Understanding Aging with Cerebral Palsy

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Välkommen till CPUP-dagarna!

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FINANCIAL DISCLOSURE

Speaker Name: Mark Peterson

1. Disclosure of Relevant Financial Relationships
I have no financial relationships to disclose.

2. Disclosure of Off-Label and/or investigative uses:
I will not discuss off label use and/or investigational use in my presentation.

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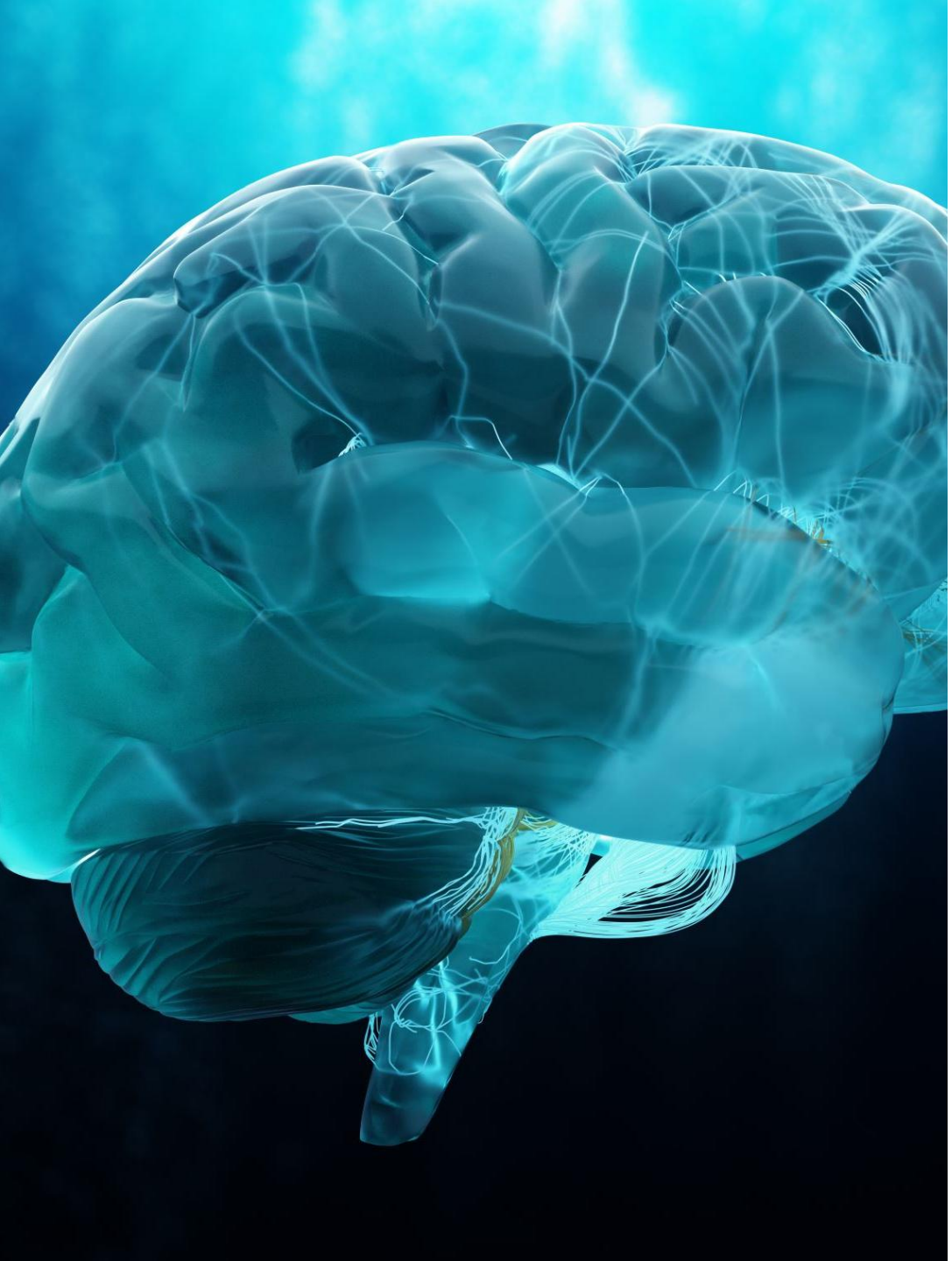
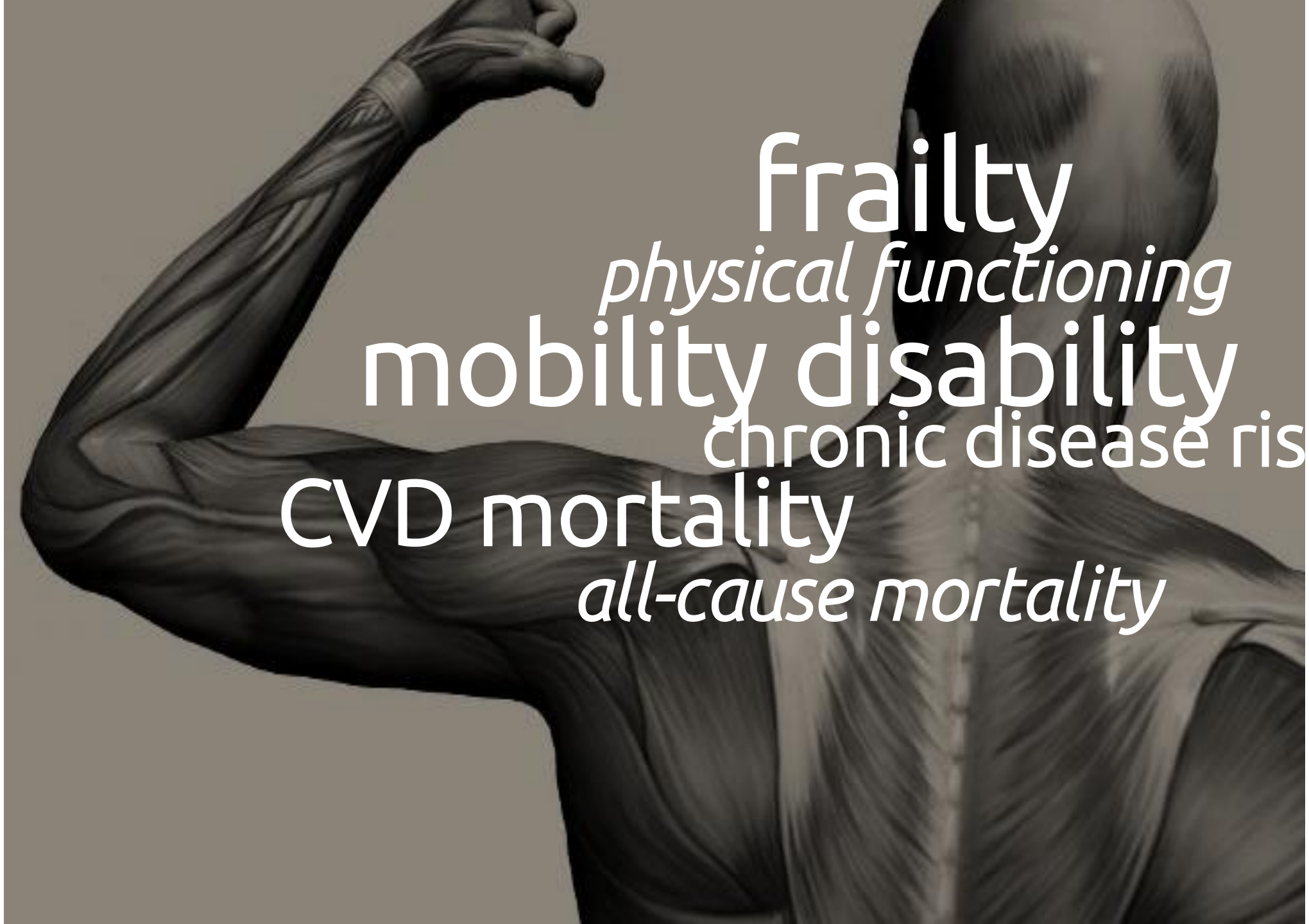


