

# Pilot Study of the Feasibility of the Non-Communicating Children's Pain Checklist Revised for Pain Assessment for Adults with Intellectual Disabilities



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## Abstract

It is suspected that those with intellectual disabilities (ID) experience more pain than the general population, yet there are no well-validated measures for pain assessment in adults with ID. This research aims to respond to this need by validating the Non-Communicating Children's Pain Checklist - Revised (NCCPC-R) for use with adults with ID during chronic or recurrent pain. Staff at a regional residential facility observed participants ( $N = 16$ ) during two conditions (pain; no-pain) for 5-minute periods. The two staff independently completed both the NCCPC-R and a 10 cm visual analogue scale (VAS) of pain. Analyses indicated 6 of the 30 items should be removed from the NCCPC-R. Internal consistency (Cronbach's  $\alpha = .86$ ), inter-rater reliability ( $ICC = .83$ ) and construct validity ( $r(15) = 7.03$ ,  $p < .001$ ) of a new 24-item scale indicate good psychometric properties. A cut-off score of 10 provided 94% sensitivity and 87% specificity for pain. Results indicated revisions should be made to the NCCPC-R to improve psychometric properties when used for chronic or recurrent pain in adults with ID. Our new scale, which we have called the Chronic Pain Scale for Nonverbal Adults with Intellectual Disabilities (CPS-NAID), displays good psychometric properties in this pilot study. Future studies should include both the NCCPC-R and the CPS-NAID to confirm these results.

## Introduction

- Pain is especially difficult to assess in those with intellectual disabilities (ID) due to limited communication, behavioural problems and behavioural inconsistencies.
- Adults with ID have more medical conditions, many of which cause pain (Beange, McElduff, & Baker, 1995).
- There is currently no well-validated observational assessment tool specifically designed to measure pain in adults with ID.
- The Non-Communicating Children's Pain Checklist Revised (NCCPC-R) has been used previously to assess pain in adults during vaccination (Defrin, Lotan, & Pick, 2006); however, vaccination pain differs from chronic pain in frequency, intensity and duration.
- The purpose of this study is to provide preliminary evidence in support of using the NCCPC-R for pain assessment in adults with ID.

## Methods

- Participants:** ( $N = 16$ )
- Residents of Kings Regional Rehabilitation Centre, non-verbal and had chronic pain
- Painful Medical Conditions:**
- Constipation, dysmenorrhea, seizures, spasticity, cerebral palsy, self injury, scoliosis
- Measures:**
- Health record information
  - Vineland II Adaptive Behaviour Scales (Sparrow, Cicchetti & Balla, 2005)
  - Non-Communicating Children's Pain Checklist
  - 10 cm Visual Analogue Scale of Pain anchored with "no pain at all" and "worst pain ever"
- Procedure:**
- Participants observed by two staff members during pain and independently by each staff member after the 5-minute observation period.
  - no pain conditions
  - The NCCPC-R and VAS of pain were completed

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## Results

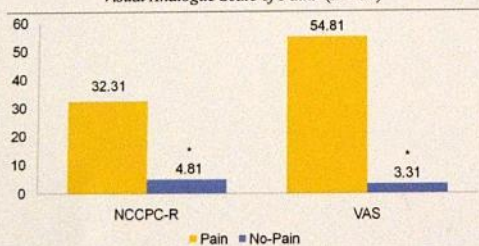
Demographics: ( $N = 16$ )

- Gender: 9 males 7 females
- Age:  $M = 43$  years 6.6 months ( $SD = 12.3$  months)

### Vineland-II Adaptive Behaviour Scales Age Equivalencies ( $N = 16$ )

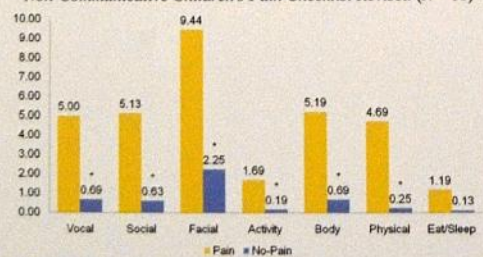
Functioning area:	$M =$ (years; mos)	$SD =$ (mos)
Communication	3 yrs; 7.4 mos	27.5 mos
Daily living skills	3 yrs; 1 mos	49.2 mos
Socialization	1 yr; 5.3 mos	20.8 mos
Motor Skills	1 yr; 4.7 mos	18.7 mos

