

Mapping the scope of pain assessment in studies of youth with brain-based developmental disabilities: A systematic review

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The Problem

Pain occurs more often in youth with brain-based developmental disabilities than their peers. Yet, their pain is difficult to ascertain, we do not know how their pain is being assessed.

Our Goal

To identify and map the scope of self and observer-reported pain assessment measures of youth with brain-based developmental disabilities.

Our Team

Parents/caregivers, health professionals (pain, complex care, neuro-developmental disabilities), and researchers across Canada.

Methods

Registered on PROSPERO (CRD42021237444)

Academic database searches included: CINAHL, Medline, Web of Science, CENTRAL, PsychINFO, and EMBASE



Inclusion Criteria

- Children 3-24 years old with a brain-based developmental disability
 - Individuals with a diagnosis of a brain-based disorder (e.g., autism spectrum disorder, ADHD, FASD, cerebral palsy, intellectual or learning disabilities), and individuals at high risk for a brain-based disorder (e.g., preterm birth, congenital heart disease, genetic anomaly).
- Pain experience of any kind (e.g., acute, chronic)
- Empirical studies [quantitative or qualitative], review articles, commentary, editorials, letters to the editor
- Published in English
- Behavioural or patient-reported assessment measures (e.g., self-report, observer-report, behavioural observation)

Conclusions

Pain assessment for youth with brain-based developmental disabilities predominantly focuses on pain severity/intensity via observer-report.



