

# Symptom Profiles, Health Care Utilization, and Health Behaviors in Long-term Survivors of the Childhood Cancer Survivor Study

---

Rachel Tillery Webster, Wei Liu, Meghan E. McGrady, Nicole M. Alberts, Tara M. Brinkman, Kirsten K. Ness, Bernard Fuemmeler, Alicia S. Kunin-Batson, Deokumar Srivastava, I-Chan Huang, Gregory T. Armstrong, Rebecca M. Howell, Daniel M. Green, Yutaka Yasui, Kevin R. Krull

**CCSS**

Childhood Cancer  
Survivor Study



**St. Jude Children's  
Research Hospital**

Finding cures. Saving children.  
ALSAC • DANNY THOMAS, FOUNDER

- **Nearly all survivors will develop a chronic health condition<sup>1,2</sup>**
- **Even in the absence of a diagnosed chronic health condition, survivors experience ongoing symptom burden<sup>3,4</sup>**
  - Fatigue
  - Pain
  - Cardiac symptoms
  - Pulmonary symptoms
  - Motor movement difficulties
  - Sensory abnormalities
  - Psychological symptoms
- **Physical and psychological symptom burden tend to co-occur BUT in varying degrees across survivors<sup>5</sup>**
- **Symptom burden is associated with healthcare utilization and risky health behaviors for some survivors<sup>6,7</sup>**
  - Presentation of symptom burden (i.e., collection of symptoms) may differentially predict health behavior engagement
- **Need to identify subgroups based on symptom presentation to identify:**
  - Correlates of those at risk for symptom burden
  - Associations with health care utilization and risky health behaviors

# Research Aims

CCSS

1

Identify latent classes of survivors with similar psychological and physical symptoms (self-report at Baseline)

2

Identify demographic and medical correlates of symptom latent classes for survivors at Baseline

3

Evaluate association between latent classes at Baseline with healthcare utilization and health behaviors at follow-up (year 2 or year 5/6)

# Participants

All 5-year survivors who participated in the CCSS Baseline assessment

At least 18 years old

Completed either Follow-up 2 (original), Follow-up 5 (expansion) or Follow-up 6 surveys

No cognitive or sensory deficits that prevent completion of assessments

N=17,232	
Mean Age (SD)	27.4 (5.98)
Race/Ethnicity	
% Hispanic	8.3
% Non-Hispanic Black	6.3
% Non-Hispanic White	80.0
% American Indian/Alaska Native (Non-Hispanic)	0.5
% Asian or Pacific Islander (Non-Hispanic)	1.5
% Unknown	3.4
Sex	
% Female	47.6
% Male	52.3
Diagnosis	
% Leukemia	29.4
% CNS Tumor	16.7
% Hodgkin's Lymphoma	16.1
% Bone Tumor	10.2
% Non-Hodgkin's Lymphoma	10.0
% Wilms Tumor	7.6
% Neuroblastoma	5.0
% Soft Tissue Sarcoma	5.0

CCSS

## Medical Conditions

- Sensation symptoms
- Motor Symptoms
- Cardiac Symptoms
- Pulmonary Symptoms
- Pain
- Nausea
- Fatigue
- Memory
- Anxiety
- Depression

## Socio-demographic correlates

- Sex
- Race
- Age
- Education level
- Household income
- Insurance coverage

## Medical correlates

- Treatment Exposures (Surgery, Radiation, Chemotherapy)
- Diagnosis
- Grade 3 or 4 Chronic Health Conditions