### Mean total scores for pain and no-pain conditions for the Non-Communicating Children's Pain Checklist Revised and the Visual Analogue Scale of Pain. ( $N = 16$ )



Note. \* Significant at  $p < .001$ , VAS  $M = 54.81$  (21.64)  $M = 3.31$  (4.87)  $t = 9.58$ ,  $p < .001$  NCCPC  $M = 32.31$  (13.78)  $M = 4.81$  (5.18)  $t = 7.76$ ,  $p < .001$

### Mean subscale scores for pain and no-pain conditions for the Non-Communicating Children's Pain Checklist Revised ( $N = 16$ )



Note. \* Significant at  $p < .001$ ,  $T(1, 15) = 60.26$ ,  $p < .001$ ,  $S(1, 15) = 19.06$ ,  $p < .001$ ,  $T(1, 15) = 6.74$ ,  $p < .001$ ,  $T(1, 15) = 58.01$ ,  $p < .001$ ,  $S(1, 15) = 16.35$ ,  $p < .001$ ,  $T(1, 15) = 6.76$ ,  $p < .001$

### Statistical indications of required revisions for the Non-Communicating Children's Pain Checklist Revised ( $N = 16$ )

NCCPC-R Score	Paired Samples t-test * $t =$	$p$ value
Eating/ Sleeping subscale	2.35	.03**
Total (30 items)	7.76	<.001

Item	Item total correlation
Jumping around	-.34
Screaming	-.06
Floppy	.04

### Psychometric properties of the revised version of the Non-Communicating Children's Pain Checklist Revised for Adults with ID (24 items)

Psychometric	Test	Significance
Construct Validity	Paired Samples t-test	$p < .001$
Internal Consistency	Cronbach's alpha	$\alpha = .86$
Concurrent Validity	Pearson correlation	$r = .66$ $p = .005$
Inter-rater Reliability	Intraclass Correlation Coefficient	$ICC = .83$
Cut-off Scores	ROC curve	Cut-off = 10 94% sensitivity 87% specificity

## Discussion

- Revisions are necessary to obtain acceptable reliability and validity for the use of the NCCPC-R with adults who have ID
- The Eating/Sleeping subscale was removed because our analysis indicated it was not sensitive to chronic pain in this group of adults
- Items "floppy", "screaming", and "jumping around" because of low item total correlation and failure to show differentiation between pain and no-pain conditions
- The new 24 item scale shows good psychometric properties
- These strong psychometric properties suggest that the reduced observation period of 5 minutes was successful

## Strengths and Limitations

- A limitation is the small sample size ( $N = 16$ ); yet, results were significant
- A major strength of this study is that it was carried out in a natural non-experimental environment with a heterogeneous sample. This increases the generalizability of the results.

## Implications

- The NCCPC-R should not be used for adults with ID, as the CPS-NAID shows stronger psychometrics with this group of adults
- Future research should include both the NCCPC-R and the CPS-NAID to replicate the results found in this study

### The 24 items of the Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities ( $N = 16$ )

1. Moaning, whining, whimpering (fairly soft)
2. Crying (moderately loud)
3. A specific sound or word for pain (e.g. A word, cry or type of laugh)
4. Not cooperating, irritable, unhappy
5. Less interaction with others, withdrawn
6. Seeking comfort of physical closeness
7. Being difficult to distract, not able to satisfy or pacify
8. A furrowed brow
9. A change in eyes, including: squinching of eyes opened wide, eyes frowning
10. Turning down of mouth, not smiling
11. Lips puckering up, tight, pouting or quivering
12. Clenching or grinding teeth, chewing or thrusting tongue out
13. Not moving, less active, quiet
14. Stiff, spastic, tense, rigid
15. Gesturing to or touching part of the body that hurts
16. Protecting, favouring or guarding part of body that hurts
17. Flinching or moving the body part away, being sensitive to touch
18. Moving the body in a specific way to show pain (e.g. Head back, arms down, curls up, etc.)
19. Shivering
20. Change in colour, pallor
21. Sweating, perspiring
22. Tears
23. Sharp intake of breath, gasping
24. Breath holding

## References

- Beange H, McElduff A, Baker W. (1995). Medical disorders of adults with mental retardation: a population study. *Am J Ment Retard*, 99(6):595-604.
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