

HOW DO YOU ASSESS PAIN IF THE PATIENT CAN'T COMMUNICATE VERBALLY?

OR

” “CHEW BEFORE YOU SWALLOW

GEORGE W. BUSH

Lynn Breau, Ph.D., Registered Psychologist

Departments of Nursing, Pediatrics & Psychology, Dalhousie University;
Complex Pain Team & Centre for Pediatric Pain Research, IWK Health Centre;
Halifax, Nova Scotia, Canada



I HAVE NO CONFLICTS OF INTEREST
TO DISCLOSE.

OBJECTIVES

- ◎ Participants will gain an understanding of the criteria used to select valid observational pain tools for assessing pain in individuals with intellectual disabilities.
- ◎ Participants will learn about the pain tools for children and adults with intellectual disabilities that have the greatest evidence base at this time.
- ◎ Participants will gain an understanding of a sound approach to integrating pain tool information with other clinical factors in conducting a pain assessment.

AN EXPERIMENT IS A QUESTION
WHICH SCIENCE POSES TO NATURE,
AND A MEASUREMENT IS THE
RECORDING OF NATURE'S ANSWER.

Max Planck, *Scientific Autobiography and Other Papers*, 1949

PAIN ASSESSMENT AS SCIENCE

- ◎ We know people with intellectual disabilities have pain,
- ◎ We know people with pain show behaviour (overt and covert) that indicates they have pain,
- ◎ Our question is:
 - ◎ Which specific behaviours reflect pain and only pain?
- ◎ Our measurement is:
 - ◎ Any tool that answers our question?

IT'S NOT THAT SIMPLE

- ⊙ How precise is the question?
 - "How do people with ID show pain?"
- ⊙ Not usually!
 - "How does.....
 - ⊙ a 4 year old girl,
 - ⊙ who has an ID,
 - ⊙ with no verbal ability,
 - ⊙ show pain at home,
 - ⊙ due to constipation?"

SCIENCE IS BUILT UP OF FACTS, AS A
HOUSE IS BUILT OF STONES; BUT AN
ACCUMULATION OF FACTS IS NO
MORE A SCIENCE THAN A HEAP OF
STONES IS A HOUSE.

HENRI POINCARÉ, *SCIENCE AND HYPOTHESIS*, 1905

They must be the right facts for the question!

They must be assembled in a way that
provides a cohesive answer!

5 MINUTE PSYCHOMETRICS LESSON

Your Handout has More Details.....

THE “YARDSTICKS” OF A GOOD MEASUREMENT TOOL

- ◎ Validity

- ◎ Does it measure what I think it does?

- ◎ Reliability

- ◎ Does it measure the same way each time?
 - Different groups
 - Different settings
 - Different observers
 - Different types of pain

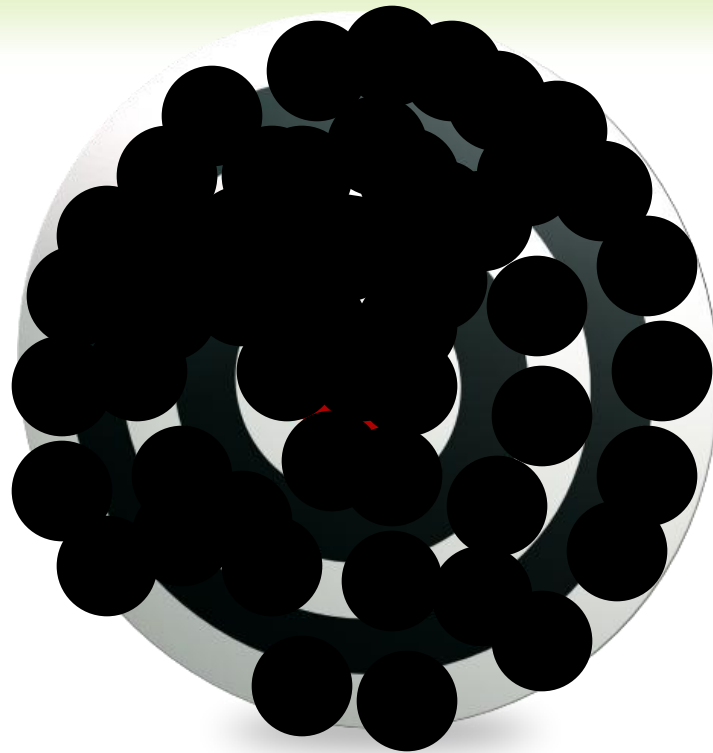
VALIDITY IS THE CORNERSTONE

- ◎ A tool that is valid *may be* reliable,
but measure the wrong thing!
- ◎ Validity
 - ◎ is the foundation of a tool
 - ◎ can be the weakness of a tool, but the data will just look like poor reliability
 - ◎ requires selection of items from the full **UNIVERSE** of possible items for your construct

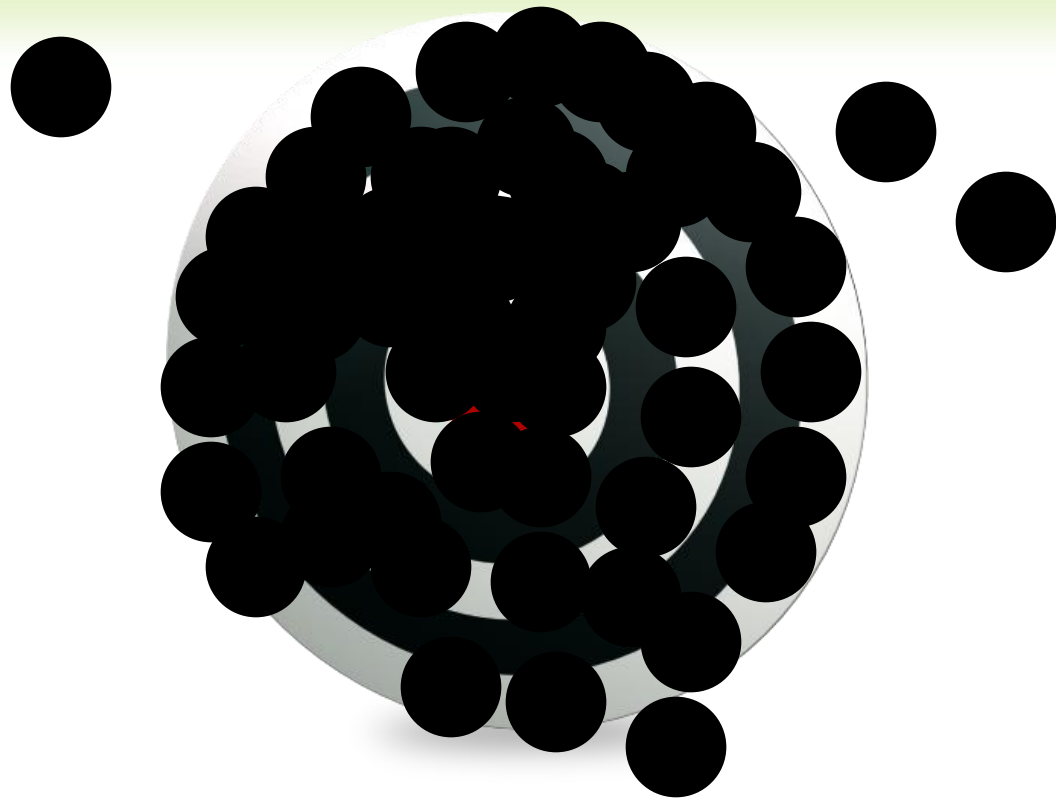
YOUR TARGET



YOUR TARGET



YOUR TARGET



RELIABILITY

- ⊙ Must come after validity is established.
- ⊙ CANNOT be estimated if the tool has:
 - ⊙ Open-ended questions / write-in answers
 - ⊙ These mean it is no longer standardized (comparable across people)
- ⊙ Must be established for each
 - ⊙ Subgroup
 - ⊙ Setting
 - ⊙ Type of observer
 - ⊙ Type of pain

IN ALL SCIENCE, ERROR PRECEDES
THE TRUTH, AND IT IS BETTER IT
SHOULD GO FIRST THAN LAST.

HUGH WALPOLE

To be considered valid and reliable,
a pain assessment tool must be tested
over and over and over again!

BACK TO OUR QUESTION OF PAIN ASSESSMENT IN PEOPLE WITH AN INTELLECTUAL DISABILITY

A look at the scientific literature

FANURIK, KOH, SCHMITZ, HARRISON & CONRAD (1999)

- ⊙ Parents / caregivers of 145 children
- ⊙ Cognitive impairment:
 - Borderline (6%), mild (17%), moderate (24%), severe (15%), profound (38%)

“How do you know
when your child is in pain”?