## Health Care Utilization

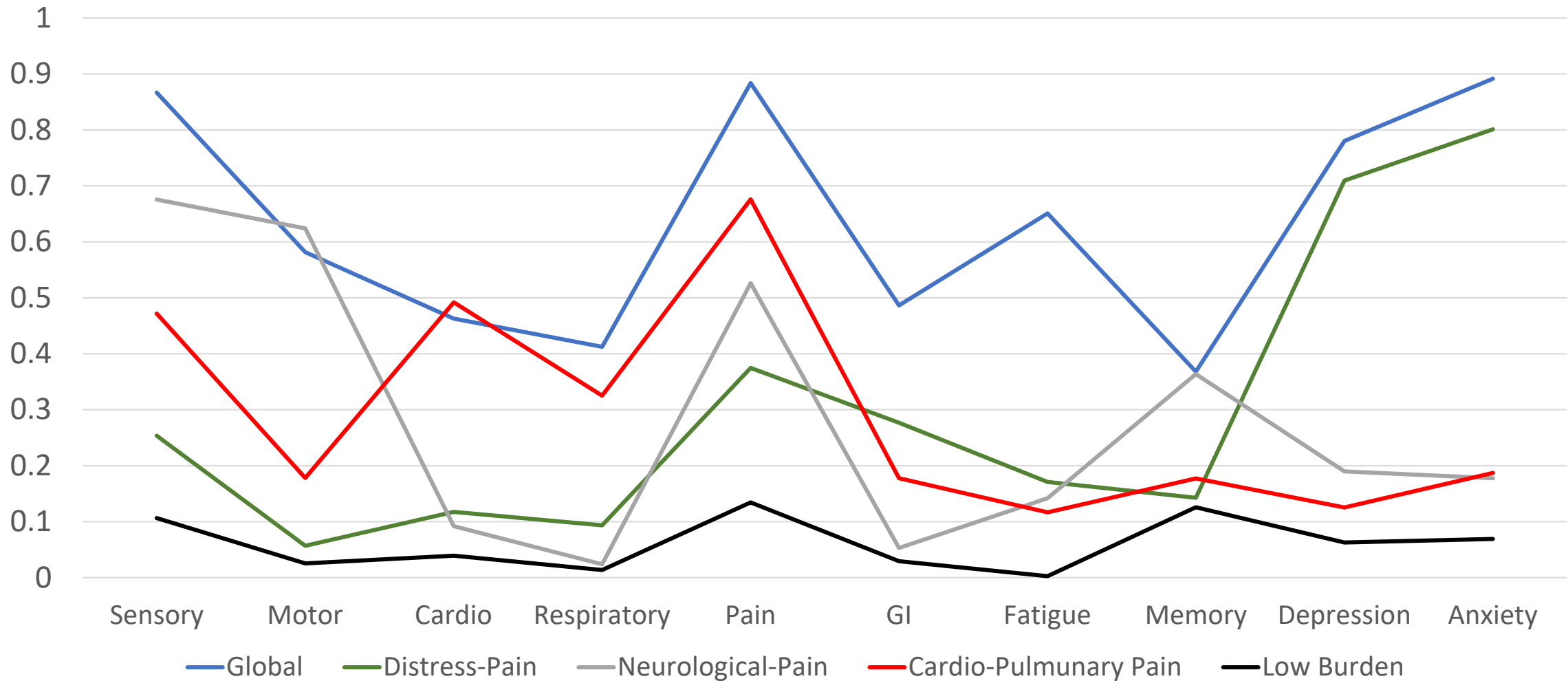
- No health care
- General survivor care
- Long-term follow-up care
- Emergent care

## Health Behaviors

- Smoking (never, former, current)
- Physical inactivity (metabolic equivalent score)