Cerebral Palsy

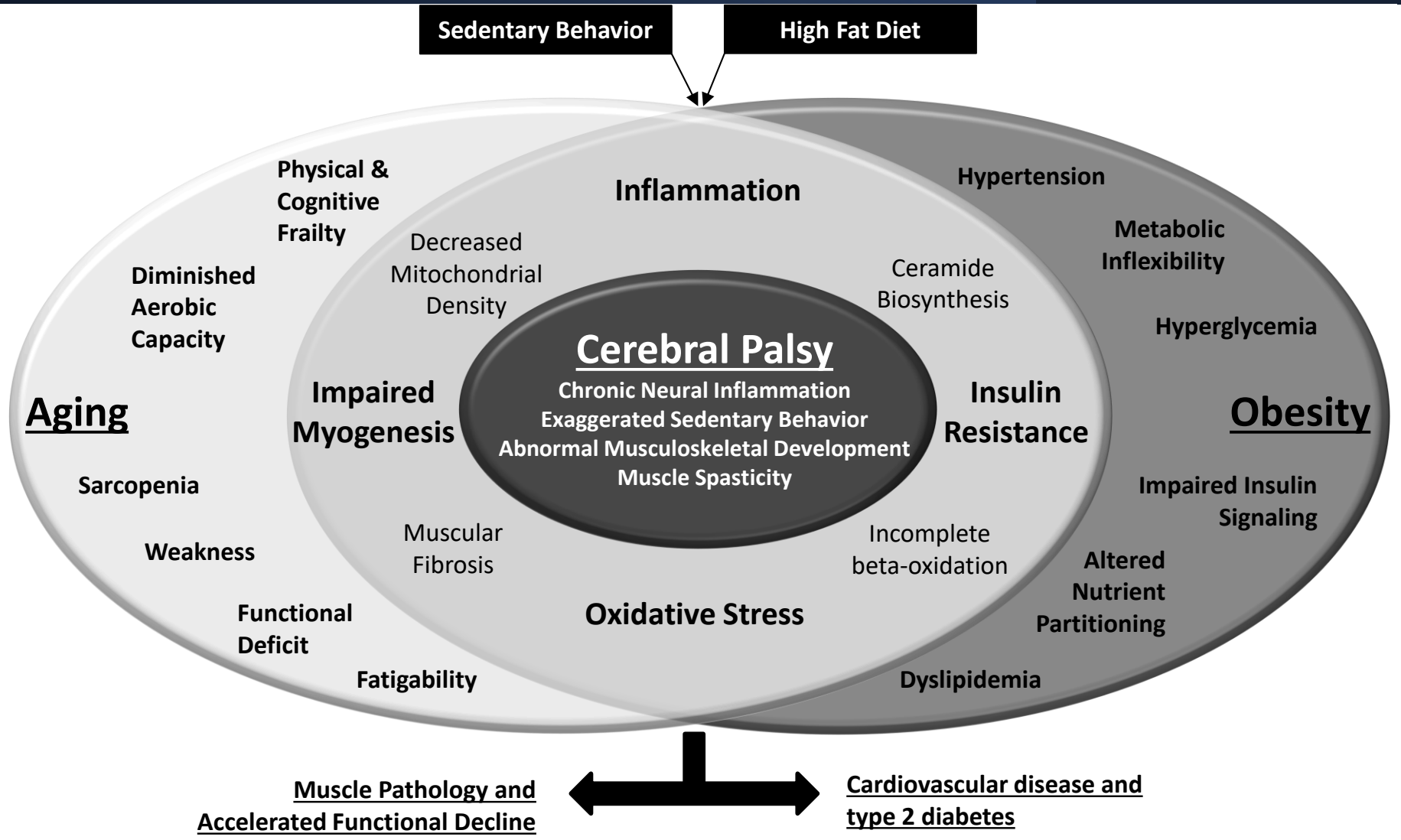
- CP is caused by a malformation or insult to the developing brain which affects motor control centers, and causes alterations in growth, development, and overall health
- Many individuals with CP can expect normal life expectancies, and yet there is a lack of clinical follow-up and coordination for patients after they transition from pediatric to adult primary care


frailty
physical functioning
mobility disability
chronic disease ris
CVD mortality
all-cause mortality

Lifespan Expectations in CP

- What happens to children, adolescents, and young adults with CP as they transition throughout adulthood?
- Currently there are more adults with CP living in the US than children with CP
- Contemporary jargon:
  - Accelerated aging
  - Premature frailty phenotype
  - Normal weight obesity
  - Exaggerated sedentariness

Natural History of Cerebral Palsy



ORIGINAL RESEARCH

Greater Adipose Tissue Distribution and Diminished Spinal Musculoskeletal Density in Adults With Cerebral Palsy

Mark D. Peterson, PhD, MS,[a] Peng Zhang, PhD,[b,c] Heidi J. Haapala, MD,[a] Stewart C. Wang, MD, PhD,[b,c] Edward A. Hurvitz, MD[a]

From the [a]Department of Physical Medicine and Rehabilitation; [b]Department of Surgery; and [c]Morphomic Analysis Group, University of Michigan, Ann Arbor, MI.

Abstract

Objectives: To examine differences in adipose tissue distribution, lumbar vertebral bone mineral density (BMD), and muscle attenuation in adults with and without cerebral palsy (CP), and to determine the associations between morphologic characteristics.

Design: Cross-sectional, retrospective analyses of archived computed tomography scans.

Setting: Clinical treatment and rehabilitation center.

Participants: Adults (N=352) with CP (age, 38.8±14.4y; body mass, 61.3±17.1kg; Gross Motor Function Classification System levels, I–V) and a matched cohort of neurotypical adults. Of the 41 adults with CP included in the study, 10 were not matchable because of low body masses.

Interventions: Not applicable.

Main Outcome Measures: Computed tomography scans were assessed for visceral adipose tissue (VAT) and subcutaneous adipose tissue (SAT) areas, psoas major area and attenuation in Hounsfield units (Hu), and cortical and trabecular BMDs.

Results: Adults with CP had lower cortical (β=−63.41 Hu, $P<.001$) and trabecular (β=−42.24 Hu, $P<.001$) BMDs and psoas major areas (β=−374.51mm^2, $P<.001$) and attenuation (β=−9.21 Hu, $P<.001$) after controlling for age, sex, and body mass. Adults with CP had greater VAT (β=3914.81mm^2, $P<.001$) and SAT (β=4615.68mm^2, $P<.001$). Muscle attenuation was significantly correlated with trabecular ($r=.51$, $P=.002$) and cortical ($r=.46$, $P<.01$) BMD, whereas VAT was negatively associated with cortical BMD (β=−.037 Hu/cm^2, $r^2=.13$, $P=.03$).

Conclusions: Adults with CP had lower BMDs, smaller psoas major area, greater intermuscular adipose tissue, and greater trunk adiposity than neurotypical adults. VAT and cortical BMD were inversely associated.

Archives of Physical Medicine and Rehabilitation 2015;96:1828-33

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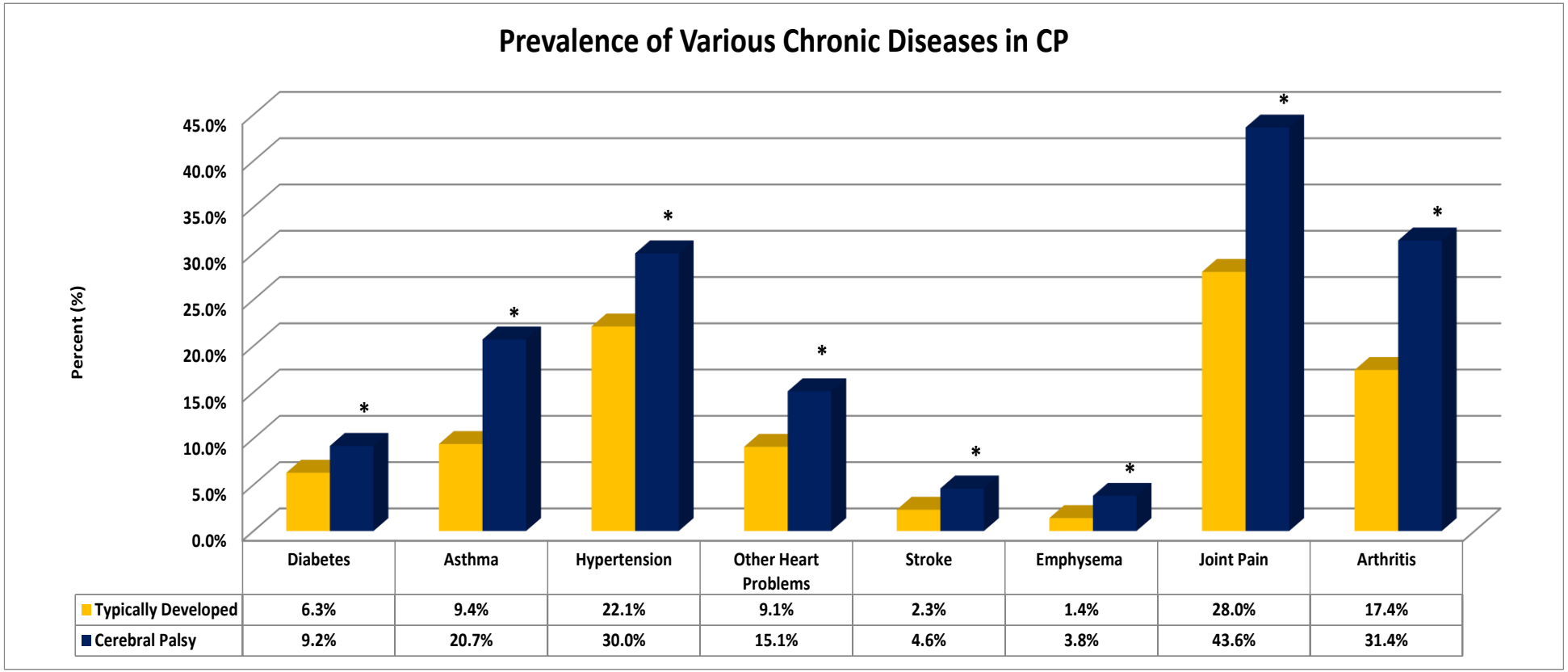
Given the loss/absence of lean body mass (muscle and bone), and increased storage of visceral and muscular adipose tissue, is there an increased risk for chronic diseases in CP?



	Diabetes	Asthma	Hypertension	Other Heart Problems	Stroke	Emphysema	Joint Pain	Arthritis
Typically Developed	6.3%	9.4%	22.1%	9.1%	2.3%	1.4%	28.0%	17.4%
Cerebral Palsy	9.2%	20.7%	30.0%	15.1%	4.6%	3.8%	43.6%	31.4%

Peterson, M.D., et al. *JAMA*. 314(21): 2303-05, 2015.

Is there evidence of “Early Aging”?

Clinical Epidemiology

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ORIGINAL RESEARCH

Noncommunicable disease and multimorbidity in young adults with cerebral palsy

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Purpose: Individuals with cerebral palsy (CP) are at increased risk for frailty and chronic disease due to factors experienced throughout the lifespan, such as excessive sedentary behaviors and malnutrition. However, little is known about noncommunicable diseases (NCDs) and multimorbidity profiles in young adults with CP. The study objective was to compare NCD and multimorbidity profiles between young adults with and without CP.