FANURIK, KOH, SCHMITZ, HARRISON & CONRAD (1999)

<i>Pain Behaviour Category (N = 145)</i>	<i>% of Children by Level of Cognitive Impairment</i>	
	<i>Mild / Moderate</i>	<i>Severe / Profound</i>
Direct Pain Expression		
Verbalizes	57	7
Verbalizes, does not localize	1	1
Localizes only	7	1
Indirect Pain Expression		
Cries	10	22
Facial expression	1	5
Physical / body movement	1	1
Behavioural / emotional changes	7	10
Combination of indirect behaviours	12	45
Self-injurious behaviour (with other behaviour)	1	5

TESTS OF SELF-REPORT ABILITY

- ◎ Fanurik, Koh, Harrison, Conrad, Tomerlin (1998)
 - ◎ 47 children (age 8 to 17) with intellectual disabilities scheduled for surgery
 - ◎ Passed by
 - 50% of Borderline ID group,
 - < 30% Mild ID group,
 - 0% Moderate, Severe and Profound ID groups
- ◎ Voepel-Lewis, Malviya & Tait (2005)
 - ◎ 52 children aged 4 to 19 having surgery
 - ◎ Passed by 24%

Defrin, Lotan & Pick (2006)



- ◉ 65 adults with mild/moderate ID
- ◉ Rated pain from influenza vaccination
- ◉ Most chose a “smiley” face before and after vaccination
 - ◉ Unable to use scale?
 - ◉ Vaccination not very painful (NCCPC-R change significant but small)

RECOMMENDATION

- ② Insufficient evidence at this time that self-report of pain is sound for children or adults with ID
- ② DO NOT use as a sole indicator of pain

FANURIK, KOH, SCHMITZ, HARRISON & CONRAD (1999)

<i>Pain Behaviour Category (N = 145)</i>	<i>% of Children by Level of Cognitive Impairment</i>	
	<i>Mild / Moderate</i>	<i>Severe / Profound</i>
Direct Pain Expression		
Verbalizes	57	7
Verbalizes, does not localize	1	1
Localizes only	7	1
Indirect Pain Expression		
Cries	10	22
Facial expression	1	5
Physical / body movement	1	1
Behavioural / emotional changes	7	10
Combination of indirect behaviours	12	45
Self-injurious behaviour (with other behaviour)	1	5



TOOLS DESIGNED SPECIFICALLY FOR PEOPLE WITH ID: CHILDREN

More similarities than differences!

- ◎ Echelle Douleur Enfant San Salvador
 - French; only 2 studies
- ◎ Pain Indicator for Communicatively Impaired Children
 - All items on NCCPCs or PPP, only 2 studies
- ◎ Paediatric Pain Profile Pain (PPP)
 - Only 2 studies; differing cut-off scores
- ◎ Non-communicating Children's Pain Checklists (NCCPCs)

WHICH TOOL TO USE?

- ◎ More similarities than differences!
- ◎ 3 of the 4 scales developed to date have 20-30 items suggesting that number may be a **basic set** necessary for this population as a whole
- ◎ NCCPCs
 - ◎ most research to date; different groups, researchers, situations
 - ◎ Used across settings; home, hospital
 - ◎ Used across observers
 - ◎ Used across types of pain

OBSERVATIONAL PAIN TOOLS FOR CHILDREN WITH ID

- ◉ **Echelle Douleur Enfant San Salvador**

(Giusiano, Jimeno, Collignon & Chau, 1995; Collignon & Giusiano, 2001)

- ◉ **Pediatric Pain Profile**

(Hunt, Golman, Seers, Crichton, Mastroyannopoulou, Moffat, Oulton & Brady, 2004; Hunt, Wisbeach, Seers, Goldman, Crichton, Perry & Mastroyannopoulou, 2007)

- ◉ **FLACC-Revised**

(Voepel-Lewis, Merkel, Tait, Trzcinka, & Malviya, 2002; Malviya, Voepel-Lewis, Burke, Merkel & Tait, 2006)

- ◉ **Non-communicating Children's Pain Checklist (Revised & Postoperative Version)**

(Breau, McGrath, Camfield, Rosmus & Finley, 2000; Breau, McGrath, Camfield, Rosmus & Finley, 2001; Breau, McGrath, Camfield & Finley, 2002; Breau, Finley, McGrath & Camfield, 2002; Hadden & von Baeyer, 2002; Breau, Camfield, Symons, Bodfish, McKay, Finley, & McGrath, 2003; Hadden & von Baeyer, 2005; Symons & Danov, 2005; Kleinknecht, 2007; Johansson et al., 2010; Breau & Camfield, in press)

- **Grille d'évaluation de la Douleur - Déficience Intellectuelle (GED-DI)**
- **Batten Observational Pain Scale (BOPS)**
- **Chronic Pain Scale for Nonverbal Adults with Intellectual Disabilities (CPS-NAID)**
- **Non-communicating Adult Pain Checklist**



NON-COMMUNICATING CHILDREN'S PAIN CHECKLISTS

- ⊙ Two versions
 - ⊙ “**Revised**”: everyday pain, 2-hour observations
 - ⊙ “**Postoperative**”: 10 minute observations; 5-minute in newer studies
 - ⊙ Difference: postoperative version has no eating and sleeping items
- ⊙ Recommend Postoperative Version for most situations

Non-communicating Children's Pain Checklist – Revised (NCCPC-R)

NAME: _____ UNIT/FILE #: _____ DATE: _____ (dd/mm.yy)
 OBSERVER: _____ START TIME: _____ AM/PM STOP TIME: _____ AM/PM

How often has this child shown these behaviours in the last 2 hours? Please circle a number for each item. If an item does not apply to this child (for example, this child does not eat solid food or cannot reach with his/her hands), then indicate "not applicable" for that item.

0 = NOT AT ALL 1 = JUST A LITTLE 2 = FAIRLY OFTEN 3 = VERY OFTEN NA = NOT APPLICABLE

I. Vocal

1. Moaning, whining, whimpering (fairly soft).....	0	1	2	3	NA
2. Crying (moderately loud).....	0	1	2	3	NA
3. Screaming/yelling (very loud).....	0	1	2	3	NA
4. A specific sound or word for pain (e.g., a word, cry or type of laugh).....	0	1	2	3	NA

II. Social

5. Not cooperating, cranky, irritable, unhappy.....	0	1	2	3	NA
6. Less interaction with others, withdrawn.....	0	1	2	3	NA
7. Seeking comfort or physical closeness	0	1	2	3	NA
8. Being difficult to distract, not able to satisfy or pacify.....	0	1	2	3	NA

III. Facial

9. A furrowed brow.....	0	1	2	3	NA
10. A change in eyes, including: squinching of eyes, eyes opened wide, eyes frowning.....	0	1	2	3	NA
11. Turning down of mouth, not smiling.....	0	1	2	3	NA
12. Lips puckering up, tight, pouting, or quivering.....	0	1	2	3	NA
13. Clenching or grinding teeth, chewing or thrusting tongue out	0	1	2	3	NA

IV. Activity

14. Not moving, less active, quiet.....	0	1	2	3	NA
15. Jumping around, agitated, fidgety.....	0	1	2	3	NA

V. Body and Limbs

16. Floppy	0	1	2	3	NA
17. Stiff, spastic, tense, rigid	0	1	2	3	NA
18. Gesturing to or touching part of the body that hurts	0	1	2	3	NA
19. Protecting, favoring or guarding part of the body that hurts	0	1	2	3	NA
20. Flinching or moving the body part away, being sensitive to touch.....	0	1	2	3	NA
21. Moving the body in a specific way to show pain (e.g. head back, arms down, curls up, etc.)	0	1	2	3	NA

VI. Physiological

22. Shivering	0	1	2	3	NA
23. Change in color, pallor	0	1	2	3	NA
24. Sweating, perspiring	0	1	2	3	NA
25. Tears.....	0	1	2	3	NA
26. Sharp intake of breath, gasping.....	0	1	2	3	NA
27. Breath holding.....	0	1	2	3	NA

VII. Eating/Sleeping

28. Eating less, not interested in food.....	0	1	2	3	NA
29. Increase in sleep.....	0	1	2	3	NA
30. Decrease in sleep.....	0	1	2	3	NA

SCORE SUMMARY:

Category:	I	II	III	IV	V	VI	VII	TOTAL
Score:								

NCCPC-PV

Items

(Breau, McGrath,
Camfield & Finley,
2002)

How often has this child shown these behaviours in the last 10 minutes? Please circle a number for each behaviour. If an item does not apply to this child (for example, this child cannot reach with his/her hands), then indicate "not applicable" for that item.