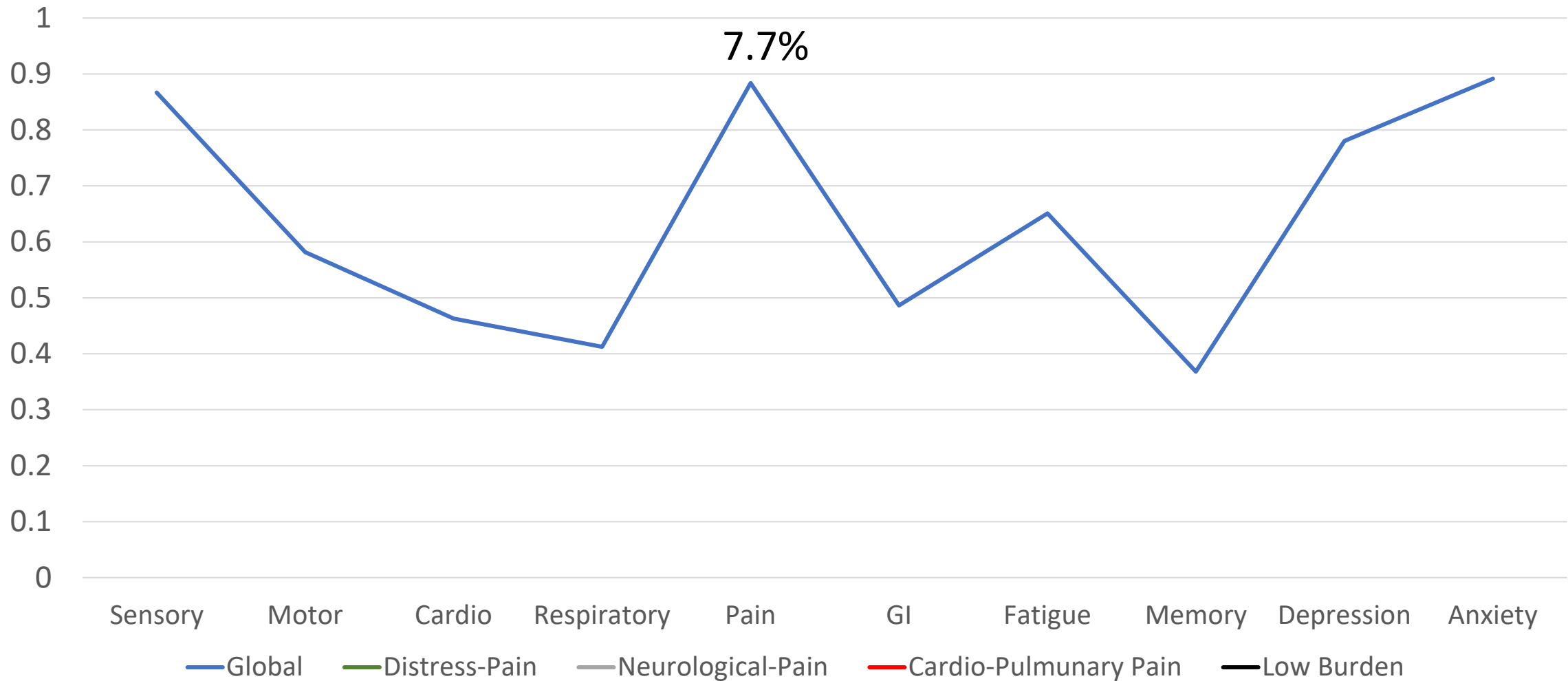
# Results: Latent Classes of Symptom Burden

