

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

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- **Nearly all survivors will develop a chronic health condition^{1,2}**
- **Even in the absence of a diagnosed chronic health condition, survivors experience ongoing symptom burden^{3,4}**
 - 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 survivors⁵**
- **Symptom burden is associated with healthcare utilization and risky health behaviors for some survivors^{6,7}**
 - 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

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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

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Measures

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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

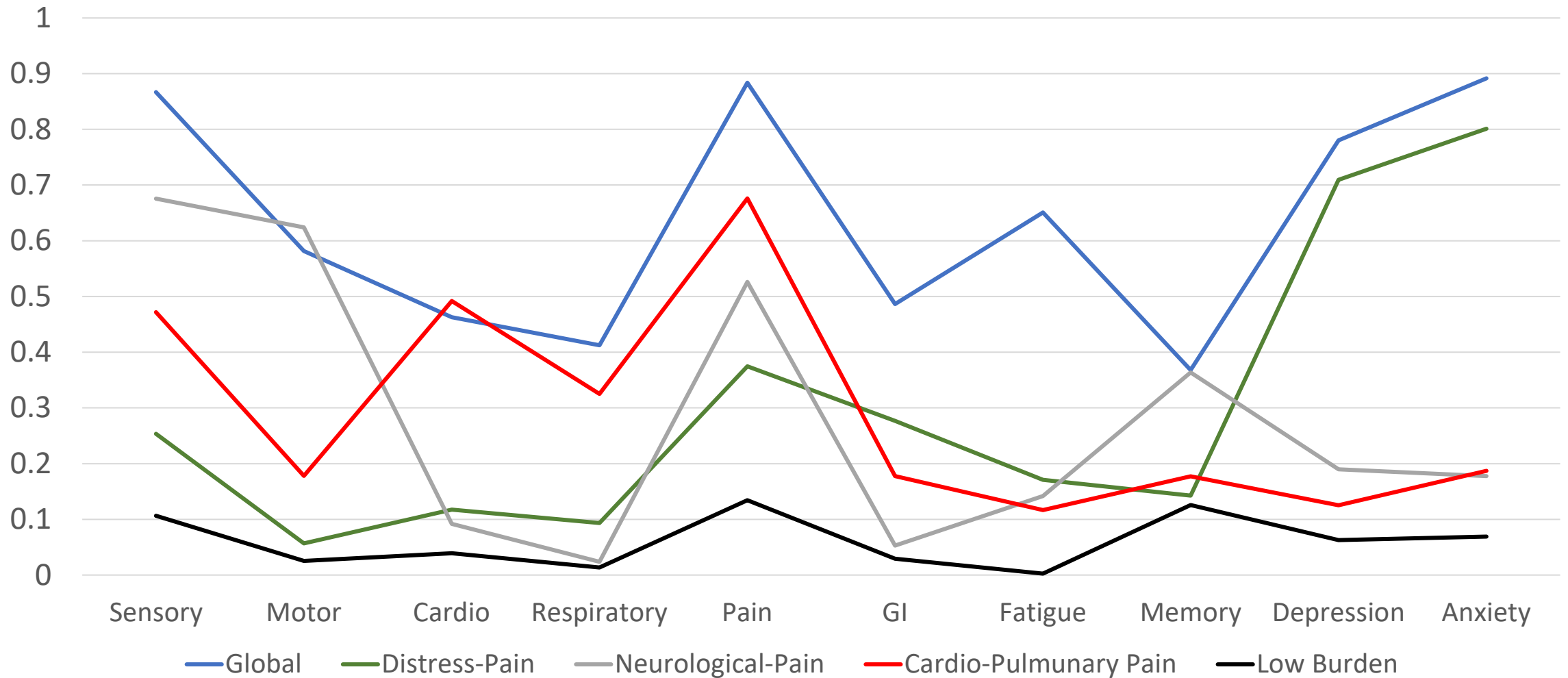
- No health care
- General survivor care
- Long-term follow-up care
- Emergent care