Results

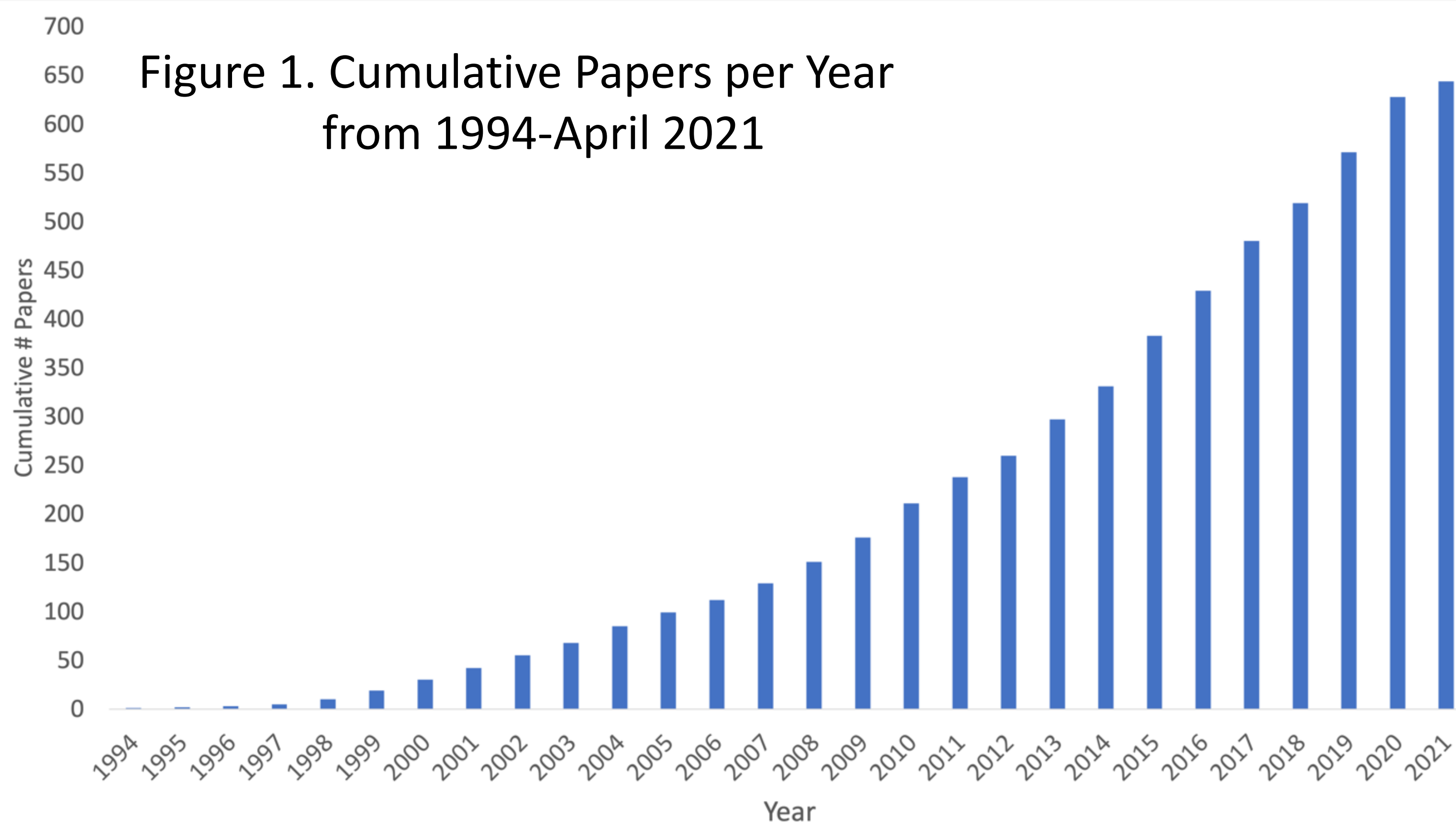
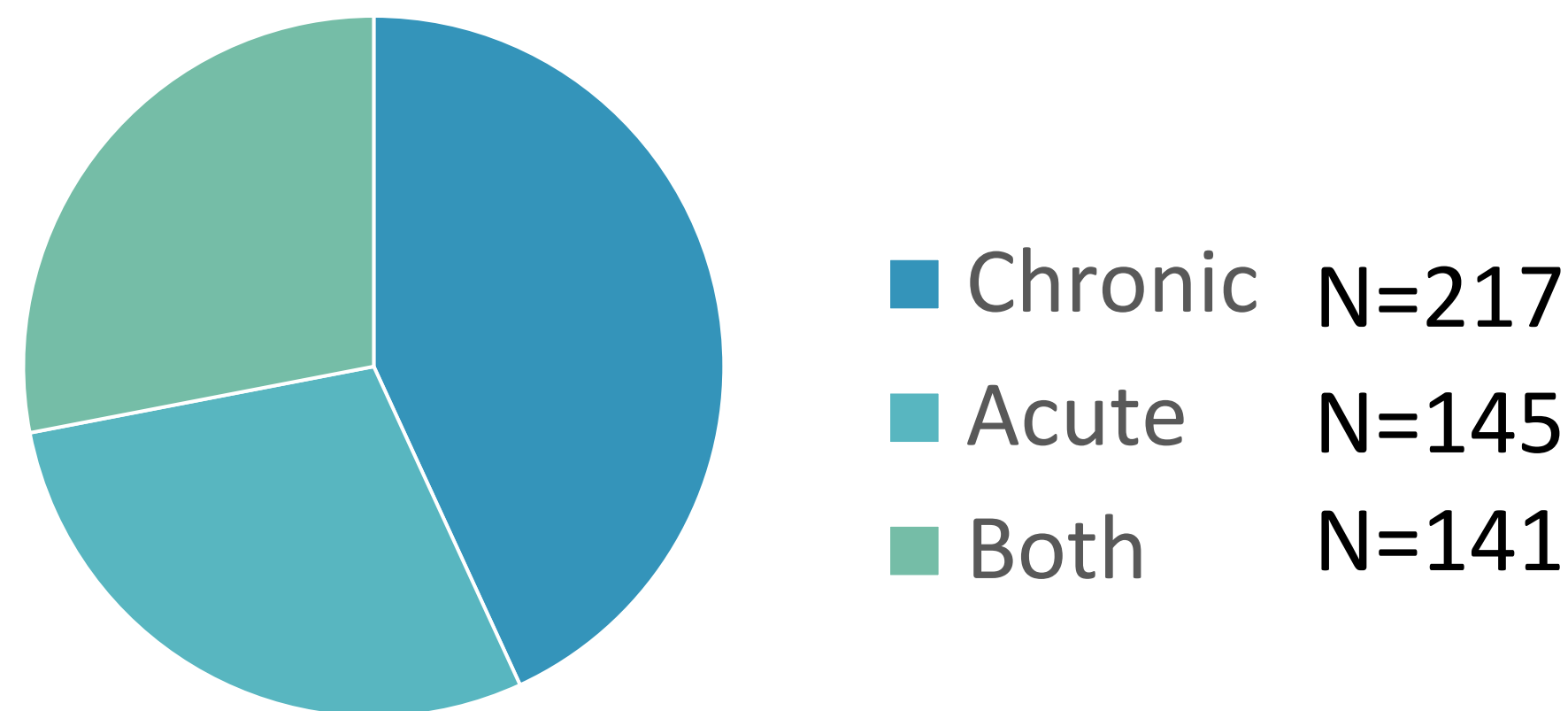


Figure 2. Types of Included Articles



Figure 3. Proportion of Articles Assess Type of Pain



- 9,117 non-duplicate records were screened**
 - 644 articles met inclusion criteria**
- Patient populations included:
 - cerebral palsy (n=307; 47.6%)
 - intellectual disability (n=64; 9.9%)
 - Autism Spectrum Disorder (n=57; 8.8%)
 - ADHD (n=25; 3.9%)
 - Other (n=191; 29.7%)
- 18 self-report and 30 observer-report measures were used

Next Steps

Phase 2 of this review will provide recommendations based on further analyses and the findings of this review.