ccss



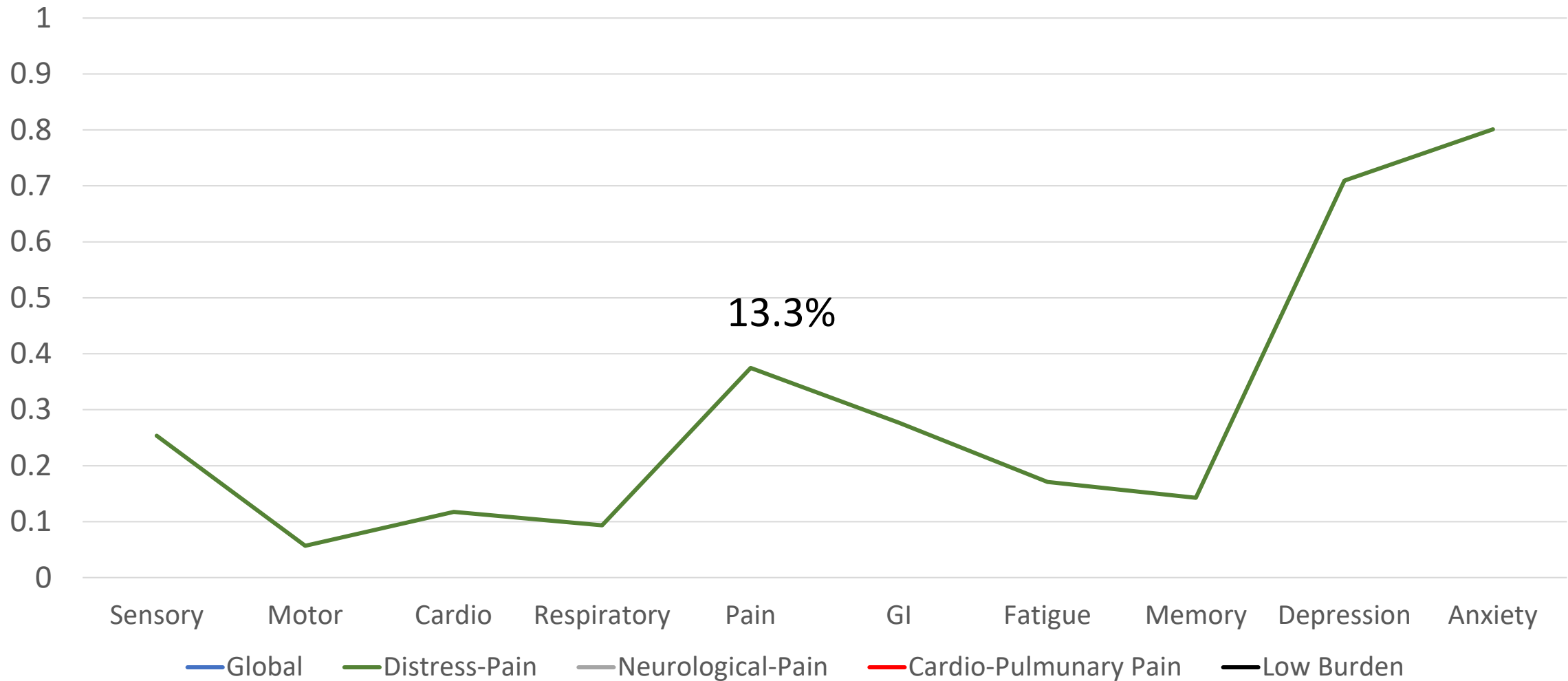
# Results: Latent Classes of Symptom Burden