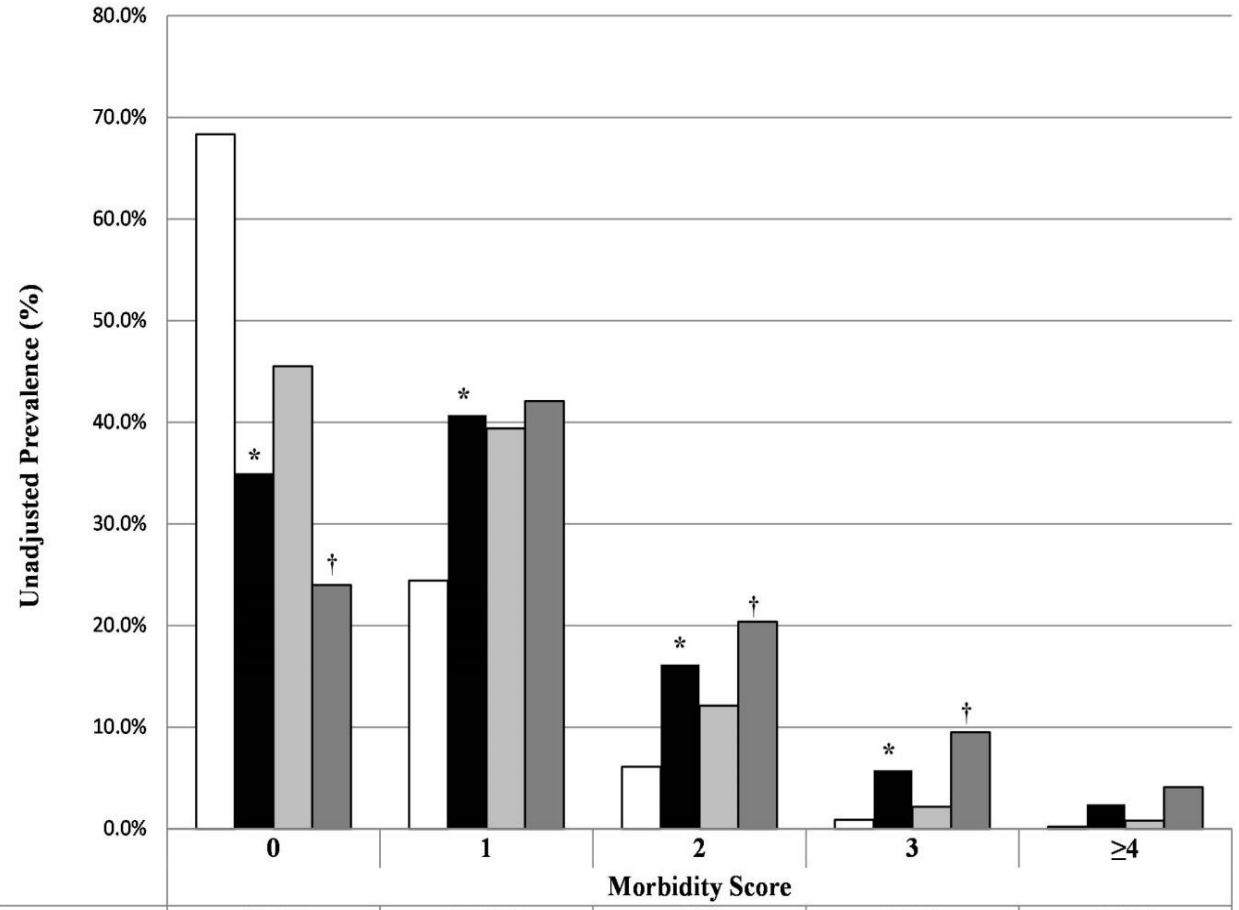
Methods: A clinic-based sample of adults (18–30 years) with (n=452) and without (n=448) CP was examined at the University of Michigan Medical Center. The prevalence and predictors of 13 NCDs were evaluated, including existing diagnoses or historical record of musculoskeletal, cardiometabolic, and pulmonary morbidities. The level of motor impairment was determined by the Gross Motor Function Classification System (GMFCS) and stratified by less vs more severe motor impairment (GMFCS I–III vs IV–V). Logistic regression was used to determine the odds of NCD morbidity and multimorbidity in adults with CP compared to adults without CP, and for GMFCS IV–V compared to GMFCS I–III in those with CP, after adjusting for age, sex, body mass index, and smoking.

Results: Adults with CP had a higher prevalence of osteopenia, osteoporosis, hypertension, myocardial infarction, hyperlipidemia, asthma, and multimorbidity compared to adults without CP, and higher odds of musculoskeletal (odds ratio [OR]: 6.97) and cardiometabolic morbidity (OR: 1.98), and multimorbidity (OR: 2.67). Adults with CP with GMFCS levels IV–V had a higher prevalence of osteopenia/osteoporosis, osteoarthritis, hypertension, other cardiovascular conditions, pulmonary embolism, and multimorbidity, and higher odds of musculoskeletal (OR: 3.41), cardiometabolic (OR: 2.05), pulmonary morbidity (OR: 1.42), and multimorbidity (OR: 3.45) compared to GMFCS I–III.

Conclusion: Young adults with CP have a higher prevalence of chronic NCDs and multimorbidity compared to young adults without CP, which is pronounced in those with more severe motor impairment. These findings reiterate the importance of early screening for prevention of NCDs in CP.

Keywords: cerebral palsy, noncommunicable disease, multimorbidity, osteoporosis, osteoarthritis, cardiovascular disease, diabetes, pulmonary disease

Is there evidence of “Early Aging”?



	0	1	2	3	≥4
□ Adults without Cerebral Palsy	68.3%	24.4%	6.1%	0.9%	0.2%
■ Adults with Cerebral Palsy	35.0%	40.7%	16.2%	5.8%	2.4%
▒ Adults with Cerebral Palsy: GMFCS I-III	45.5%	39.4%	12.1%	2.2%	0.8%
▒ Adults with Cerebral Palsy: GMFCS IV-V	24.0%	42.1%	20.4%	9.5%	4.1%

*Significant differences between adults with and without CP (*), and between GMFCS levels I-III vs IV-V (†); $p<0.05$.

ARTICLE OPEN ACCESS

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY ORIGINAL ARTICLE

Risk of early- and late-onset Alzheimer disease and related dementia in adults with cerebral palsy

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ORIGINAL RESEARCH

CME Article • 2021 Series • Number 10

Psychological, Cardiometabolic, and Musculoskeletal Morbidity and Multimorbidity Among Adults With Cerebral Palsy and Spina Bifida

A Retrospective Cross-sectional Study

Mark D. Peterson, PhD, MS, FACSM, Paul Lin, MS, Neil Kamdar, MA, Edward A. Hurvitz, MD, and Elham Mahmoudi, PhD

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n medical conditions and health care resource utilization and
as compared to adults without CP

Contents lists available at ScienceDirect

Bone

rnal homepage: www.elsevier.com/locate/bone

Review

OPEN

Blood pressure in adults with cerebral palsy: a systematic review and meta-analysis of individual participant data

Suzie Noten[a,b], Rita J.G. van den Berg-Emons[a], Deborah E. Thorpe[c], Patricia C. Heyn[d,e], Christina M. Marciniak[f,g], Patrick G. McPhee[h,i,j], Robert P. Lamberts[k,l], Nelleke G. Langerak[m], Olaf Verschuren[n], Tommi Salokivi[o], Katherine M. Morrison[p], Mark D. Peterson[q], Chonnanid Limsakul[r], Henk J. Stam[a], Grigorios Papageorgiou[s,t], Jorie Versmissen[u], and Wilma M.A. Van Der Slot[a,b]

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osteoporosis and inflammatory musculoskeletal
oral palsy: A population-based cohort study

nith[b], Mark D. Peterson[c], Nicola Ryan[d,e], Silvia Liverani[f],
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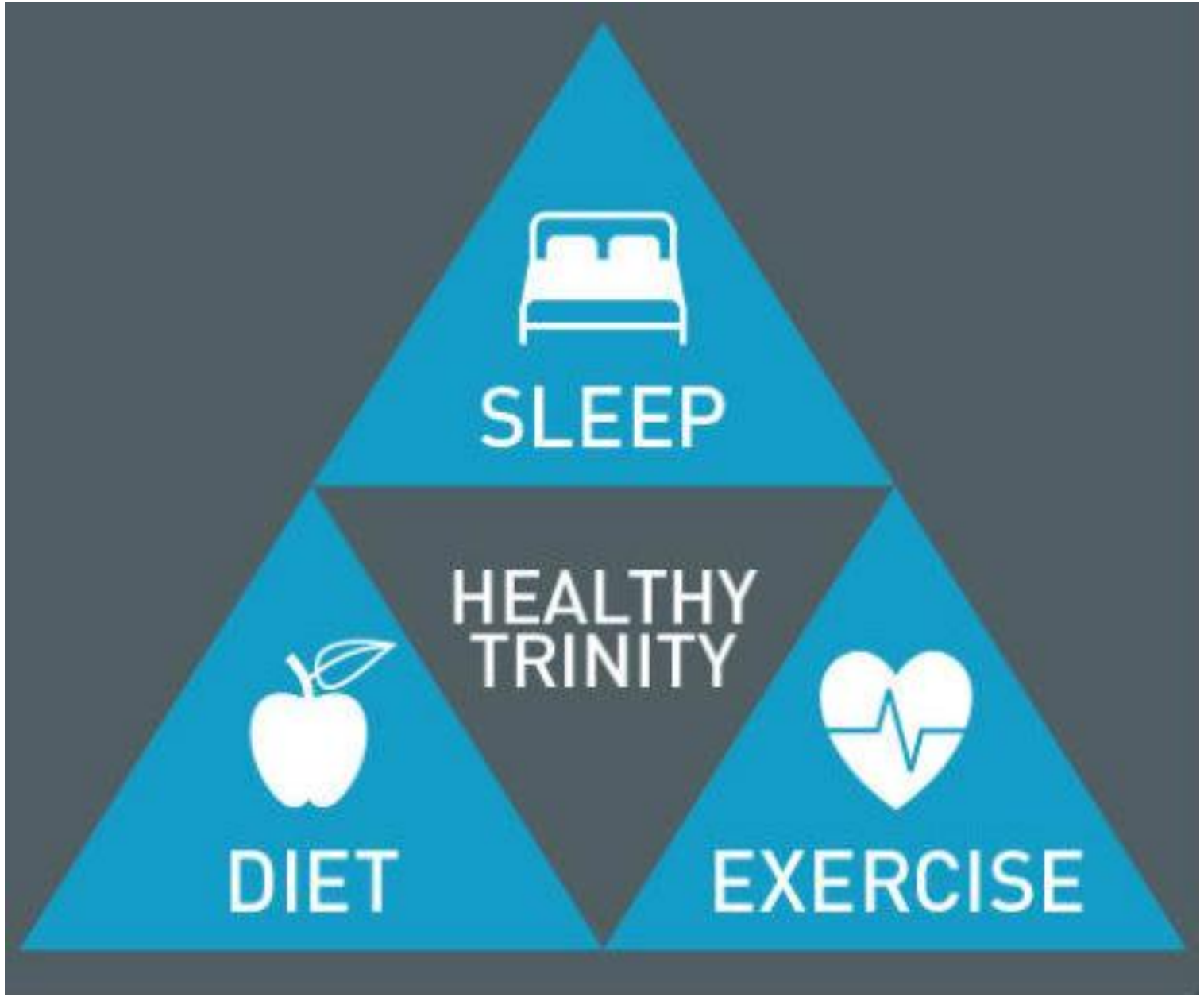
SLEEP
HEALTHY
TRINITY
DIET
EXERCISE