Health Behaviors

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

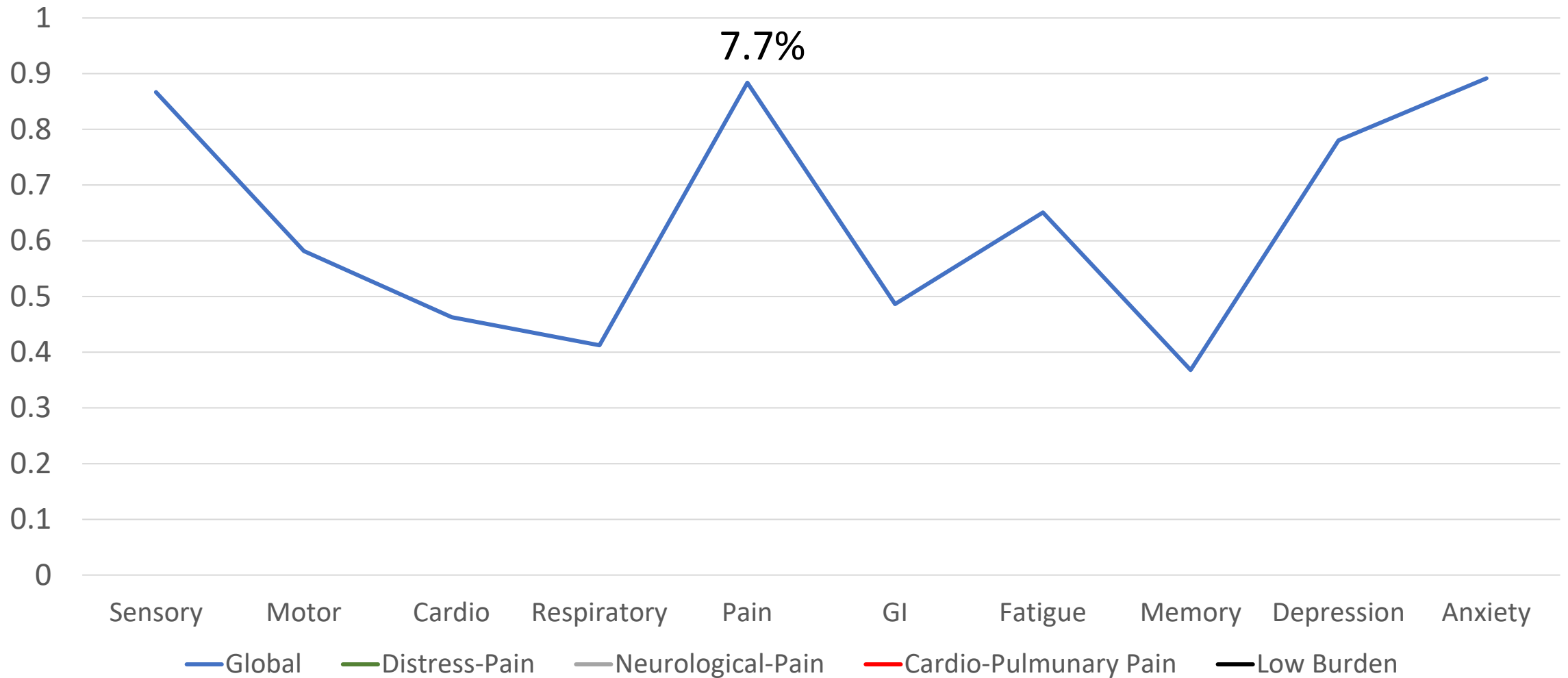
Results: Latent Classes of Symptom Burden