0 = NOT AT ALL

1 = JUST A LITTLE

2 = FAIRLY OFTEN

3 = VERY OFTEN

NA = NOT APPLICABLE

I. Vocal

1. Moaning, whining, whimpering (fairly soft).....	0	1	2	3	NA
2. Crying (moderately loud).....	0	1	2	3	NA
3. Screaming/yelling (very loud).....	0	1	2	3	NA
4. A specific sound or word for pain (e.g., a word, cry or type of laugh).....	0	1	2	3	NA

II. Social

5. Not cooperating, cranky, irritable, unhappy.....	0	1	2	3	NA
6. Less interaction with others, withdrawn.....	0	1	2	3	NA
7. Seeking comfort or physical closeness.....	0	1	2	3	NA
8. Being difficult to distract, not able to satisfy or pacify.....	0	1	2	3	NA

III. Facial

9. A furrowed brow.....	0	1	2	3	NA
10. A change in eyes, including: squinching of eyes, eyes opened wide, eyes frowning.....	0	1	2	3	NA
11. Turning down of mouth, not smiling.....	0	1	2	3	NA
12. Lips puckering up, tight, pouting, or quivering.....	0	1	2	3	NA
13. Clenching or grinding teeth, chewing or thrusting tongue out.....	0	1	2	3	NA

IV. Activity

14. Not moving, less active, quiet.....	0	1	2	3	NA
15. Jumping around, agitated, fidgety.....	0	1	2	3	NA

V. Body and Limbs

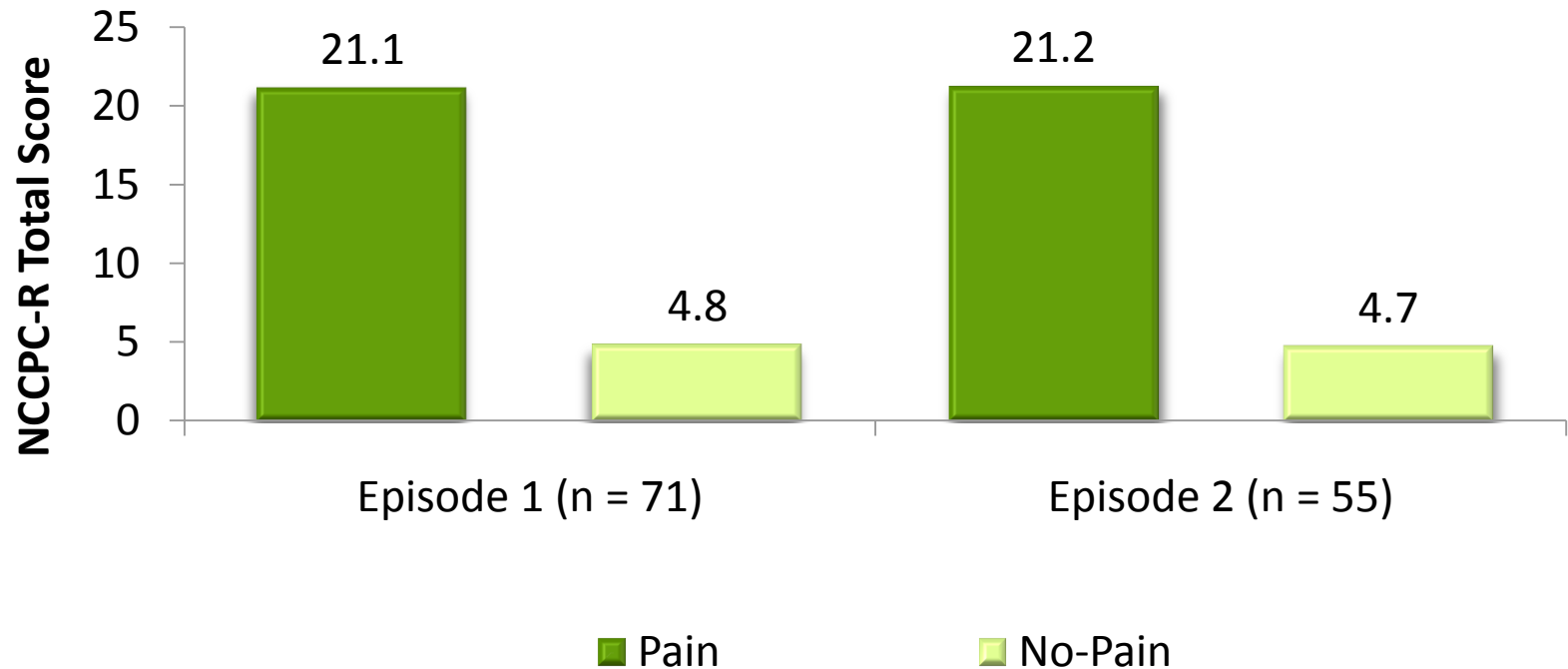
16. Floppy.....	0	1	2	3	NA
17. Stiff, spastic, tense, rigid.....	0	1	2	3	NA
18. Gesturing to or touching part of the body that hurts.....	0	1	2	3	NA
19. Protecting, favoring or guarding part of the body that hurts.....	0	1	2	3	NA
20. Flinching or moving the body part away, being sensitive to touch.....	0	1	2	3	NA
21. Moving the body in a specific way to show pain (e.g. head back, arms down, curls up, etc.).....	0	1	2	3	NA

VI. Physiological

22. Shivering.....	0	1	2	3	NA
23. Change in color, pallor.....	0	1	2	3	NA
24. Sweating, perspiring.....	0	1	2	3	NA
25. Tears.....	0	1	2	3	NA
26. Sharp intake of breath, gasping.....	0	1	2	3	NA
27. Breath holding.....	0	1	2	3	NA

NCCPC-REVISED TOTAL SCORES

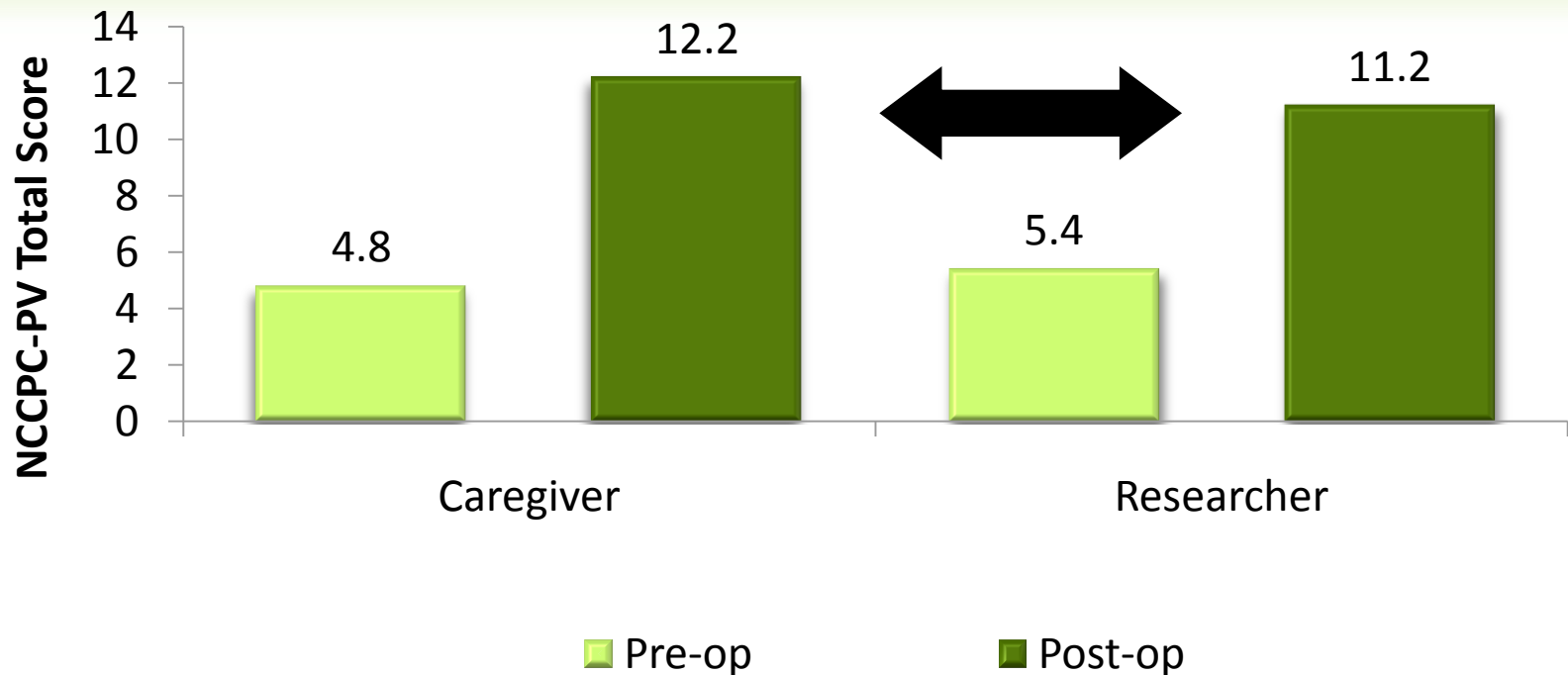
BREAU, MCGRATH, CAMFIELD & FINLEY (2002), *PAIN*.



$N = 71$, 30-items. All differences significant, $p \leq .001$.

NCCPC-PV: MEAN TOTAL SCORES

BREAU, FINLEY, McGRATH & CAMFIELD (2002), *ANESTHESIOLOGY*.



$N = 24$, 27-items. ($t(23) = -3.36, p = .003$) and ($t(23) = -3.72, p = .01$)

Visual Analogue Pain Scale

Most children and
adults say they want
medicine for pain that is
3/10 or more.