Information Base is Growing

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY REVIEW

Exercise and physical activity recommendations for people with cerebral palsy

OLAF VERSCHUREN[1] | MARK D PETERSON[2] | ASTRID C J BALEMANS[1,3] | EDWARD A HURVITZ[2]

1 Brain Center Rudolf Magnus and Center of Excellence for Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat Rehabilitation, Utrecht, the Netherlands. **2** Department of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, MI, USA. **3** Department of Rehabilitation Medicine, MOVE Research Institute Amsterdam, VU University Medical Center, Amsterdam, the Netherlands.

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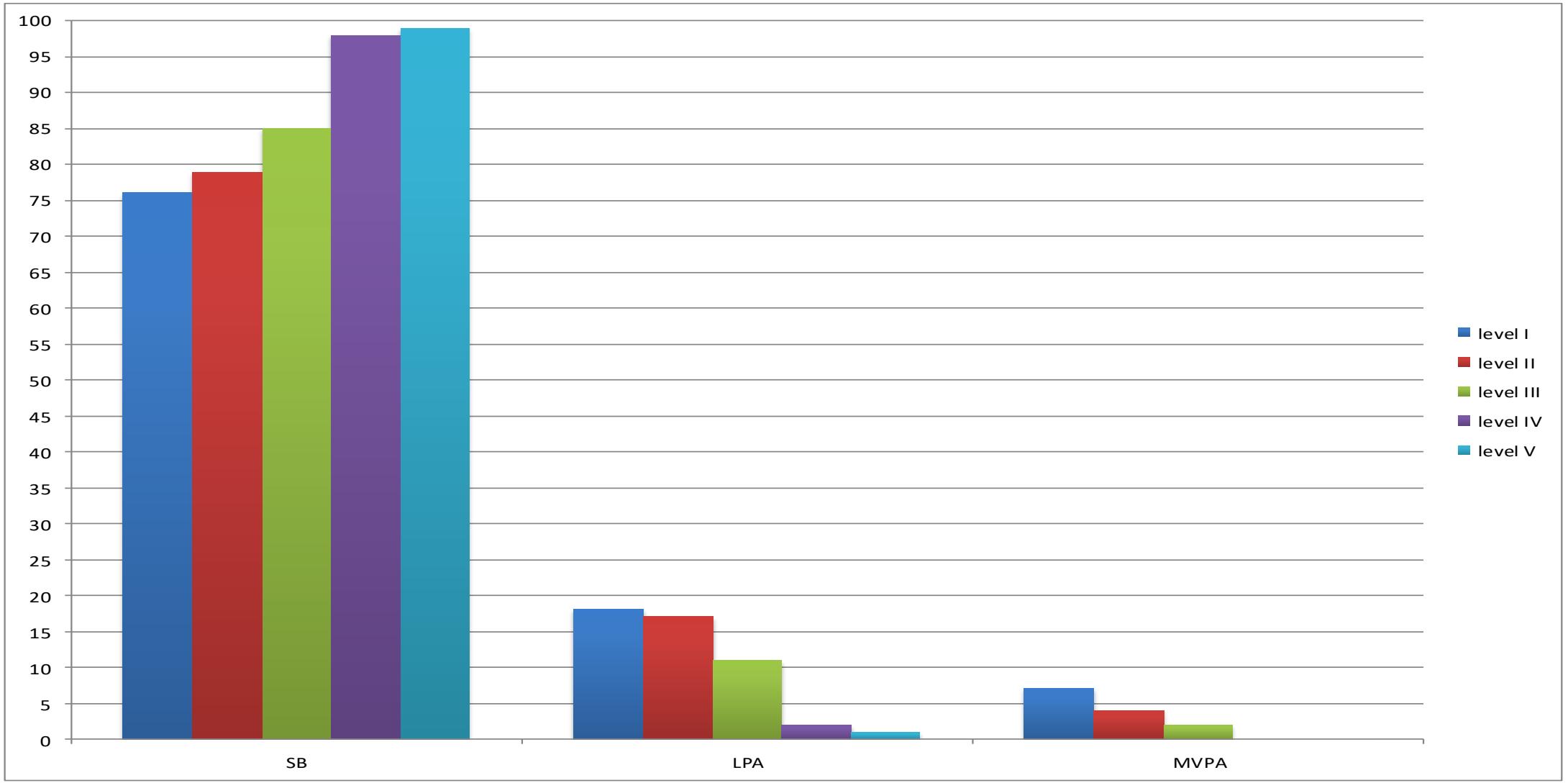
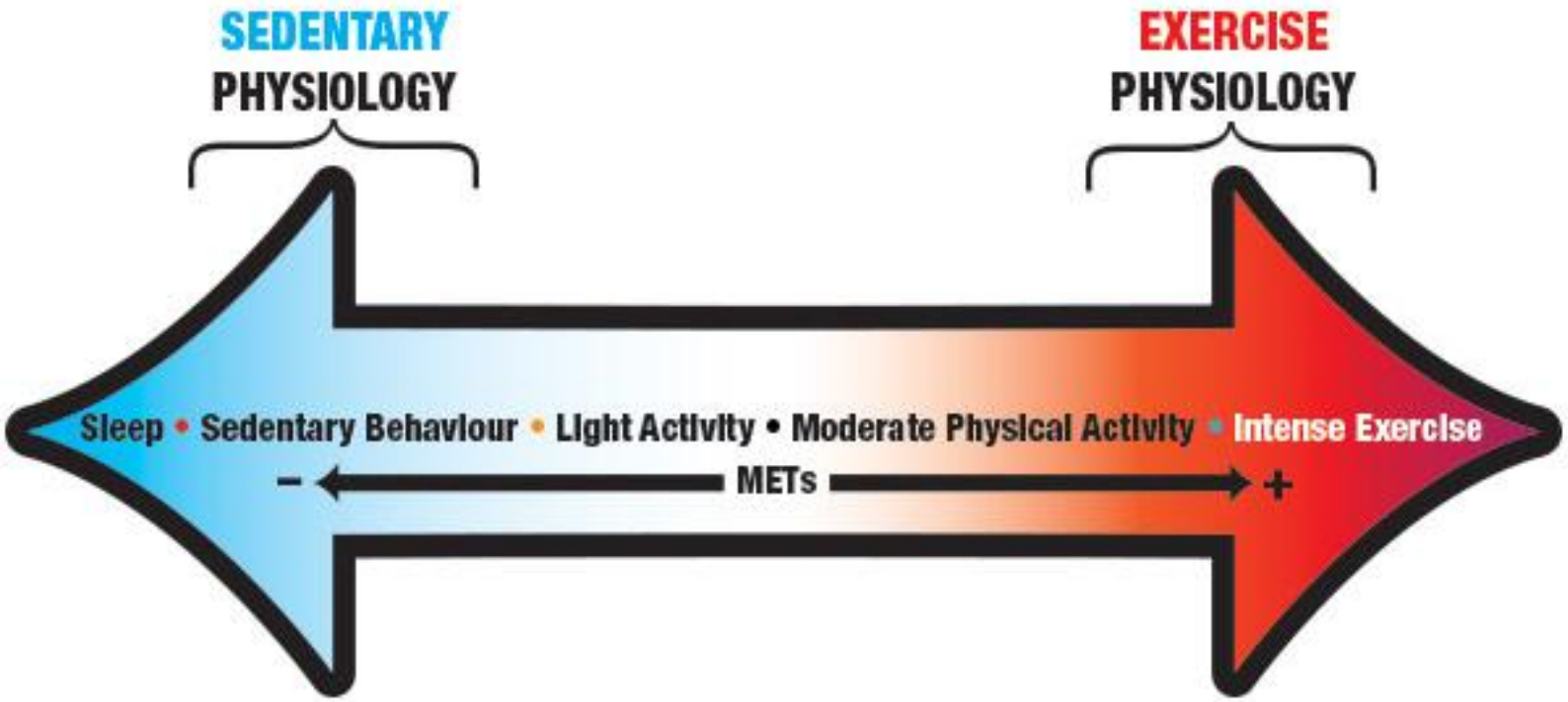
When we combine the findings from several studies:



