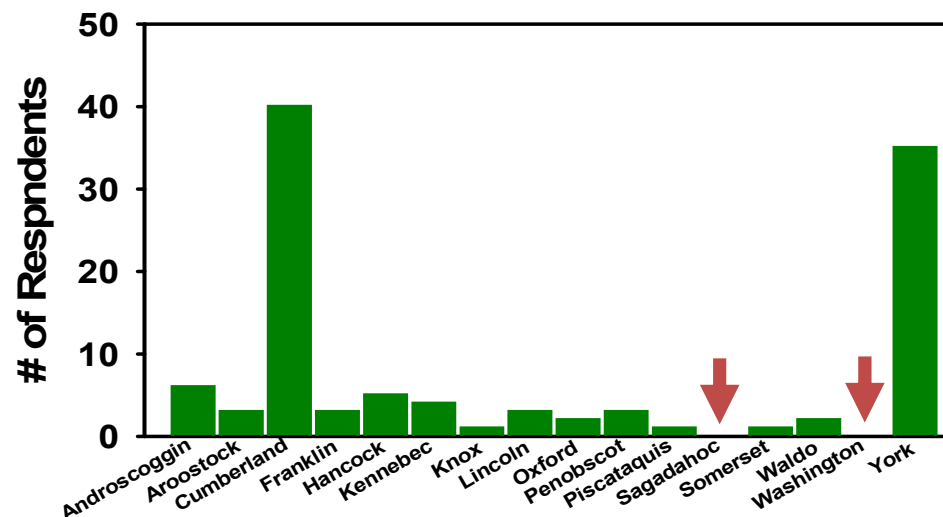
Urban counties in Maine:

Androscoggin, Cumberland, Penobscot, Sagadahoc, and York

- 84 urban respondents
- 25 rural respondents



Metro Nonmetro



No significant correlations between county of residence and individual pain domain measures was found.

<https://www.ruralhealthinfo.org/states/maine>

Results – Education vs. Pain domains

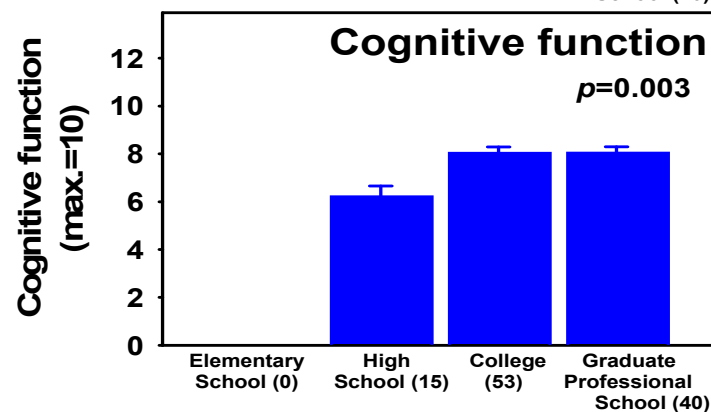
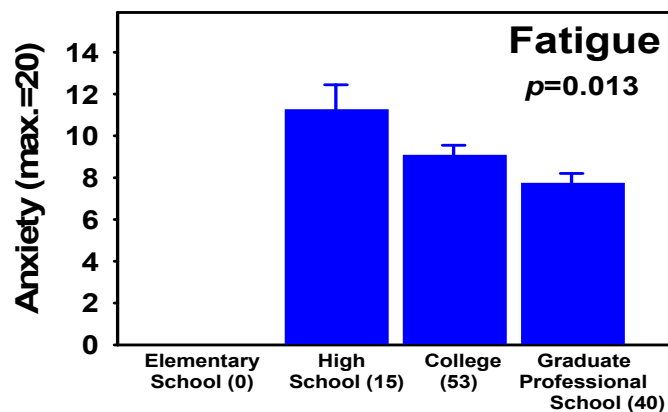
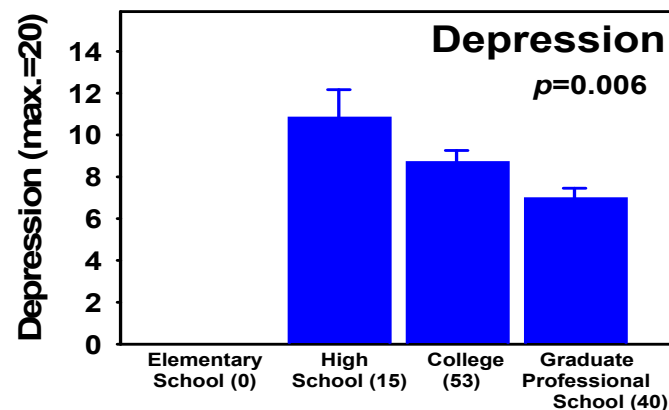
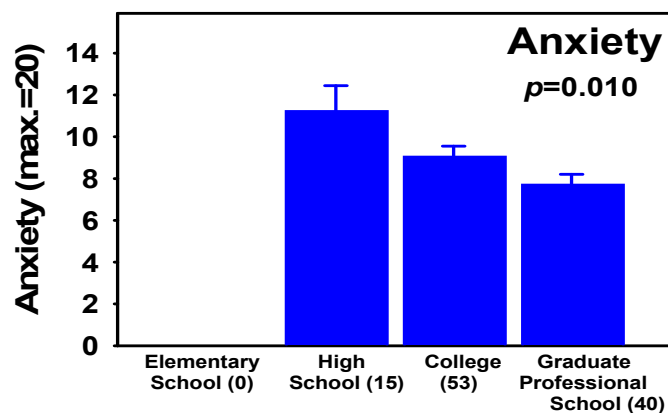