Översatt med tillstånd
av P. A. Mc Grath
av Drottning Silvias Barn- & Ungdomsjukhus
Göteborg

10
9
8
7
6
5
4
3
2
1
0

MORFIN BIOGLAN®
Tlf. 046-280 81 60

NCCPC-PV CUT-OFF SCORES

NCCPC-PV = 11+

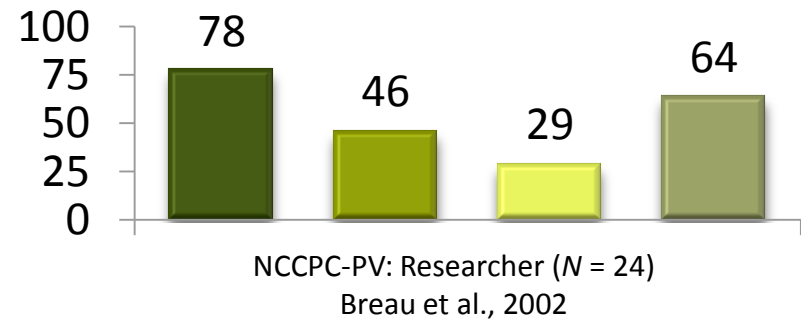
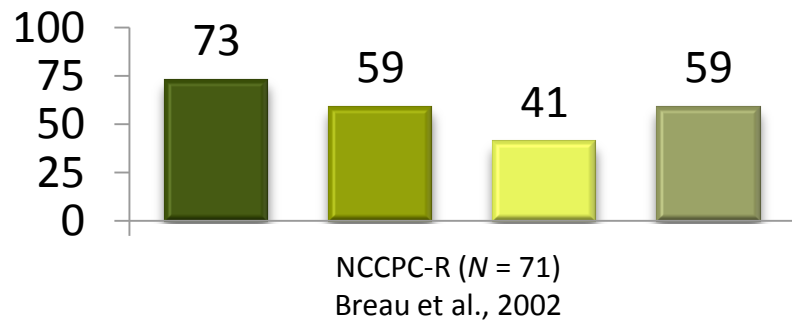
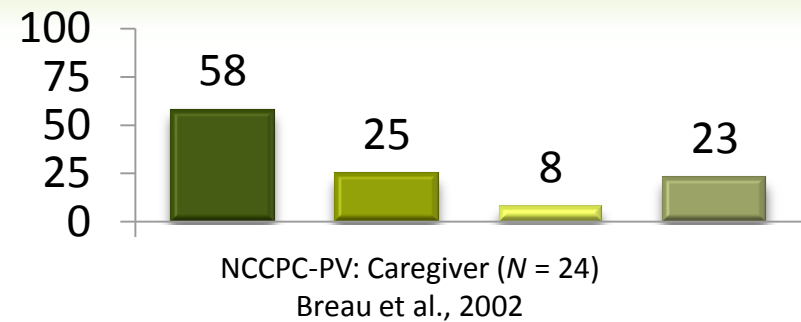
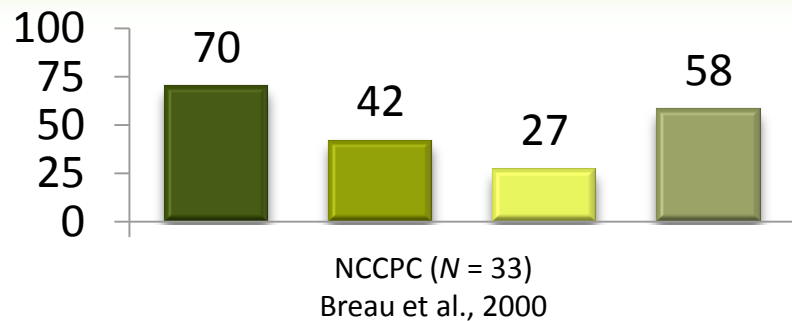
Sensitivity = 88%,
specificity = 81%

NCCPC-PV = 6-10

Sensitivity = 75%,
specificity = 67%

NCCPC-PV < 6

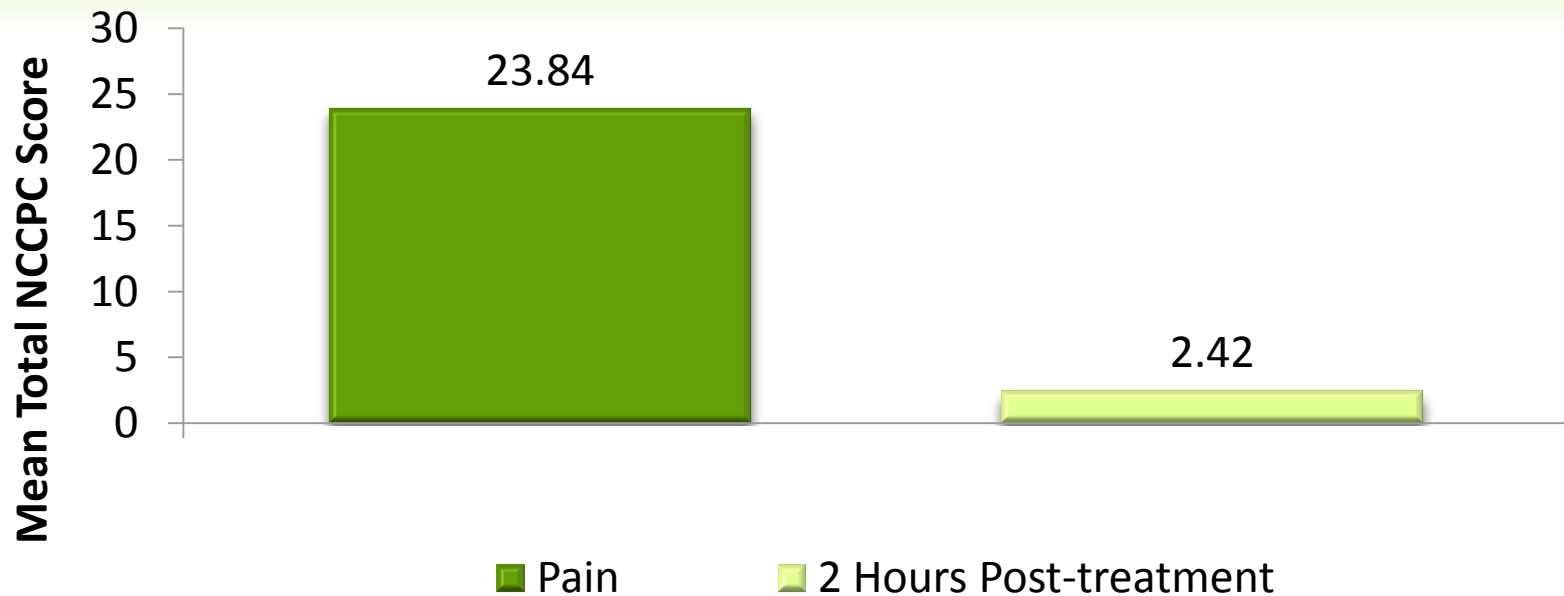
NCCPCs: CONSISTENT PATTERNS OF BEHAVIOURS SHOWN ACROSS STUDIES: VOCAL SUBSCALE AS AN EXAMPLE (BREAU, 2003)