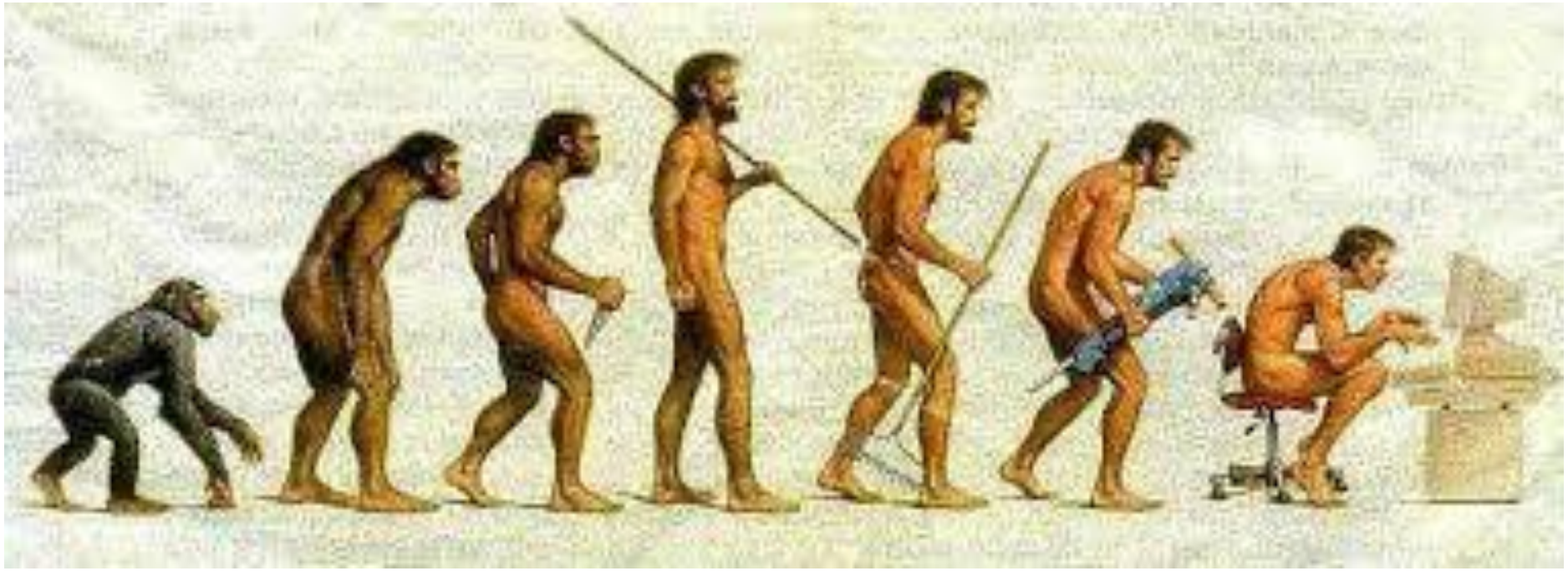
What is the Difference between Sedentary Vs. Inactive?



“If exercise could be packed in a pill, it would be the single most widely prescribed and beneficial medicine in the nation.”

Robert N. Butler, M.D.
Former Director,
National Institute on Aging

Dangers of Sedentary Behavior



***van der Ploeg HP, Chey T, Korda RJ, Banks E, Bauman A. Sitting time and all-cause mortality risk in 222,497 Australian adults. *Arch Intern Med.* 2012; 172(6): 494-500.**

A Packaging Problem

Received: 23 April 2021 | Accepted: 17 January 2022

DOI: 10.1111/dmcn.15181

ORIGINAL ARTICLE

A core outcome set for multimorbidity risk in individuals with cerebral palsy

Patrick G. McPhee[1,2,3] | Joyce L. Benner[4] | Liam Sanvido[5] | Marij E. Roebroeck[4] | Rita J. van den Berg-Emons[4] | Wilma M. van der Slot[4] | Olaf Verschuren[6] | Edward A. Hurvitz[7] | Mark D. Peterson[7] | Jan Willem Gorter[1,2,3]

Research Question and Clinical Vignette

- **Many patients and parents have raised concerns about mental health, especially from the context of lifespan health development.**
- **Is there increased risk for mental health disorders among adults with CP?**
- **How does chronic pain contribute to the burden of mental health concerns?**

Psychological Morbidity in the UK

Research

JAMA Neurology | Original Investigation

Risk of Depression and Anxiety in Adults With Cerebral Palsy

Kimberley J. Smith, PhD; Mark D. Peterson, PhD; Neil E. O'Connell, PhD; Christina Victor, PhD; Silvia Liverani, PhD; Nana Anokye, PhD; Jennifer M. Ryan, PhD

- 1,705 adults with CP and 5,115 matched adults from the UK
- Objective: Determine the incidence of depression and anxiety in adults with CP compared with an age-, sex-, and practice-matched reference group of adults without CP, using primary care data

Main Findings

		Events n (%)	*Person years in 10,000s*	*Incidence per 10,000 person years*	*Unadjusted HR (95% CI) and p-value*	*Adjusted HR †(95% CI) and p-value*
Depression	***No CP***	867 (16.95%)	49.93	0.017 (0.016-0.019)	1	1
	CP	312 (18.30%)	12.64	0.025 (0.022-0.028)	1.43 (1.24-1.64), *p<.001*	1.28 (1.09-1.51), *p=.003*
Anxiety	***No CP***	697 (13.63%)	51.67	0.013 (0.013-0.015)	1	1
	CP	261 (15.31%)	12.93	0.020 (0.018-0.023)	1.40 (1.21-1.63), *p<.001*	1.38 (1.15-1.64), *p<.001*

† Adjusted for baseline (i.e., pre-depression or pre-anxiety diagnosis) diagnosis of diabetes, heart disease, lung disease, osteoarthritis, epilepsy, pain conditions and GP visits per year.

Secondary Findings

- People with CP and no co-morbid ID had a higher risk of incident depression (HR 1.44: 95% CI 1.20-1.72) and anxiety (HR 1.55: 95%CI 1.28-1.87) than matched controls.

Prevalence of mental health disorders in the US

Annals of Internal Medicine

ORIGINAL RESEARCH

Prevalence of Mental Health Disorders Among Adults With Cerebral Palsy

A Cross-sectional Analysis

Daniel G. Whitney, PhD; Seth A. Warschausky, PhD; Sophia Ng, MPH, PhD; Edward A. Hurvitz, MD; Neil S. Kamdar, MA; and Mark D. Peterson, PhD, MS

- The prevalence of 37 mental health disorders was compared between adults with (n=7,348) and without (n=8.7+ million) CP- after adjusting for sociodemographics and neurodevelopmental comorbid conditions

Methods: Outcomes

1. “Schizophrenia, schizotypal disorder, delusional, and other non-mood psychotic disorders”
2. “Mood affective disorders”
3. “Anxiety, dissociative, stress-related, somatoform and other nonpsychotic mental disorders”
4. “Behavioral syndromes associated with physiological disturbances and physical factors”
5. “Disorders of adults personality and behavior”
6. “Alcohol or opioid related disorders”

Table 2. Age-Standardized Prevalence of Mental Health Disorder Categories for Study Participants

Category	Women			Men		
	CP Alone, % (95% CI)	CP and ND Disorder, % (95% CI)	Without CP, %	CP Alone, % (95% CI)	CP and ND Disorder, % (95% CI)	Without CP, %
Schizophrenia, schizotypal disorder, delusional, and other nonmood psychotic disorders	3.2 (2.5 to 3.9)	7.3 (5.8 to 8.8)	0.6	2.8 (2.2 to 3.4)	6.5 (5.1 to 7.9)	0.7
Mood affective disorders	28.6 (26.8 to 30.4)	28.8 (26.1 to 31.5)	14.3	19.5 (18.0 to 21.0)	23.3 (20.9 to 25.7)	8.1
Anxiety, dissociative, stress-related, somatoform, and other nonpsychotic mental disorders	28.6 (26.8 to 30.4)	29.6 (26.9 to 32.3)	18.0	19.5 (18.0 to 21.0)	21.7 (19.4 to 24.0)	11.1
Behavioral syndromes associated with physiologic disturbances and physical factors	2.0 (1.5 to 2.5)	1.7 (0.9 to 2.5)	1.8	2.1 (1.5 to 2.7)	2.1 (1.3 to 2.9)	1.7
Disorders of adult personality and behavior	1.2 (0.8 to 1.6)	4.4 (3.2 to 5.6)	0.4	1.2 (0.8 to 1.6)	4.1 (3.0 to 5.2)	0.3
Alcohol- and/or opioid-related disorders	2.8 (2.2 to 3.4)	2.2 (1.3 to 3.1)	1.8	4.7 (3.9 to 5.5)	2.4 (1.5 to 3.3)	3.0

CP = cerebral palsy; ND = neurodevelopmental.

Pain phenotypes in CP and SB

Pain Taxonomy

- **Nociceptive Pain**: [or peripheral pain] pain that originates from physical damage or overuse/injury

- **Neuropathic Pain**: pain caused by damage or disease affecting the somatosensory nervous system.