CCSS



# Results: Latent Classes of Symptom Burden

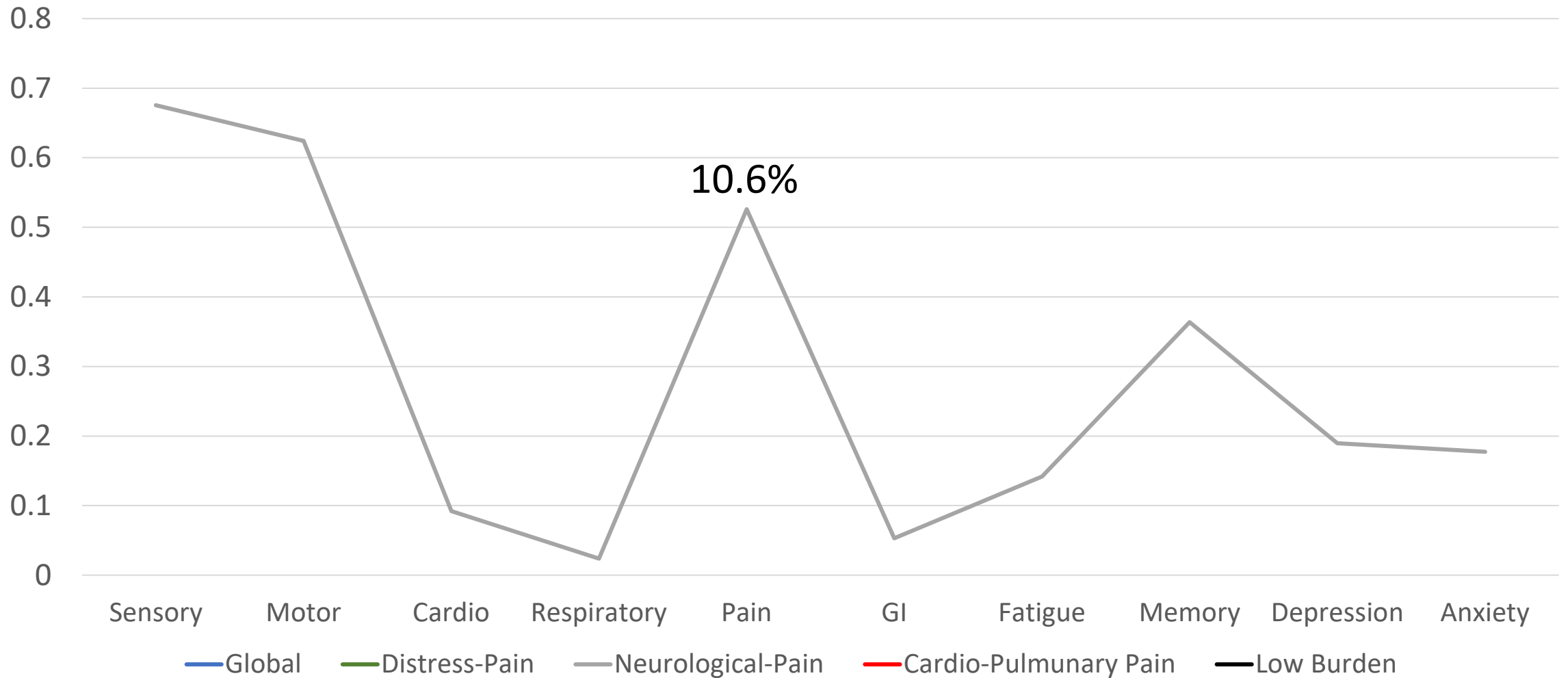
CCSS





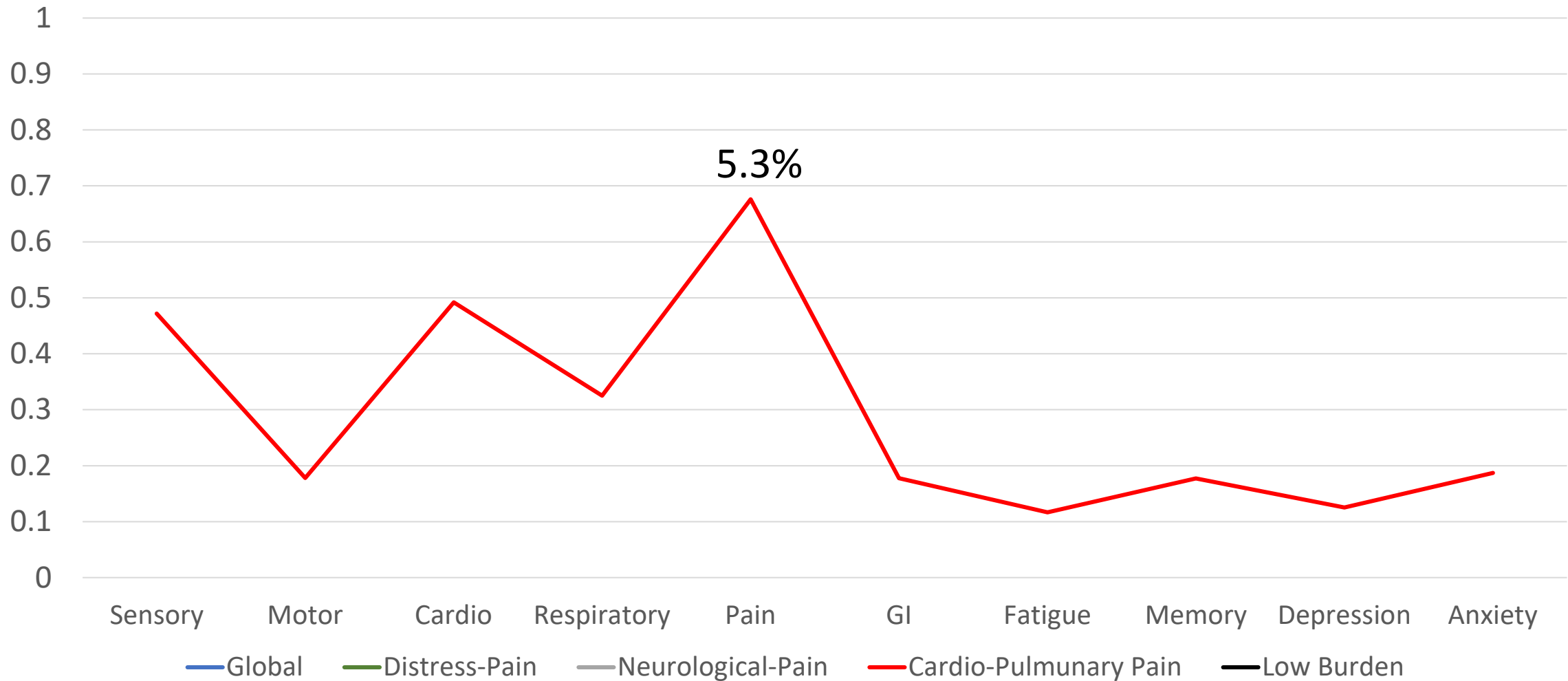
# Results: Latent Classes of Symptom Burden