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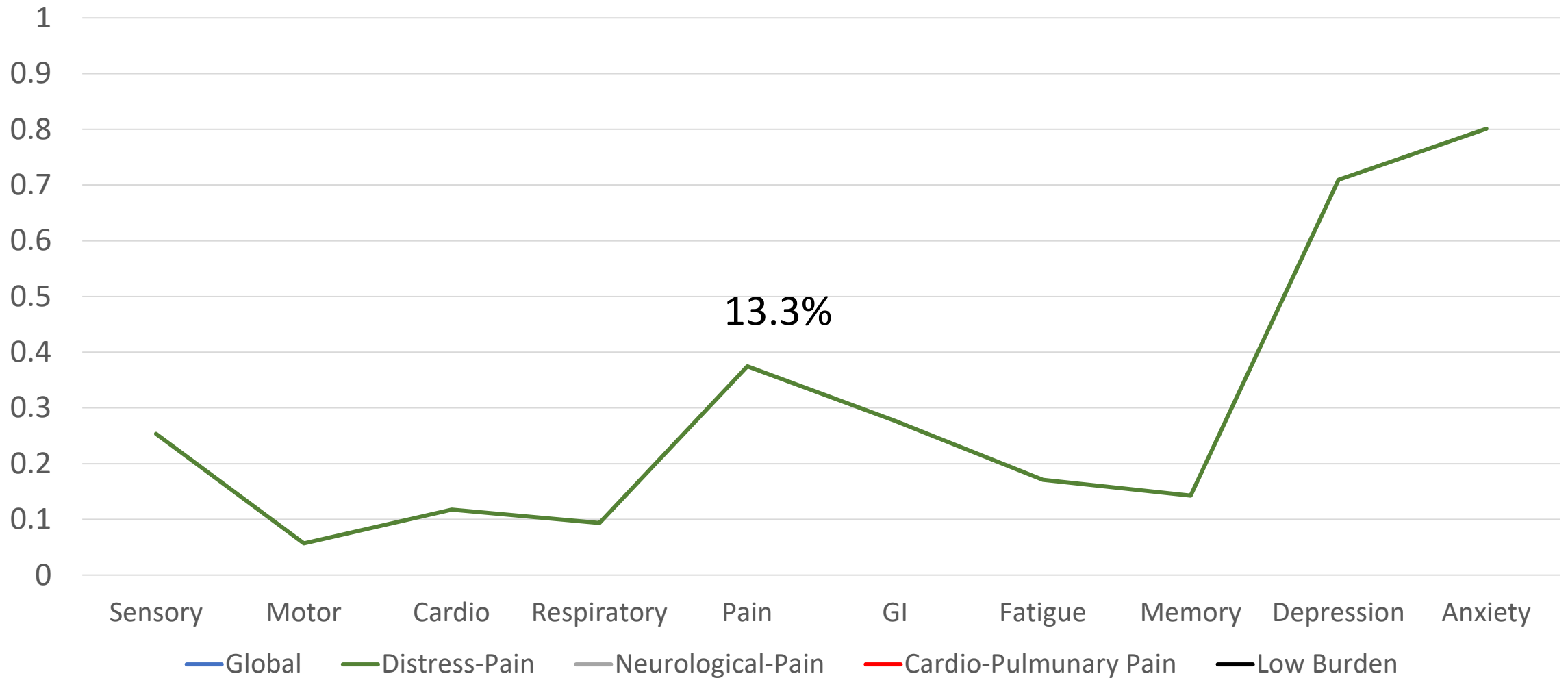
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