- **Nociplastic (Centralized) Pain**: [newer designation] central nervous system augmented pain processing that manifests as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage
  - International Association for the Study of Pain (IASP) task Force

Research Paper

PAIN®

Pain phenotypes among adults living with cerebral palsy and spina bifida

Mark D. Peterson[a,b,*], Heidi Haapala[a], Neil Kamdar[b,c,d,e], Paul Lin[b], Edward A. Hurvitz[a]

- Methods: Privately-insured beneficiaries were included if they had an ICD-9-CM diagnostic code for CP or SB (n= 24,497). Adults without CP or SB were also included (n= 931,528).
- Results: Adults living with CP or SB had a higher prevalence of *any* pain disorders (55.9% vs. 35.2%) and pain multimorbidity (21.8% vs 8.4%), as compared to adults without CP or SB, and differences were to a clinically meaningful extent.

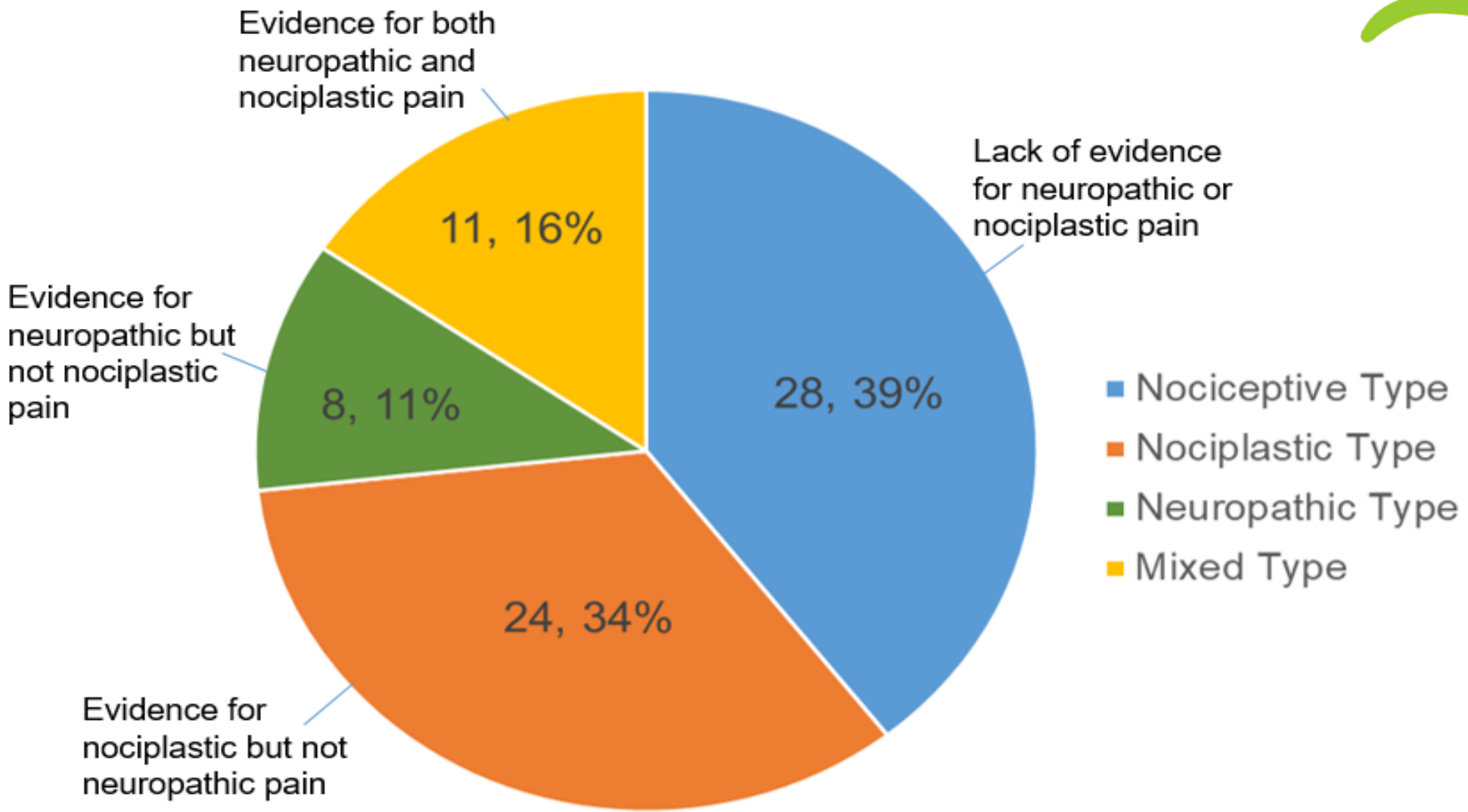
- Crude Pain Prevalence (CP/SB vs controls):
  - Nociceptive Pain: 44.0% vs. 26.7%
  - Nociplastic Pain: 26.1% vs. 11.9%
  - Neuropathic Pain: 9.6% vs. 5.6%

- Adjusted logit models (reference: controls):
  - Nociceptive Pain: OR = 2.20 (95%CI: 2.15, 2.24)
  - Nociplastic Pain: OR = 2.47 (95%CI: 2.41, 2.53)
  - Neuropathic Pain: OR = 2.71 (95%CI: 2.54, 2.89)

Pain phenotypes in adults living with CP: A deeper dive at UM

- Aim: To identify pain phenotypes among adults with CP based on putative mechanisms.

- Methods: Data were collected from n=71 adults with CP who presented to the University of Michigan Medicine (mean age = 39.3±16.2; 43 females, 28 males).


Evidence for both neuropathic and nociplastic pain
11, 16%
Lack of evidence for neuropathic or nociplastic pain
28, 39%
Evidence for neuropathic but not nociplastic pain
8, 11%
24, 34%
Evidence for nociplastic but not neuropathic pain
Nociceptive Type
Nociplastic Type
Neuropathic Type
Mixed Type

Secondary Analyses

- **Scoring positive for nociplastic pain predicted significantly worse self-reported (PROMIS) depression and perceived stress** above and beyond the effects of pain intensity
- Findings suggest that *type of pain is highly variable among adults with CP*, and may arise through multiple mechanisms.
- Although nociceptive pain is common in CP, pain arising from neuropathic and/or nociplastic mechanisms correlates with poorer HRQOL outcomes compared to pain that arises from purely nociceptive mechanisms.

JAMA Network

JAMA Neurology

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August 5, 2024

Pain Phenotypes and Pain Multimorbidity Among Medicare Beneficiaries With Cerebral Palsy

Mark D. Peterson, PhD, MS[1,2]; Kathryn Ashbaugh, BS[2]; Michael O'Leary, BS[2]; Mary Schmidt, DO[1]; Heidi Haapala, MD[1]; Neil Kamdar, MA[2,3,4]; Edward A. Hurvitz, MD[1]

» Author Affiliations | Article Information

JAMA Neurol. 2024;81(9):1004-1005. doi:10.1001/jamaneurol.2024.2443

Results

- A total of 21 767 patients **(89.0%)** had 1 or more documented pain diagnoses, 2697 (11.0%) had no pain diagnosis, 3708 (15.2%) had a single pain condition throughout the study period, 18 059 (73.8%) exhibited pain multimorbidity (ie, ≥2 diagnoses), and 7259 (**29.7%**) had pain extreme multimorbidity (ie, ≥5 diagnoses).

- The distribution of patients by pain phenotype was 21 101 (86.3%) with *any* evidence of nociceptive pain, 11 213 (45.8%) with *any* evidence of nociplastic pain, and 4139 (16.9%) with *any* evidence of neuropathic pain.