CCSS



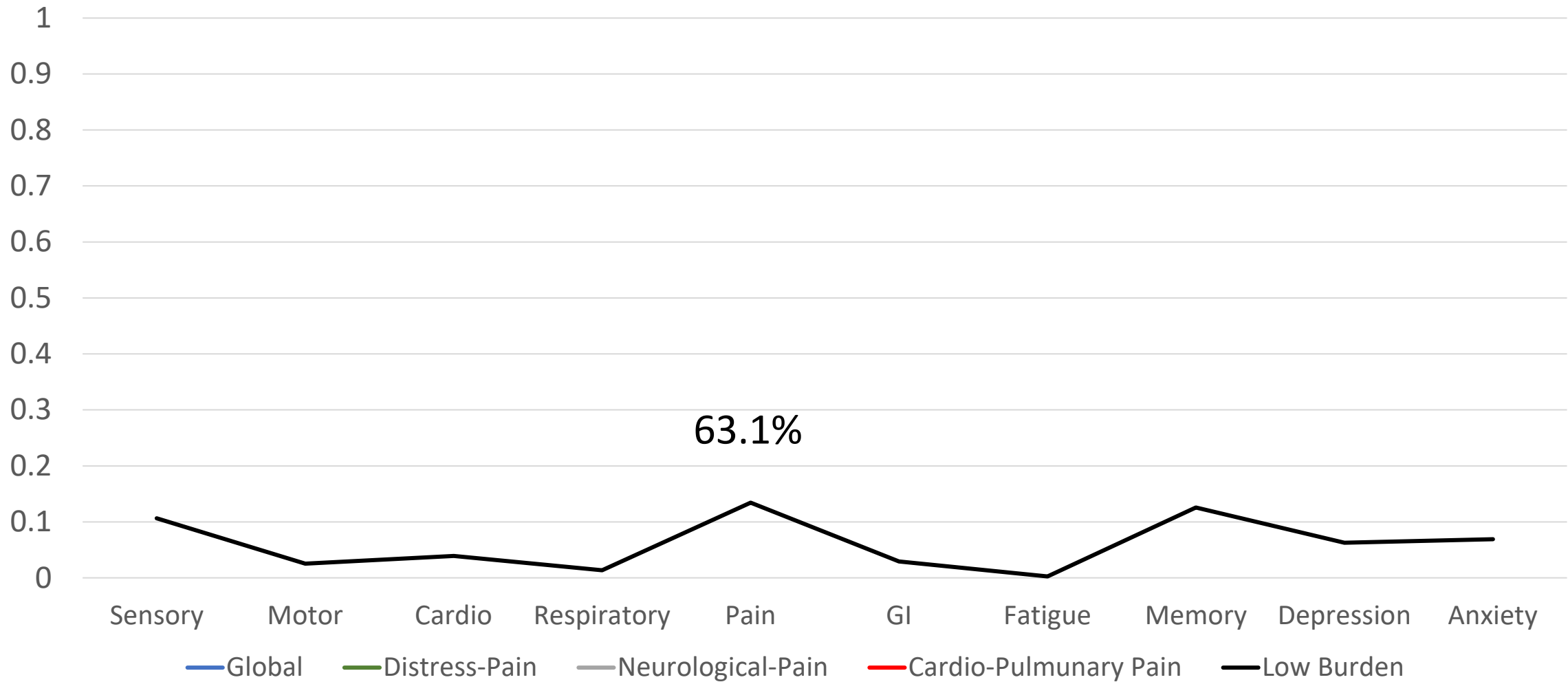
# Results: Latent Classes of Symptom Burden