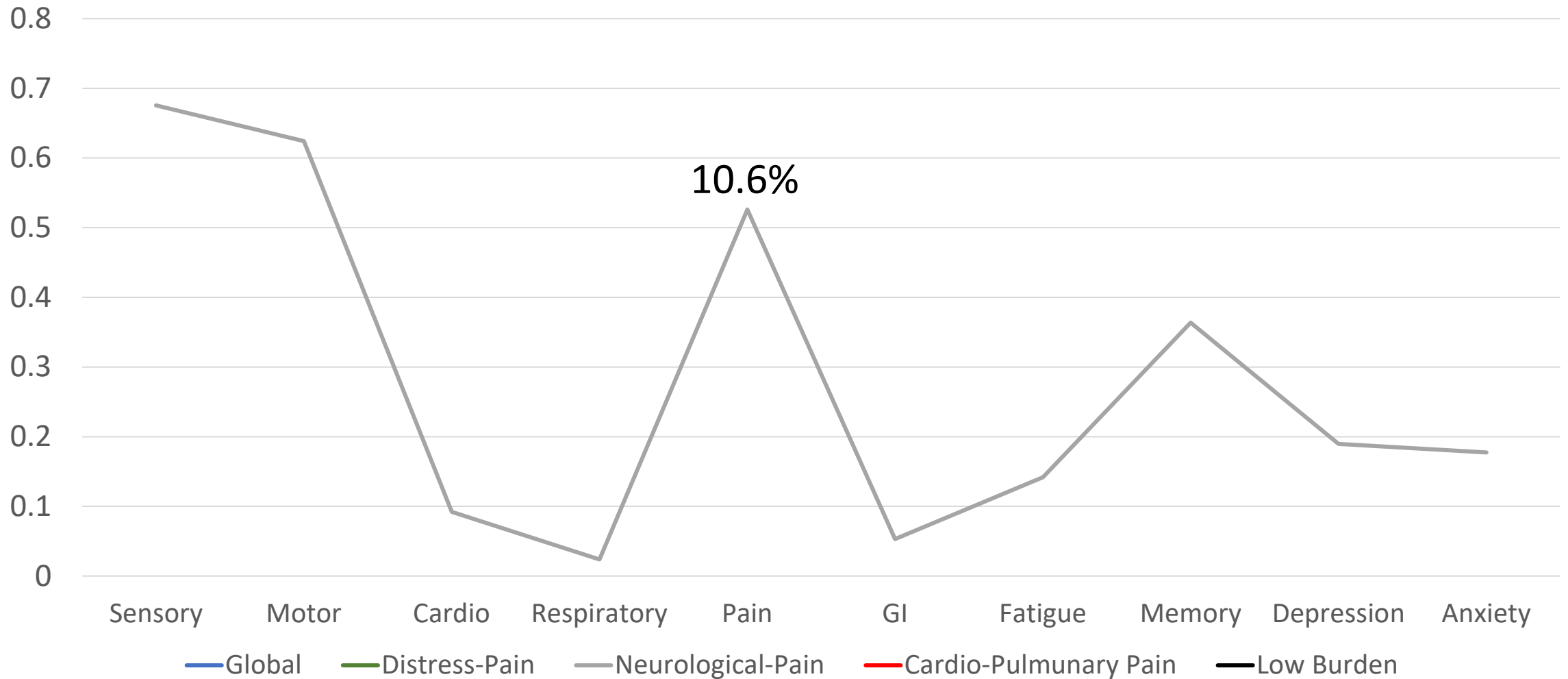
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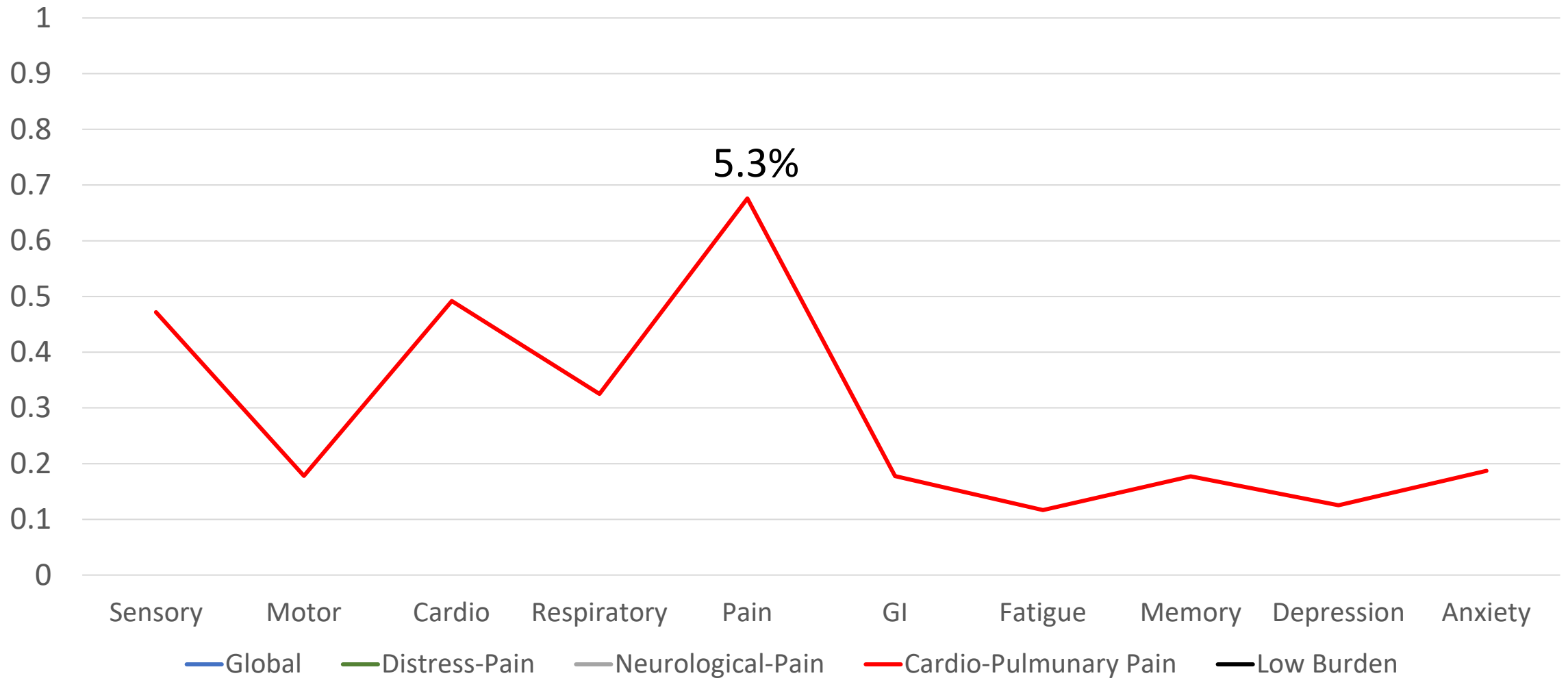