MAYO CLINIC

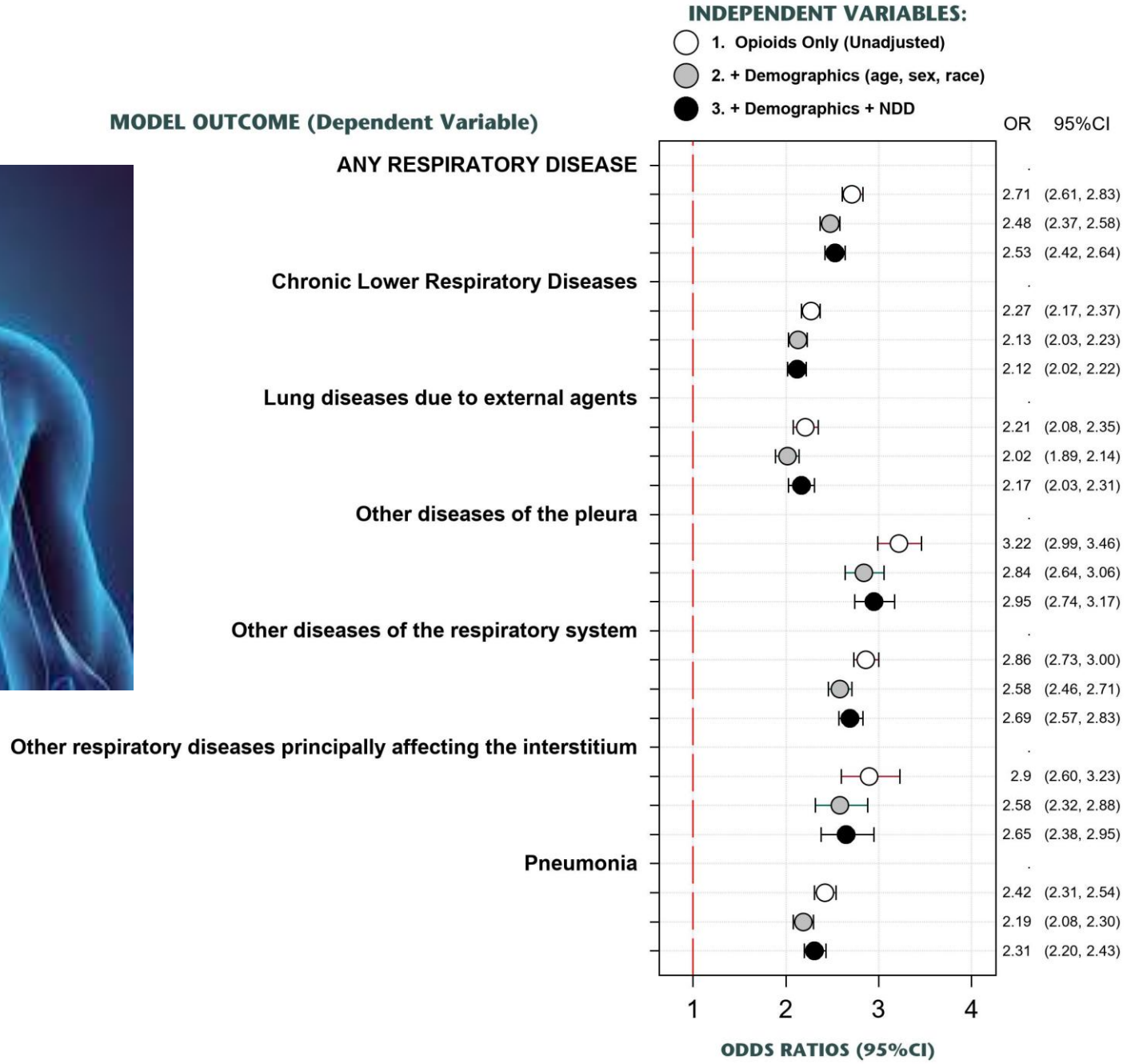
MAYO CLINIC PROCEEDINGS:
INNOVATIONS, QUALITY & OUTCOMES

ORIGINAL ARTICLE

Medication and Therapy Profiles for Pain and Symptom Management Among Adults With Cerebral Palsy

Mark D. Peterson, PhD, MS; Michael O'Leary, BS; Kathryn Ashbaugh, BS; Heidi Haapala, MD; Mary Schmidt, DO; Neil Kamdar, MA; and Edward A. Hurvitz, MD

	No Pain	Neuropathic Pain/Nociceptive Pain	Neuropathic Pain/Nociceptive Pain/Nociplastic Pain	Nociceptive Pain	Nociceptive Pain/Nociplastic Pain
	(N=5,529, 13.3%)	(N=1,856, 4.5%)	(N=5,229, 12.6%)	(N=15,973, 38.4%)	(N=11,887, 28.6%)
Botulinum toxin A injections, n (%)	41 (0.7%)	153 (8.2%)	661 (12.6%)	958 (6.0%)	912 (7.7%)
Non-perioperative opioids, n (%)	872 (15.8%)	1046 (56.4%)	4175 (79.8%)	5149 (32.2%)	6054 (50.9%)
PT/OT, n (%)	423 (7.7%)	1086 (58.5%)	3517 (67.3%)	6180 (38.7%)	5871 (49.4%)
Anti-depressants, n (%)	1630 (29.5%)	1051 (56.6%)	3940 (75.3%)	6302 (39.5%)	6786 (57.1%)
Anti-epileptics, n (%)	2395 (43.3%)	1245 (67.1%)	4172 (79.8%)	8857 (55.4%)	7010 (59.0%)
Anticholinergics, n (%)	411 (7.4%)	190 (10.2%)	508 (9.7%)	1876 (11.7%)	1506 (12.7%)
Antihistamines, n (%)	55 (1.0%)	23 (1.2%)	66 (1.3%)	255 (1.6%)	143 (1.2%)
Antipsychotics, n (%)	1328 (24.0%)	584 (31.5%)	2209 (42.2%)	4725 (29.6%)	4675 (39.3%)
Benzodiazepines, n (%)	1549 (28.0%)	816 (44.0%)	2896 (55.4%)	6806 (42.6%)	5387 (45.3%)
CNS Stimulants, n (%)	131 (2.4%)	58 (3.1%)	274 (5.2%)	255 (1.6%)	316 (2.7%)
Clonidine, n (%)	301 (5.4%)	329 (17.7%)	1602 (30.6%)	1339 (8.4%)	1571 (13.2%)
IBS medications, n (%)	372 (6.7%)	407 (21.9%)	2037 (39.0%)	2320 (14.5%)	3145 (26.5%)
Metoclopramide, n (%)	95 (1.7%)	112 (6.0%)	486 (9.3%)	948 (5.9%)	856 (7.2%)
Migraine medications, n (%)	19 (0.3%)	24 (1.3%)	483 (9.2%)	68 (0.4%)	517 (4.3%)
Muscle Relaxants, n (%)	557 (10.1%)	790 (42.6%)	3117 (59.6%)	3873 (24.2%)	4211 (35.4%)
NSAIDs, n (%)	972 (17.6%)	907 (48.9%)	3647 (69.7%)	5418 (33.9%)	6422 (54.0%)
Parkinson's Tremors, n (%)	47 (0.9%)	106 (5.7%)	501 (9.6%)	374 (2.3%)	468 (3.9%)



NOTE: 95% Confidence Intervals (|-----|) that do not cross the red reference line (OR=1) are statistically significant (p<0.001); NDD= neurodevelopmental disorders, OR= odds ratio, CI= confidence interval

- Must extend work into understanding:
  - Long term consequences of opioid use in CP, as well as the effectiveness of alternative therapies (e.g., cbd/thc, behavioral interventions [sleep interventions, cbt, exercise], others.)
  - Preventive screening to reduce preventable morbidity and mortality
  - Reduce healthcare disparities across the lifespan by improving care coordination and continuity through transition
  - Develop clinical practice guidelines for adults with CP
  - What are the biological/physiological/epigenetic mechanisms of premature aging in CP
  - Change the definition of CP to acknowledge lifespan…

Reframing Cerebral Palsy as a Lifelong Physical Disability

“My doctor told me that I couldn’t have cerebral palsy because I am no longer a child.”

“Things I took for granted as a kid — physical therapy consistently covered by insurance, an understanding of how CP would affect my life, and an assumption that all of my CP-related questions had answers— were totally upended in my 30s."

“A medical support structure carefully built over decades, gone in a minute."

There is wide variation in functioning and health status among people with [cerebral palsy]. But care for adults remains siloed in subspecialties carried over from pediatrics.

PERSPECTIVE

Mark D. Peterson, Ph.D.

The NEW ENGLAND JOURNAL of MEDICINE

EXPERT-CONSENSUS REPORT

Proposed updated description of cerebral palsy

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Abstract

'Cerebral palsy' ('CP') is a widely used descriptive label for a spectrum of motor impairments caused by non-progressive brain injury or malformation occurring during early development. Advances in research have significantly refined our understanding of CP, including insights into its genetic, inflammatory, and neurophysiological underpinnings. Research across global contexts, including low- and middle-income countries, has expanded knowledge of clinical features. Shifting societal perceptions, driven by individuals with lived experience, have further influenced how CP is understood, challenging ableist attitudes and promoting inclusive frameworks. Additionally, increased recognition of the needs and experiences of adults with CP has highlighted the importance of further developing appropriate services. The primary aim of this paper is to propose an updated description of CP, developed through a collaborative, multidisciplinary process, as a preliminary formulation that integrates stakeholder perspectives at this stage of the process. By framing it as a foundation for further discussion and refinement, the manuscript emphasizes the output itself rather than the process of its development. A comprehensive stakeholder analysis and mapping approach ensured broad representation, including individuals with CP, families, clinicians, researchers, advocacy groups, and others. Data were collected through surveys, interviews, focus groups, and workshops, facilitating a global dialogue that combined the expertise of those with lived experience with that of clinicians. The description is intended to serve as a preliminary framework to guide clinical practice, research, and policy, emphasizing a shared understanding of CP. The proposed updated description thus lays the foundation for continued refinement, emphasizing the importance of collaboration in advancing the care and inclusion of individuals with CP.

PERSPECTIVE AND CONTROVERSY

MAYO CLINIC

Check for updates

Cerebral Palsy Grows Up

Mark D. Peterson, PhD, MS, and Edward A. Hurvitz, MD

- 80% of all work published in the last 15 years
- U.S., Australia, Canada, U.K., Netherlands, Sweden, France, Japan, Spain, Germany, Ireland, Norway, Denmark, South Korea, and Brazil represent the vast majority of this work

ORIGINAL ARTICLE

Recent trends in National Institutes of Health funding for cerebral palsy lifespan research

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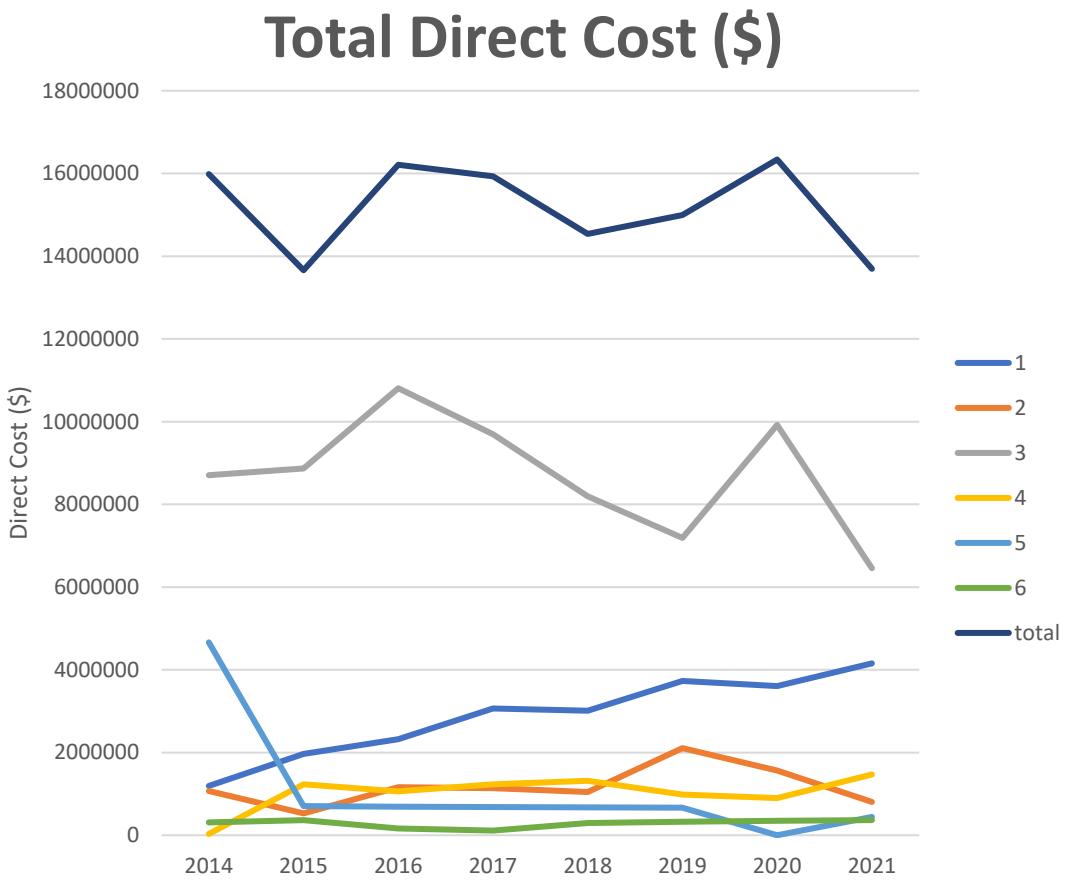
Abstract