CCSS



# Results: Latent Classes of Symptom Burden

CCSS



# Results: Symptom Burden Class with Demographic Factors

Symptom Class	Sex Female Vs. Male)  OR (95% CI)	Age at Baseline  OR (95% CI)	Education <College vs. College Graduate  OR (95% CI)	Income <\$40 vs. >\$40K  OR (95% CI)	Insurance Uninsured vs. Insured  OR (95% CI)
Low Burden	Ref	Ref	Ref	Ref	Ref
Distress-Pain	<b>1.51 (1.37, 1.66)</b>	<b>0.99 (0.98, 0.99)</b>	<b>1.27 (1.14, 1.41)</b>	<b>1.42 (1.27, 1.59)</b>	<b>1.32 (1.17, 1.48)</b>
Cardio-Pain	<b>2.16 (1.88, 2.48)</b>	<b>1.01 (1, 1.03)</b>	<b>1.8 (1.55, 2.09)</b>	<b>1.52 (1.30, 1.78)</b>	1.15 (0.96, 1.38)
Neuro-Pain	<b>1.45 (1.30, 1.62)</b>	<b>1.02(1.01, 1.03)</b>	<b>1.72 (1.53, 1.93)</b>	<b>1.36 (1.20, 1.54)</b>	0.93 (0.8, 1.08)
Global	<b>1.87 (1.66, 2.10)</b>	<b>1.03 (1.02, 1.04)</b>	<b>1.8 (1.55, 2.09)</b>	<b>1.82 (1.61, 2.06)</b>	<b>1.88 (1.63, 2.16)</b>

Univariate analyses exploring demographic risk factors associated with symptom burden class membership. Bold font indicates statistical significance at p<.05

# Results: Symptom Burden Class with Diagnosis

CCSS

Symptom Class	Bone Tumor vs Leukemia	CNS Tumor vs Leukemia	Hodgkin's Lymphoma vs Leukemia	Neuroblastoma vs Leukemia	Non-Hodgkin's Lymphoma vs Leukemia	Soft tissue Sarcoma vs Leukemia	Wilms tumor vs Leukemia
	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Low Burden	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Distress-Pain	1.09(0.92,1.28)	0.87(0.75,1.02)	1.01(0.87,1.17)	0.96(0.77,1.19)	0.97(0.82,1.15)	<b>.70(.55,.90)</b>	<b>.76(.63,.92)</b>
Cardio-Pain	<b>1.4(1.1,1.78)</b>	0.89(0.69,1.15)	<b>1.66(1.36,2.04)</b>	1.3(0.95,1.79)	<b>1.31(1.02,1.67)</b>	1.30(.95,1.78)	1.27(.98,1.64)
Neuro-Pain	<b>1.54(1.26,1.89)</b>	<b>6.99(6.05,8.08)</b>	<b>0.52(0.41,0.66)</b>	<b>1.39(1.05,1.84)</b>	0.81(0.63,1.03)	1.05(.78,1.41)	<b>.49(.36,.69)</b>
Global	<b>1.28(1.05,1.57)</b>	<b>2.01(1.7,2.37)</b>	1.03(0.86,1.24)	0.79(0.57,1.1)	0.93(0.74,1.16)	1.24(.95,1.61)	<b>.52(.38,.70)</b>