Moan Cry Scream Sound

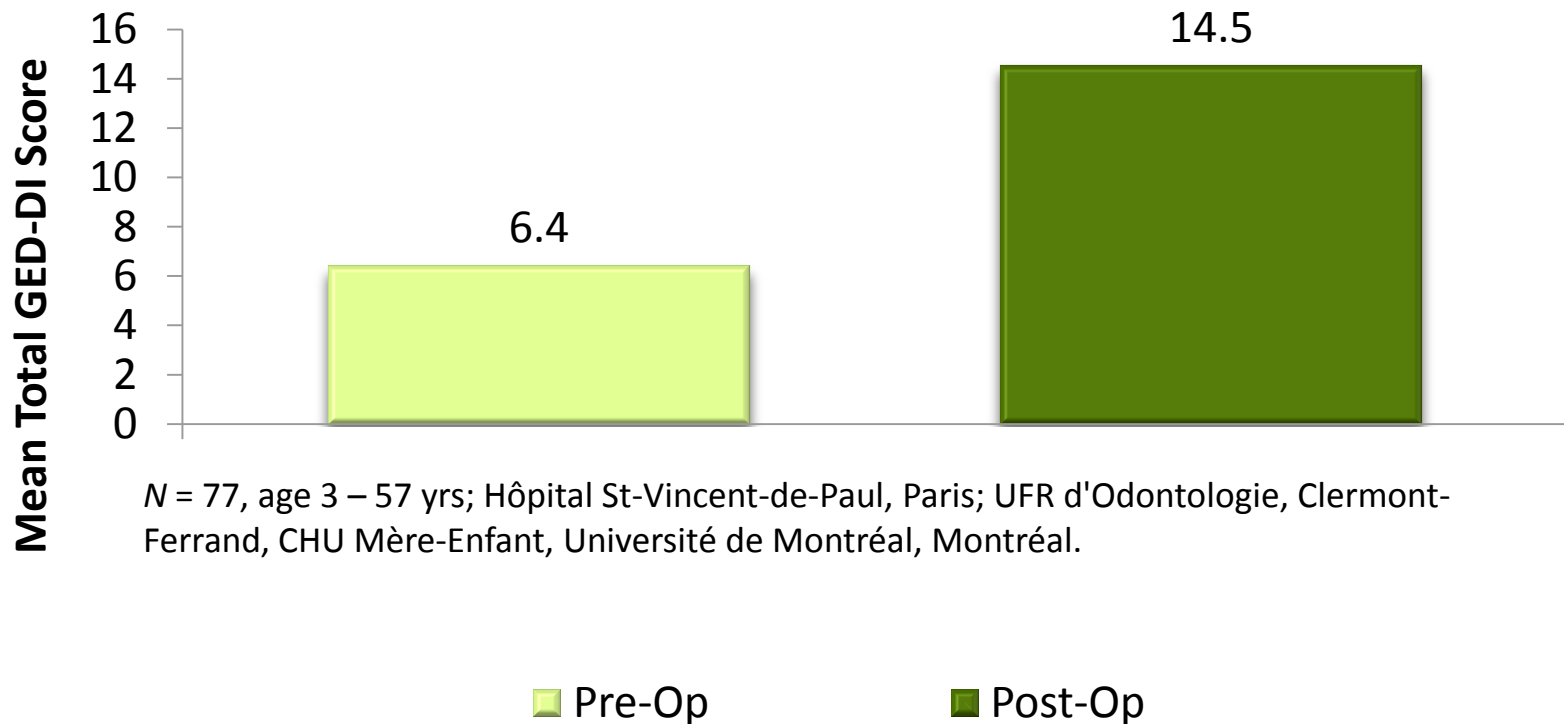
GERMAN NCCPC-R

KLEINKNECHT (2005)



$N = 19$; aged 4 to 16 years, in rehabilitation centre. Only one score > 7 after analgesic treatment. Sensitivity = .84, specificity = .78 with cut-off of 5.

LA GRILLE D'ÉVALUATION DE LA DOULEUR – DÉFICIENCE INTELLECTUELLE (GED-DI) PRELIMINARY DATA: POSTOPERATIVE PAIN BREAU, GRÉGOIRE, LÉVÈQUE, HENNEQUIN, BUREAU, WOOD (2008)



PAIN BEHAVIOUR IS NOT AFFECTED BY DEVELOPMENTAL LEVEL

BREAU & CAMFIELD (IN PRESS; DEV MED CHILD NEUROL)

Scale	Variable	Component 1: Developmental Level	Component 2: Pain Behaviour	Component 3: Motor Development	Component 4: Chronological Age
NCCPC-R	Vocal	-.201	.738	-.069	-.104
	Eating/Sleeping	.025	.680	.102	.283
	Social	-.055	.896	-.075	.003
	Facial	-.189	.701	-.317	-.092
	Activity	-.124	.719	.264	.161
	Body/Limb	-.014	.778	.148	-.150
	Physiological	.021	.826	-.217	-.006
	DIQ	.701	-.089	-.023	-.462
	Age (months)	.171	.018	-.158	.841
VABS-II Communication	Receptive	.839	.057	.285	-.222
	Expressive	.907	-.088	.229	.024
	Written	.840	-.139	.064	.297
	Personal	.720	-.063	.624	.000
Activities of Daily Living	Domestic	.697	-.116	.551	.164
	Community	.828	-.187	.245	.263
	Interpersonal	.941	-.082	.196	-.064
Socialization	Play	.936	-.044	.124	.021
	Coping	.905	-.143	.089	.208
Motor Skills	Gross Motor	.331	.000	.829	-.194
	Fine Motor	.634	.008	.708	-.104
Eigenvalue (% variance accounted for)		9.0 (45.1%)	3.9 (19.7%)	1.6 (8.0%)	1.1 (5.6%)



RECOMMENDATION FOR CHILDREN WITH ID AT THIS TIME: NCCPC's

- ◎ Only tools to meet criteria for “**Well Established Assessment**” by Society of Pediatric Psychology Assessment Task Force (J Pediatr Psychol. 2008 October; 33(9): 911–915).
- ◎ Have been tested in several languages and by different research groups (French, German, Swedish)
- ◎ Good validity and reliability
- ◎ Cut-off scores available
- ◎ Versions available for children and adults; allows comparison across lifespan (CPS-NAID)

With additional research, other scales may show similar properties.

SPIN-OFF SCALES



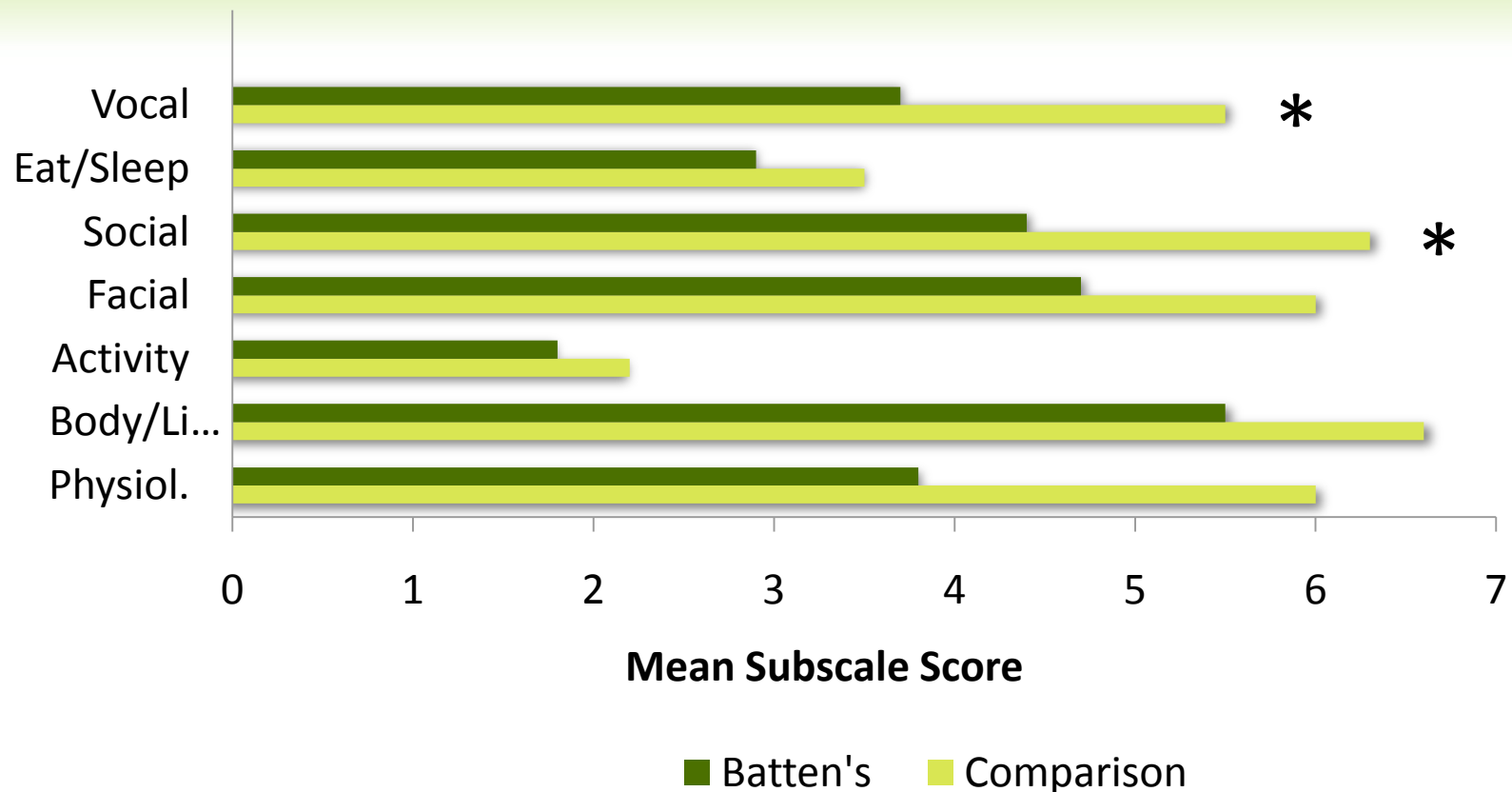
CHILDREN WITH BATTEN DISEASE

(INFANTILE AND JUVENILE NEURONAL CEROID LUPOFUSCINOSIS)

- ◎ Our studies have not included children with neurodegenerative disorders
- ◎ We do not know if the NCCPC works as well for children whose abilities are changing, deteriorating
- ◎ We do not know if the NCCPCs work for someone who previously had typical functioning
- ◎ We do not know if some of the unique aspects of Batten's affects how children show pain; e.g. psychosis

TYPICAL PAIN: BATTEN'S VERSUS COMPARISON GROUP

BREAU, CAMFIELD & CAMFIELD (SUBMITTED)



Breau, Camfield & Camfield (submitted); N = 68. BD Mean age = 13 yrs 9 mos; Comparison = 8 yrs 6 mos.; $p = .000$. Multivariate $F(7,59) = 2.1$, $p = .05$; Age $F((7,59) = 1.3$, $p = .26$). *Univariate $p < .007$ (Bonf. Corr.).