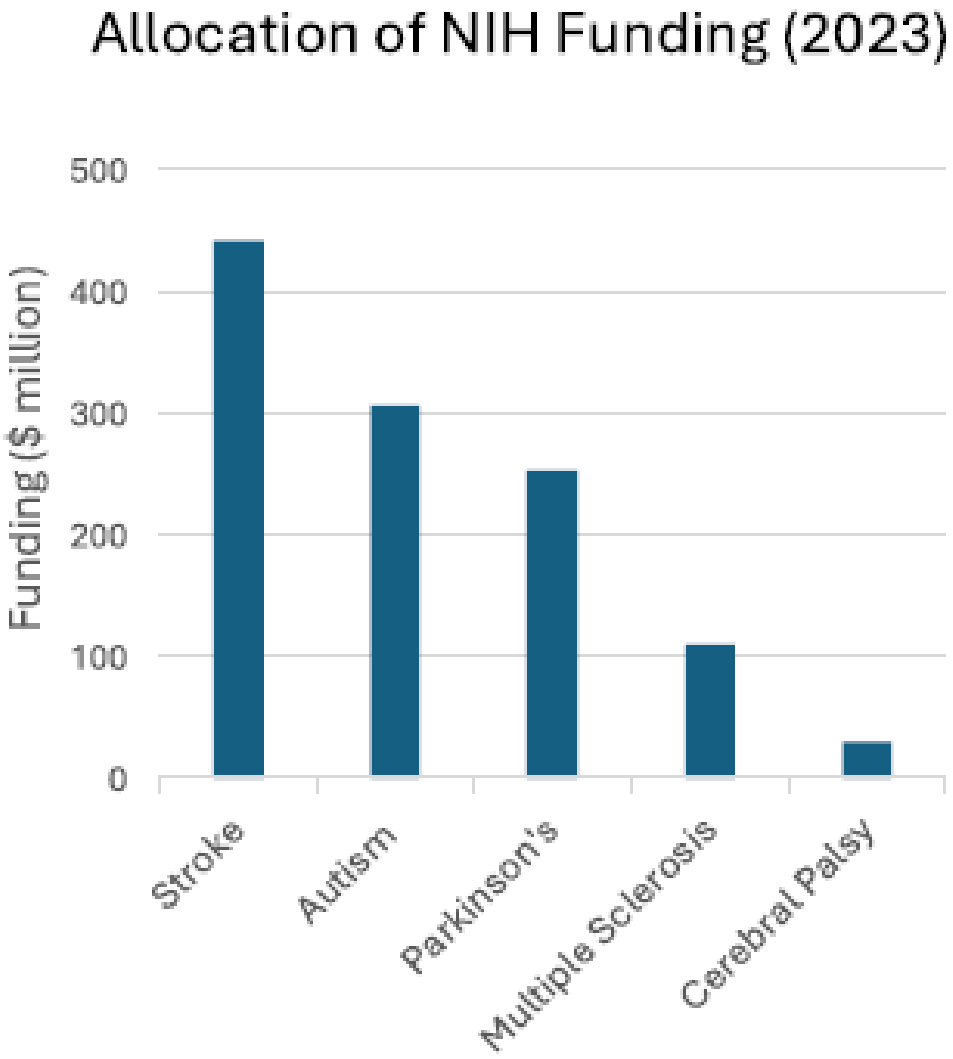
Aim: To determine the landscape of recent National Institutes of Health (NIH) funding for cerebral palsy (CP)-related research regarding lifespan issues.

Method: This longitudinal study examined NIH funding for CP-related research between 2014 and 2023, particularly focusing on lifespan issues. We searched NIH databases Research Portfolio Online Reporting Tools Expenditures and Results, and Research, Condition, and Disease Categorization for keyword 'cerebral palsy'. We classified grants by type and area of study.

Results: From 2014 to 2023, CP NIH funding averaged US$22.7 million per year, not adjusted for inflation, for a total cost of US$226.7 million. This supported research pertaining to treatments/early interventions (51.0% of total), causes/mechanisms/risk factors (22.6%), and screening/early detection/diagnosis (9.6%). Infrastructure/surveillance funding was 6.6%, whereas services/implementation research received 7.9%. Funding for lifespan/adulthood CP research represented only 2.3% of funding. Annual NIH funding for CP increased steadily over the period from US$22.0 million in 2014 to US$24.8 million in 2023; however, funding focused on lifespan studies has been relatively unchanged, never rising above US$0.91 million.

Interpretation: While NIH funding for CP studies increased over the study period, lifespan studies have not. Additional research funds are needed to improve the clinical care and understanding of lifespan needs faced by individuals living with CP.





1. Causes, Mechanisms and Risk Factors of CP (animal or human)
2. Screening and early detection/diagnosis
3. Treatments and Early Interventions
4. Services or Implementation Research for pediatric care
5. Infrastructure and Surveillance
6. Lifespan Issues (anything related to adults with CP)

Acknowledgments

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- National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
- Craig H. Neilsen Foundation
- Cerebral Palsy Foundation
- Cerebral Palsy Research Network

Thank you, members of the UM Adult group!

Edward Hurvitz, M.D.

Daniel Whitney, Ph.D.

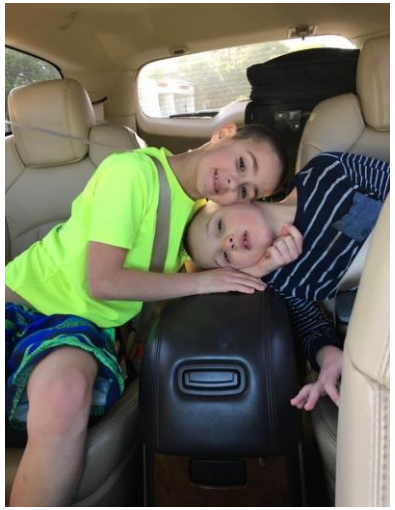
Heidi Haapala, M.D.

Mary Schmidt, DO

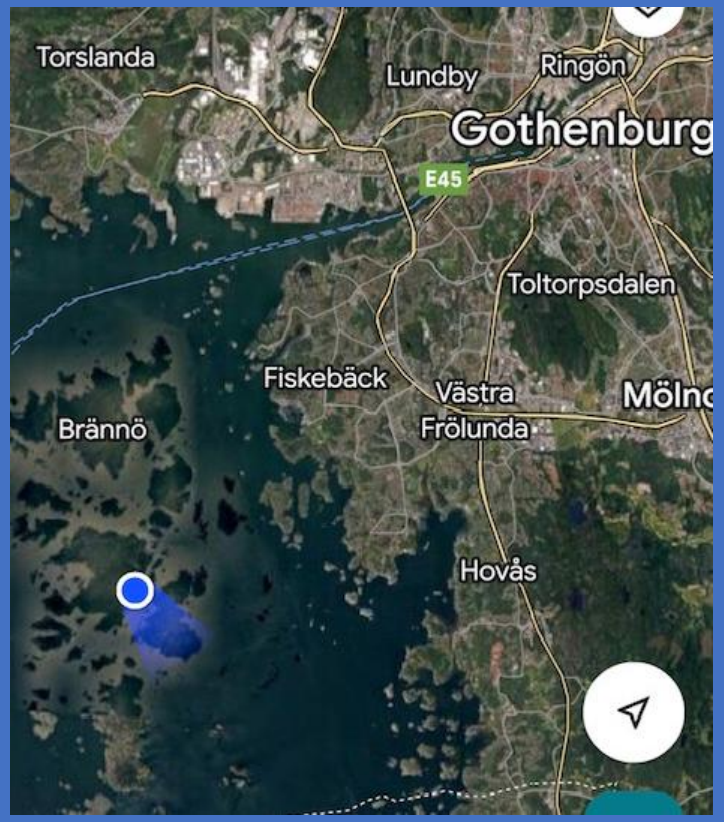
Jodi Kreschmer, MSW











Torslanda
Lundby
Ringön
Gothenburg
E45
Toltorpsdalen
Fiskebäck
Västra
Frölunda
Brännö
Hovås

Thank you!

Any Suggestions While in Western Sweden:
mdpeterz@med.umich.edu

Välkommen till CPUP-dagarna!

CPUP

6 – 7 oktober 2025
Online