Univariate analyses exploring associations between diagnosis and symptom burden class membership. Bold font indicates statistical significance at p<.05

# Results: Symptom Burden Class with Chronic Health Conditions

CCSS

## Chronic Health Conditions Grade 3-4 vs. Grade 1-2

Symptom Class	OR (95% CI)
<b>Low Burden</b>	Ref
<b>Distress-Pain</b>	<b>1.40 (1.27, 1.55)</b>
<b>Cardio-Pain</b>	<b>1.74 (1.52, 2.00)</b>
<b>Neuro-Pain</b>	<b>2.83 (2.55, 3.15)</b>
<b>Global</b>	<b>2.85 (2.54, 3.21)</b>

Univariate analysis exploring associations between Grade 3-4 vs. 1-2 chronic health conditions assessed at baseline with symptom burden class membership. Bold font indicates statistical significance at  $p < .05$

# Results: Symptom Burden Class with Healthcare Utilization

Symptom Class	No Health Care OR (95% CI)	Oncology-Focused OR (95% CI)	Long-term Follow-up OR (95% CI)	Emergency Room OR (95% CI)
Low Burden	Ref	Ref	Ref	Ref
Distress-Pain	.88 (.73, 1.08)	.94 (.78, 1.15)	1.06 (.88, 1.27)	<b>1.42 (1.27, 1.59)</b>
Cardio-Pain	.82 (.58, 1.17)	<b>1.41 (1.08, 1.85)</b>	1.08 (.80, 1.44)	<b>1.52 (1.30, 1.78)</b>
Neuro-Pain	1.18 (.95, 1.46)	.94 (.75, 1.18)	<b>1.30 (1.06-1.59)</b>	<b>1.36 (1.20, 1.54)</b>
Global	1.05 (.80, 1.37)	<b>1.34 (1.05, 1.71)</b>	<b>1.37 (1.09, 1.74)</b>	<b>1.82 (1.61, 2.06)</b>

Odds Ratio (OR) and 95% confidence intervals (CI) predicting health-care utilization vs general health care by symptom class. Models adjusted for age, sex, health insurance and CHCs. Bold font indicates statistical significance at p<.05

# Results: Symptom Burden Class with Healthcare Utilization

Symptom Class	Physical Inactivity	Current Smoker	Former Smoker
	OR (95% CI)	OR (95% CI)	OR (95% CI)
Low Burden	Ref	ref	ref
Distress-Pain	.97 (.89, 1.06)	<b>1.81 (1.54, 2.13)</b>	<b>1.06 (1.42, 1.92)</b>
Cardio-Pain	<b>1.18 (1.07,1.31)</b>	<b>1.91 (1.49, 2.46)</b>	<b>1.65 (1.30, 2.10)</b>
Neuro-Pain	<b>1.16 (1.07, 1.25)</b>	<b>1.35 (1.11, 1.66)</b>	1.02 (.83-1.24)
Global	<b>1.11 (1.01, 1.23)</b>	<b>3.25 (2.67, 3.96)</b>	<b>2.10 (1.71, 2.58)</b>

Odds Ratio (OR) and 95% confidence intervals (CI) predicting health behaviors by symptom class. Models adjusted for age, sex, health insurance and CHCs. Bold font indicates statistical significance at p<.05



- **>3<sup>rd</sup> of childhood cancer survivors experience symptom burden across various domains**
- **Psychological distress-pain accounting for the largest symptom burden profile**
- **Social determinants of health (income, sex, education-level) are associated with symptom burden**
  - Decreased resources are associated with greater symptom burden
- **Adjusting for insurance, chronic health conditions, and older age, elevated symptoms are associated with:**
  - Future emergency room use
  - Physical inactivity
  - Current smoking status
- **Pain is prevalent in all high symptom groups and suggests an important intervention target**