IMPROVING TARGET COVERAGE

- ⊙ Remove subscale with non significant pain vs. calm differences: Eating/Sleeping
- ⊙ Sequentially remove any items that are not related (item-total correlation $<.10$).
- ⊙ 6 items removed:
 - ⊙ Crying, screaming, specific sound for pain
 - ⊙ Change in eyes
 - ⊙ Floppy
 - ⊙ Shivering
 - ⊙ Gasping
 - ⊙ Breath holding
- ⊙ 17 items; scores range 0 - 51

Batten's Observational Pain Scale

Name: _____

Date: _____

Please indicate how often this person has shown the signs referred to in *items 1-17* in the last 5 minutes. Please circle a number for each item. If an item does not apply to this person (for example, this person cannot reach with his/her hands), then indicate "not applicable" for that item.

0 =	Not present at all during the observation period. (Note: If the item is not present because the person is not capable of performing that act, it should be scored as "NA". E.g. if a person cannot gesture to a part that hurts due to being unable to use her arms, mark that item "NA".
1 =	Seen or heard rarely (hardly at all), but is present.
2 =	Seen or heard a number of times, but not continuous (not all the time).
3 =	Seen or heard often; almost continuous (almost all the time); anyone would easily notice this if they saw the person for a few moments.
NA =	No applicable. This person is not capable of performing this action.

0 = NOT AT ALL 1 = JUST A LITTLE 2 = FAIRLY OFTEN 3 = VERY OFTEN NA = NOT APPLICABLE

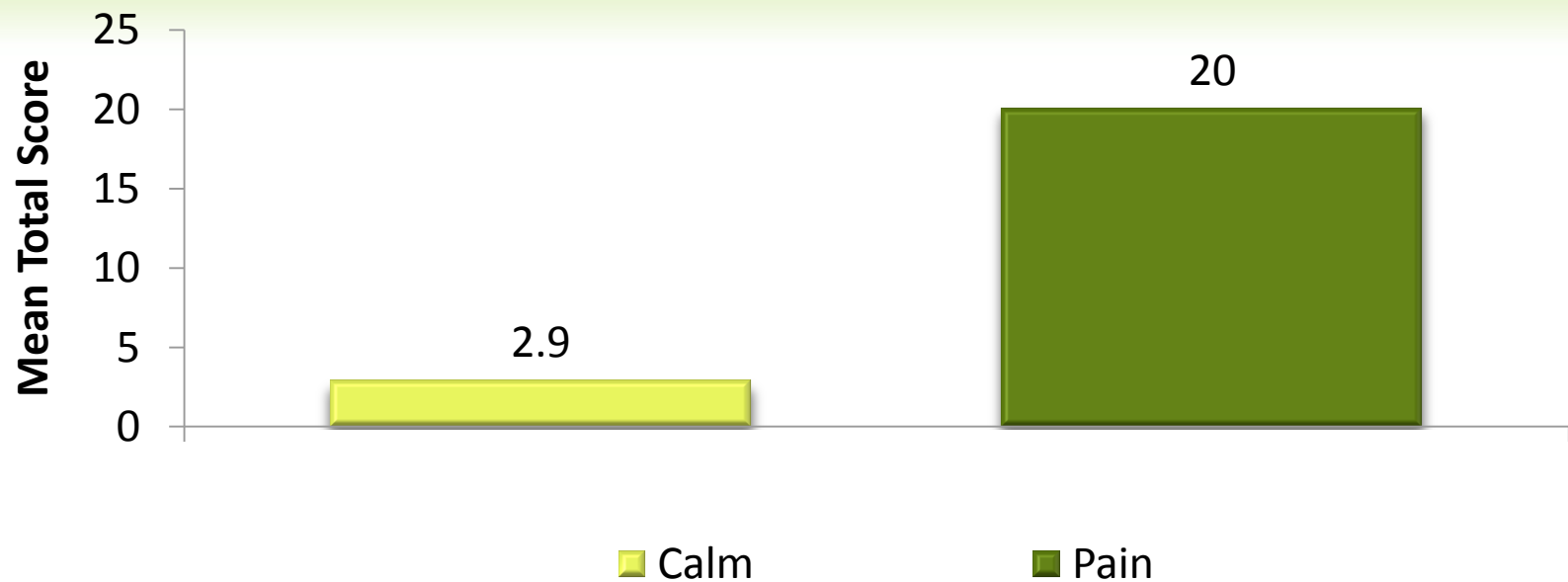
1. Moaning, whining, whimpering (fairly soft).....	0	1	2	3	NA
2. Not cooperating, cranky, irritable, unhappy.....	0	1	2	3	NA
3. Less interaction with others, withdrawn	0	1	2	3	NA
4. Seeking comfort or physical closeness	0	1	2	3	NA
5. Being difficult to distract, not able to satisfy or pacify	0	1	2	3	NA
6. A furrowed brow.....	0	1	2	3	NA
7. Turning down of mouth, not smiling	0	1	2	3	NA
8. Lips puckering up, tight, pouting, or quivering	0	1	2	3	NA
9. Clenching or grinding teeth, chewing or thrusting tongue out.....	0	1	2	3	NA
10. Stiff, spastic, tense, rigid	0	1	2	3	NA
11. Gesturing to or touching part of the body that hurts	0	1	2	3	NA
12. Protecting, favoring or guarding part of the body that hurts.....	0	1	2	3	NA
13. Flinching or moving the body part away, being sensitive to touch..	0	1	2	3	NA
14. Moving the body in a specific way to show pain (e.g. head back, arms down, curls up, etc.).....	0	1	2	3	NA
15. Change in color, pallor.....	0	1	2	3	NA
16. Sweating, perspiring	0	1	2	3	NA
17. Tears	0	1	2	3	NA

TOTAL SCORE : _____

SCORING:

- Add up the scores for each item to compute the Total Score. Items marked "NA" are scored as "0" (zero).
- Check whether the score is greater than the cut-off score.
*A score of 4 or greater means that there is a 92% chance that the person has pain.
A score of 3 or lower means that there is an 88% chance that the person does not have pain.*

BATTEN'S OBSERVATIONAL PAIN SCALE



Breau, Camfield & Camfield (submitted); Matched Sample t-tests: Pain Vs. Calm (N = 22), $p < .001$; Pain vs. Distress (N = 24), $p = .04$.



TOOLS DESIGNED SPECIFICALLY FOR PEOPLE WITH ID: ADULTS

- ◎ Adults with an ID:
 - ◎ May learn to restrain socially unacceptable pain behaviours
 - ◎ May show more of other “acceptable” behaviours
 - ◎ May have less fear reaction during acute / procedure pain that is routine
- ◎ This may mean that several scales, adapted to pain type, are called for in this group.
- ◎ **Logical starting point: behaviours they showed as children**

SCALES FOR ADULTS WITH INTELLECTUAL DISABILITIES

◎ **Chronic Pain Scale for Nonverbal Adults with Intellectual Disabilities (CPS-NAID)**

- Burkitt, Breau, Salsman, Sarsfield-Turner & Mullen (2009)

◎ **Non-communicating Adult Pain Scale (NCAPS)**

- Lotan, Ljunggren, Johnsen, Defrin, Pick, & Strand (2009)
- Lotan, Moe-Nilssen, Ljunggren & Strand (2009)

◎ **Pain and Discomfort Scale (PADS)**

- Bodfish, Harper, Deacon, Symons (Report; 2001)
- Phan, Edwards, Robinson (2005)



CHRONIC PAIN SCALE FOR NONVERBAL ADULTS WITH INTELLECTUAL DISABILITIES (CPS-NAID)

BURKITT, BREAU, SALSMAN, SARSFIELD-TURNER & MULLEN (2009)

- ⊙ NCCPC-R administered during chronic pain
 - ⊙ 16 nonverbal adults in residential care
 - ⊙ 2 observers (inter-rater reliability)
 - ⊙ VAS pain rating (concurrent validity)

REVISIONS TO IMPROVE PSYCHOMETRICS

- ⊙ Eating / sleeping scale removed
- ⊙ Items with item-total correlations that were negative sequentially removed
 - ⊙ Screaming
 - ⊙ Jumping around
 - ⊙ Floppy
- ⊙ Items with no discrimination between pain / calm removed
 - ⊙ Floppy: 19% showed pain and 19% showed during calm

Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID)

Please indicate how often this person has shown the signs referred to in *items 1-24* in the last 5 minutes. Please circle a number for each item. If an item does not apply to this person (for example, this person cannot reach with his/her hands), then indicate "not applicable" for that item.

0 =	Not present at all during the observation period. (Note if the item is not present because the person is not capable of performing that act, it should be scored as "NA").
1 =	Seen or heard rarely (hardly at all), but is present.
2 =	Seen or heard a number of times, but not continuous (not all the time).
3 =	Seen or heard often, almost continuous (almost all the time); anyone would easily notice this if they saw the person for a few moments during the observation time.
NA =	Not applicable. This person is not capable of performing this action.