Highest degree earned	# of respondents (%)
High School	13 (11.9)
GED	0 (0.0)
Vocational certificate	3 (2.8)
Associate's degree	9 (8.3)
Bachelor's degree	49 (45.0)
Master's degree	23 (21.1)
Doctorate	11 (10.1)
Prefer not to answer	1 (0.9)

Highest level of school completed	# of respondents (%)
Elementary School	0 (0.0)
High School	15 (13.8)
College	53 (48.6)
Graduate / Professional School	40 (36.7)
Prefer not to answer	1 (0.9)

Lower education levels are associated with worsened individual pain domain measures.

Results - Education vs. Pain domains



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Summary



1. Anonymous survey can be used
 - Enhanced **targeted recruitment** efforts are needed (e.g. residency, SDOH)
2. Significant suffering from **pain and pain-associated comorbidities** substantiate this public health issue
 - **Differential suffering** exists between sub-populations (e.g. age, sex, education)
3. Limitations:
 - Self-selection → needs for further recruitment effort
 - Online scamming activities → continuous monitoring
 - English only → help with translation to additional languages
 - Funding → hard to receive funding for studies that focus on collecting data

Implications

1. Inform **clinicians and patients**
 - identify risk factors, provide comprehensive pain management
2. Inform future pain **research**
 - focus areas, prevention vs. treatment

Implications

3. Promote public health interventions

- Injury prevention
- Chronic disease management
- Patient education on self-management – sub-population targeted approach
- Social services for co-morbidities
- Advocacy for lower cost on pain care – for EVERYONE
- Reduce SDOH-related risk factors
e.g. improve education, flexible working schedules when possible,
social safety net for all

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Emmaline Ashe
Deanna Williams
John Pier
Kinna Thakarar



NIGMS [U54GM115516 (PI, Rosen)]



Capstone Advisor:
Amy Knowlton, ScD, MPH

Questions?

PainRegistryforME

TO PARTICIPATE OR FMI regarding the state-wide pain registry in Maine, scan the QR code or go to



Email: PainRegistryforME@une.edu

Web link: <https://www.une.edu/research/center-pain-research/maine-pain-registry>

Would love to hear from you (Lcao@une.edu)

- Distribute the survey
- Collaboration
- Funding opportunities

