Chronic pain PROMs are not always feasible for people with cerebral palsy who have cognitive and/or communication limitations

Background

People with cerebral palsy have varying communication, cognitive, visual and functional abilities.

The feasibility of using existing chronic pain measures is unknown.

Methods

The aim was to develop and test reliability of a Cerebral Palsy Specific Feasibility Rating Tool.

Concepts of:
- Appropriateness
- Accessibility
- Practicality

Identify existing chronic pain tools with well-established measurement properties.

COSMIN

Rate feasibility of existing chronic pain measures using the Cerebral Palsy Specific Feasibility Rating Tool in 4 key areas.

- Screening
- Interference
- Pain Coping
- Observational

Results

Reliability of the 11 items of the Feasibility Rating Tool combined was almost perfect. Kappa = 0.88 (95%CI: 0.87 to 0.89)

Of the 63 existing chronic pain measures identified, the most promising for people with cerebral palsy were:

1. Screening
- Pain Burden Inventory Youth
- Pain Interference Index
- CP QoL-teen pain and bother subscale

2. Interference Measures
- PROMIS Pain Interference-sf
- Modified Brief Pain Inventory
- Bath Adolescent pain Questionnaire

3. Pain Coping Measures
- Fear of Pain Questionnaire and Fear of Pain questionnaire-sf
- Bath Adolescent Pain Questionnaire

4. Observational Measures
- Paediatric Pain Profile
- Non-Communicating Childs Pain Checklist-Revised
- CP-CHILD

Existing tools need modification to ensure that everybody has the right to self-report wherever possible.

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