0 = Not at all	1 = Just a little	2 = Fairly Often	3 = Very Often	NA = Not Applicable	
1. Moaning, whining whimpering (fairly soft)	0	1	2	3	NA
2. Crying (moderately loud)	0	1	2	3	NA
3. A specific sound or word for pain (e.g. a word, cry or type of laugh)	0	1	2	3	NA
4. Not cooperating, irritable, unhappy	0	1	2	3	NA
5. Less interaction with others, withdrawn	0	1	2	3	NA
6. Seeking comfort of physical closeness	0	1	2	3	NA
7. Being difficult to distract, not able to satisfy or pacify	0	1	2	3	NA
8. A furrowed brow	0	1	2	3	NA
9. A change in eyes, including: squinching of eyes, eyes opened wide, eyes frowning	0	1	2	3	NA
10. Turning down of mouth, not smiling	0	1	2	3	NA
11. Lips puckering up, tight, pouting or quivering	0	1	2	3	NA
12. Clenching or grinding teeth, chewing or thrusting tongue out	0	1	2	3	NA
13. Not moving, less active, quiet	0	1	2	3	NA
14. Stiff, spastic, tense, rigid	0	1	2	3	NA
15. Gesturing to or touching part of the body that hurts	0	1	2	3	NA
16. Protecting, favoring or guarding part of body that hurts	0	1	2	3	NA
17. Flinching or moving the body part away, being sensitive to touch	0	1	2	3	NA
18. Moving the body in a specific way to show pain (e.g. Head back, arms down, curls up, etc.)	0	1	2	3	NA
19. Shivering	0	1	2	3	NA
20. Change in colour, pallor	0	1	2	3	NA
21. Sweating, perspiring	0	1	2	3	NA
22. Tears	0	1	2	3	NA
23. Sharp intake of breath, gasping	0	1	2	3	NA
24. Breath holding	0	1	2	3	NA

Subtotals: _____

Total Score: _____

SCORING:

1. Add up the scores for each item to compute the Total Score. Items marked "NA" are scored as "0" (zero).

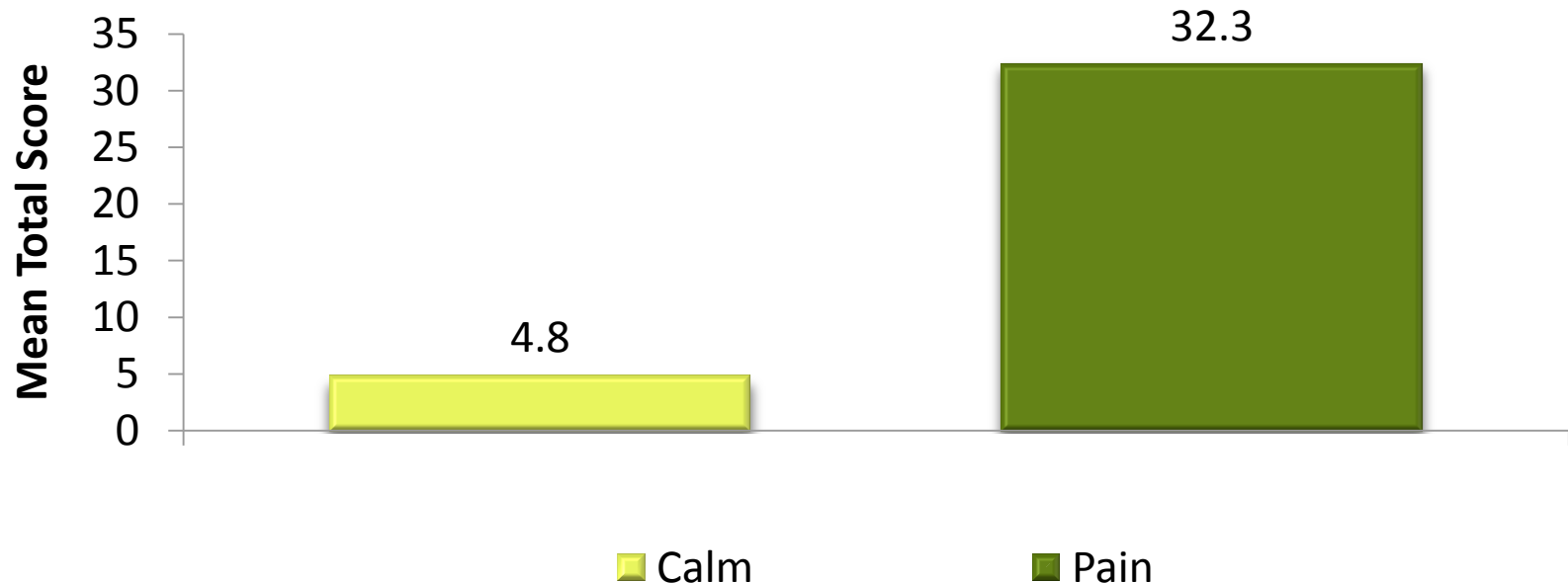
2. Check whether the score is greater than the cut-off score.

A score of 10 or greater means that there is a 94% chance that the person has pain.

A score of 9 or lower means that there is an 87% chance that the person does not have pain.

Chronic Pain Scale for Nonverbal Adults with Intellectual Disabilities

Burkitt, Breau, Salsman, Sarsfield-Turner & Mullen (2009)



Cut-off = 10

94% sensitivity

87% specificity



THE NON-COMMUNICATING ADULT PAIN CHECKLIST (NCAPC)

LOTAN ET AL., 2009A; 2009B

- ◎ Revisions to NCCPC-R for acute pain in adults with disabilities
- ◎ Items not showing good psychometrics removed
- ◎ Good signs of reliability and validity
- ◎ No cut-off scores to date
- ◎ Not ready for clinical use

PAIN AND DISCOMFORT SCALE

PHAN, EDWARDS & ROBINSON (2005)

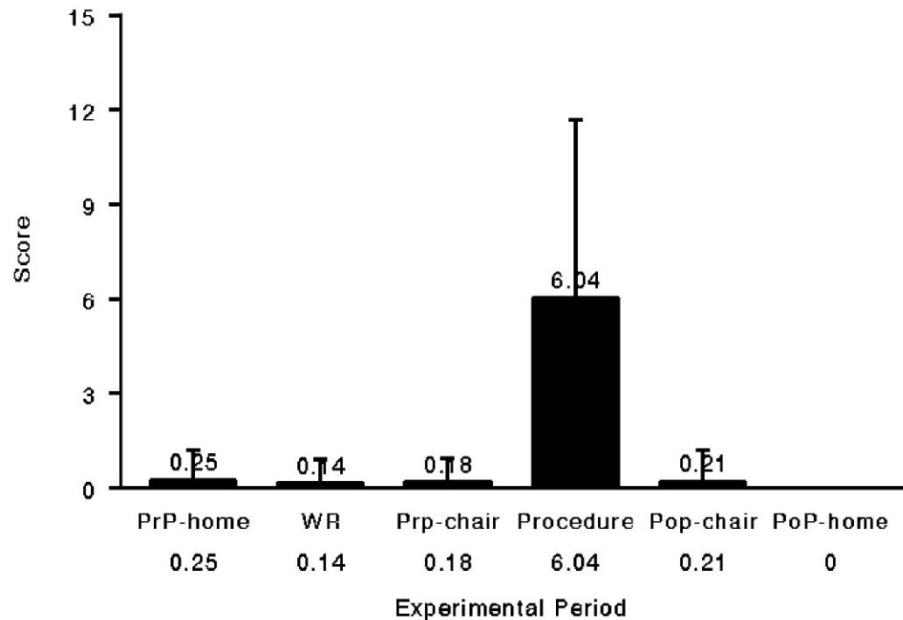
PADS scores before / during / after a dental scaling and polishing procedure (N = 28)

Mean “occurrence reliability” = 98%

Scores significantly higher during procedure

No other psychometrics examined!

Not recommended!



RECOMMENDATION FOR ADULTS WITH ID AT THIS TIME

- ◎ Chronic Pain: Chronic Pain Scale for Nonverbal Adults with Intellectual Disabilities (CPS-NAID)
 - ◎ Needs more research, but cut-off scores available and preliminary psychometrics good
 - ◎ Based on items that are very valid and reliable in children

- ◎ Acute / Procedure Pain: Non-communicating Children's Pain Checklist – Postoperative Version (NCCPC-PV)
 - ◎ Some adults in most studies
 - ◎ No evidence that chronological age affects scores
 - ◎ Cut-off scores available

The Non-communicating Adult Pain Checklist has shown better psychometrics than the NCCPC-R for needle pain , but there are no cut-off scores available to make clinical use feasible at this time.

OBSERVATIONAL PAIN TOOLS FOR ADULTS WITH DEMENTIA: **CAUTION**

- ③ Discomfort Behavior Scale

Stevenson, Brown, Dahl, Ward, Skemp & Brown (2006)

- ③ The Multi-Dimensional Pain Assessment Tool

Harper & Bell (2006)

- ③ Disability Distress Assessment Tool

Regnard, Reynolds, Watson, Matthews, Gibson, & Clarke (2007)

- ③ Pain Assessment for Seniors with Limited Ability to Communicate

Fuchs-Lacelle & Hadjistavropoulos (2004)

- ③ Pain Assessment in Advanced Dementia

Hutchison, Tucker, Kim, & Gilder (2006)

OBSERVATIONAL PAIN TOOLS FOR ADULTS WITH DEMENTIA: **CAUTION**

- ⊙ Past experience with pain affects how we feel and express pain
 - Past experience means:
 - ⊙ How much pain we have had
 - ⊙ How we understood that pain
 - ⊙ How that pain was treated
 - A person who has dementia
 - ⊙ Likely had less pain over their life than someone with an intellectual disability
 - ⊙ Probably understood that pain differently
 - ⊙ Likely had their pain treated differently

CONCLUSIONS

◎ Self-report

- ◎ We do not have sufficient evidence at this time to recommend as the sole measure of pain.