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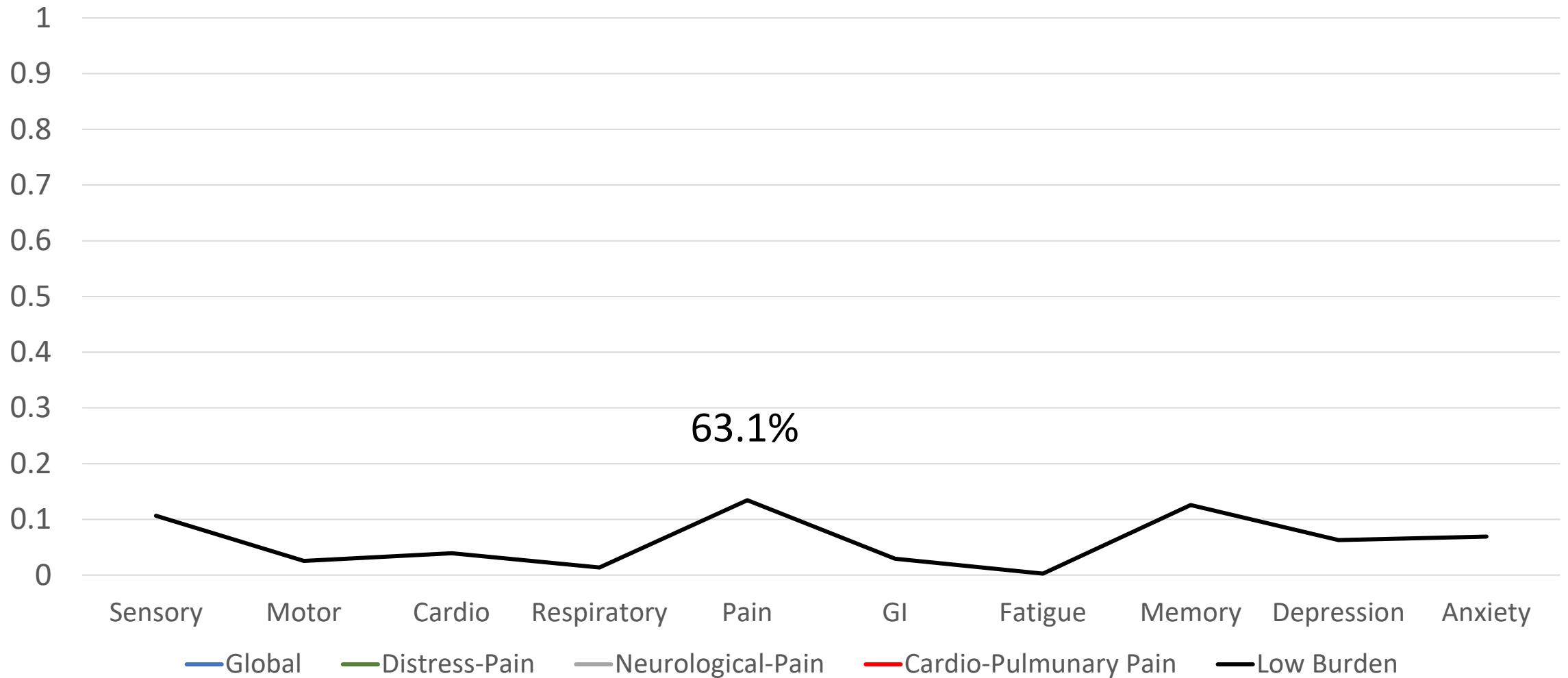
Results: Latent Classes of Symptom Burden

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Results: Latent Classes of Symptom Burden

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Results: Symptom Burden Class with Demographic Factors

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

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

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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)	.70(.55,.90)	.76(.63,.92)
Cardio-Pain	1.4(1.1,1.78)	0.89(0.69,1.15)	1.66(1.36,2.04)	1.3(0.95,1.79)	1.31(1.02,1.67)	1.30(.95,1.78)	1.27(.98,1.64)
Neuro-Pain	1.54(1.26,1.89)	6.99(6.05,8.08)	0.52(0.41,0.66)	1.39(1.05,1.84)	0.81(0.63,1.03)	1.05(.78,1.41)	.49(.36,.69)
Global	1.28(1.05,1.57)	2.01(1.7,2.37)	1.03(0.86,1.24)	0.79(0.57,1.1)	0.93(0.74,1.16)	1.24(.95,1.61)	.52(.38,.70)

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

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

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

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

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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)	1.42 (1.27, 1.59)
Cardio-Pain	.82 (.58, 1.17)	1.41 (1.08, 1.85)	1.08 (.80, 1.44)	1.52 (1.30, 1.78)
Neuro-Pain	1.18 (.95, 1.46)	.94 (.75, 1.18)	1.30 (1.06-1.59)	1.36 (1.20, 1.54)
Global	1.05 (.80, 1.37)	1.34 (1.05, 1.71)	1.37 (1.09, 1.74)	1.82 (1.61, 2.06)

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

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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)	1.81 (1.54, 2.13)	1.06 (1.42, 1.92)
Cardio-Pain	1.18 (1.07,1.31)	1.91 (1.49, 2.46)	1.65 (1.30, 2.10)
Neuro-Pain	1.16 (1.07, 1.25)	1.35 (1.11, 1.66)	1.02 (.83-1.24)
Global	1.11 (1.01, 1.23)	3.25 (2.67, 3.96)	2.10 (1.71, 2.58)

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 $p < .05$

- **>3rd 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**