◎ Observational Measures

◎ Children

- At this time, the NCCPCs have the best **science** to support their use with the general population of children with intellectual disabilities.

◎ Adults

- Three tools are available and appear to be needed for different pain situations.
- All are based on a well validated child measure, which supports their soundness.
- Data is preliminary, use with caution.

HOW TO KNOW?

- ⦿ Would most people feel pain?
- ⦿ Would most people want treatment?
- ⦿ Usually at 3 /10 or above people want pain treatment

When nothing else seems available, use information from the general population

CHILDREN'S REPORTED PAIN INTENSITY:

(N = 189, 5 TO 16 YEARS)

<i>Common Injury / Illness Related Pain</i>	<i>Treatment Related Pain</i>
3.1 sliver	3.1 teeth cleaned
3.7 pinched on arm	4.9 fingerprick
4.1 fallen and scraped knee	5.1 needle / injection in arm
4.7 stomach ache	5.5 needle / injection in leg
4.9 sunburn	5.5 braces tightened
5.1 cut finger with knife	6.5 operation
5.5 burned hand	6.8 stitches
5.5 menstrual cramps	7.6 broken arm or lag
5.7 headache	
8.0 serious injury	

Adapted from: McGrath,
Speechley, Seifert, Biehn,
Cairney, Gorodzinsky, Dickie,
McCusker, Morrissy (2000):
Pain.

USING THE NCCPC'S FOR IMMEDIATE PAIN ASSESSMENT

- ⊙ Recommend NCCPC-PV
 - ⊙ No eating / sleeping items
 - ⊙ Shorter observations time: 10 minutes
- ⊙ Cut-off scores:
 - ⊙ Mild pain = 6-10
 - ⊙ Moderate to severe pain = 11+

USING THE NCCPC's

- ◎ Watch the child
 - ◎ Do not have to know child well
- ◎ Record how often each item occurs
- ◎ Add up scores

No training required!!!!
- ◎ Compare with cut-off scores

USING THE NCCPC'S FOR ONGOING PAIN ASSESSMENT OR MONITORING

- ◎ Use cut-off scores

or:

- ◎ Compare Scores over time

- ◎ Collect baseline scores

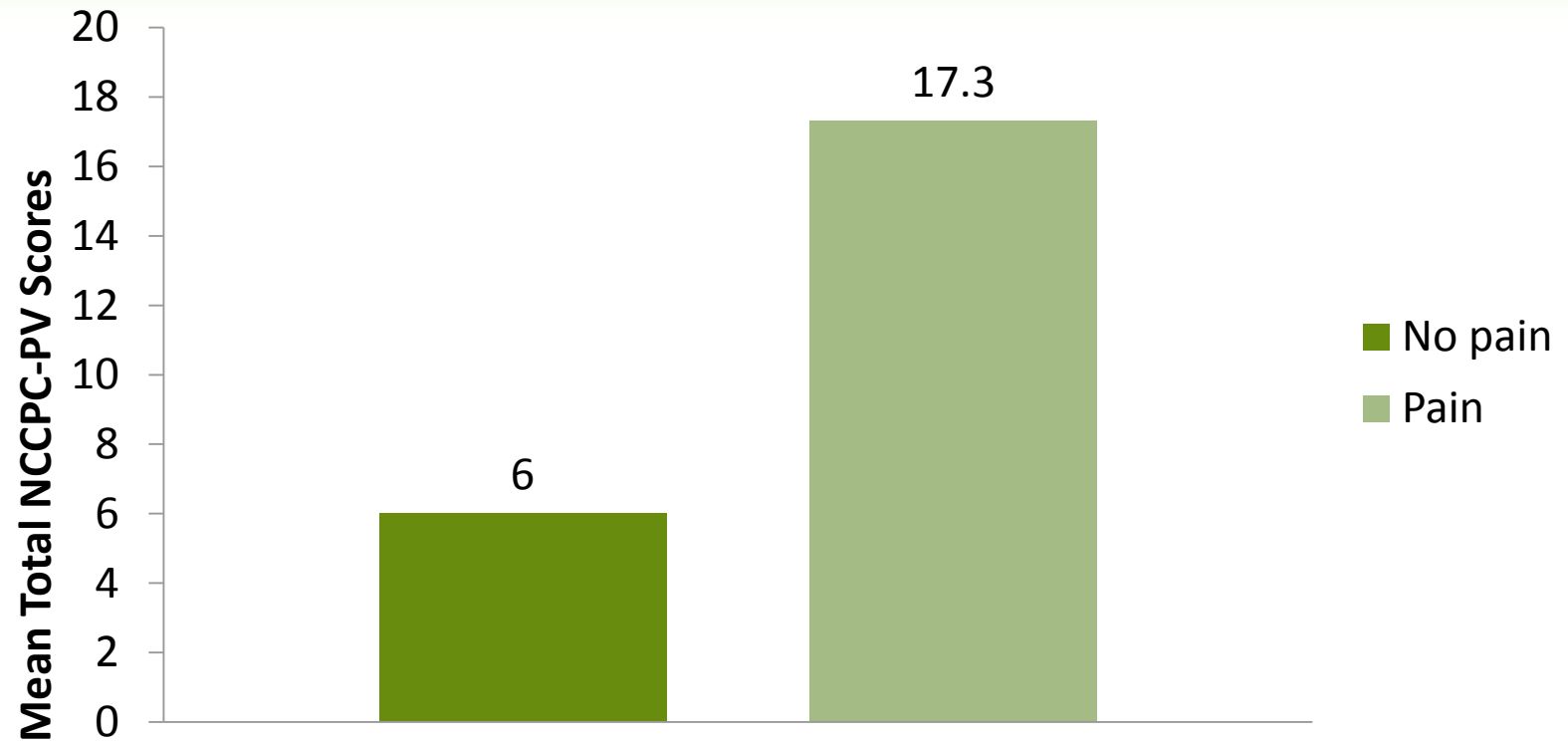
- ◎ Collect scores during pain and illness

- ◎ Collect scores after treatment

- ◎ Look for the amount of change you see for different types of pain or combinations of pain and illness

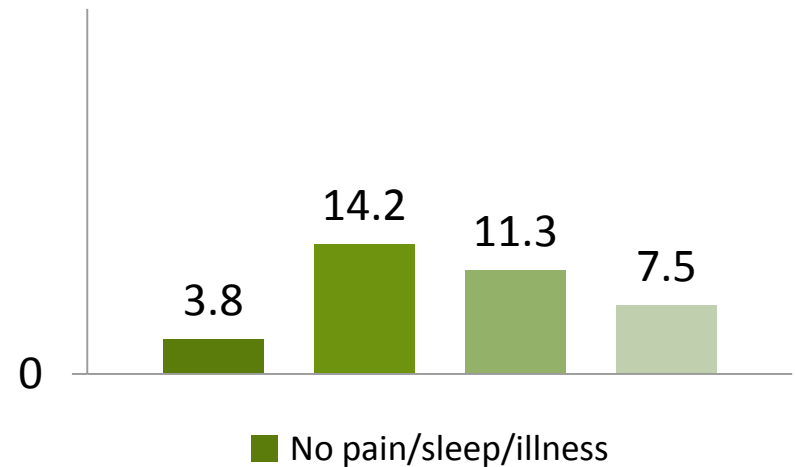
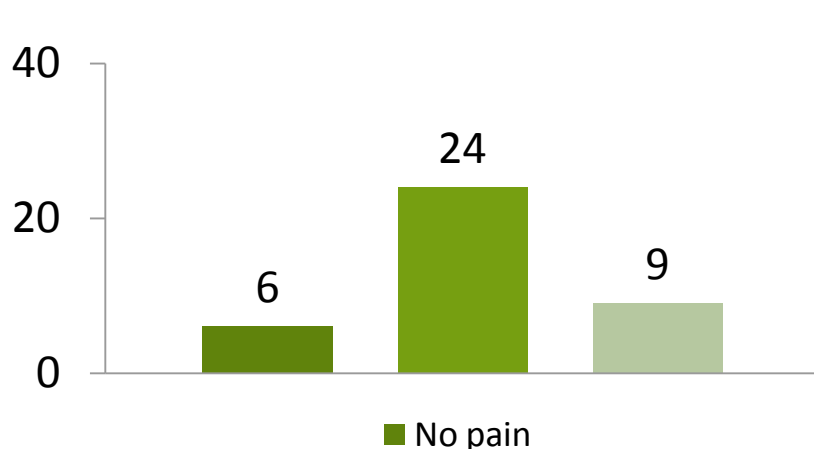
NCCPC-PV :TOTAL SCORES

GS (26 YEARS): SUSPECTED ONGOING PAIN



NCCPC-PV :TOTAL SCORES

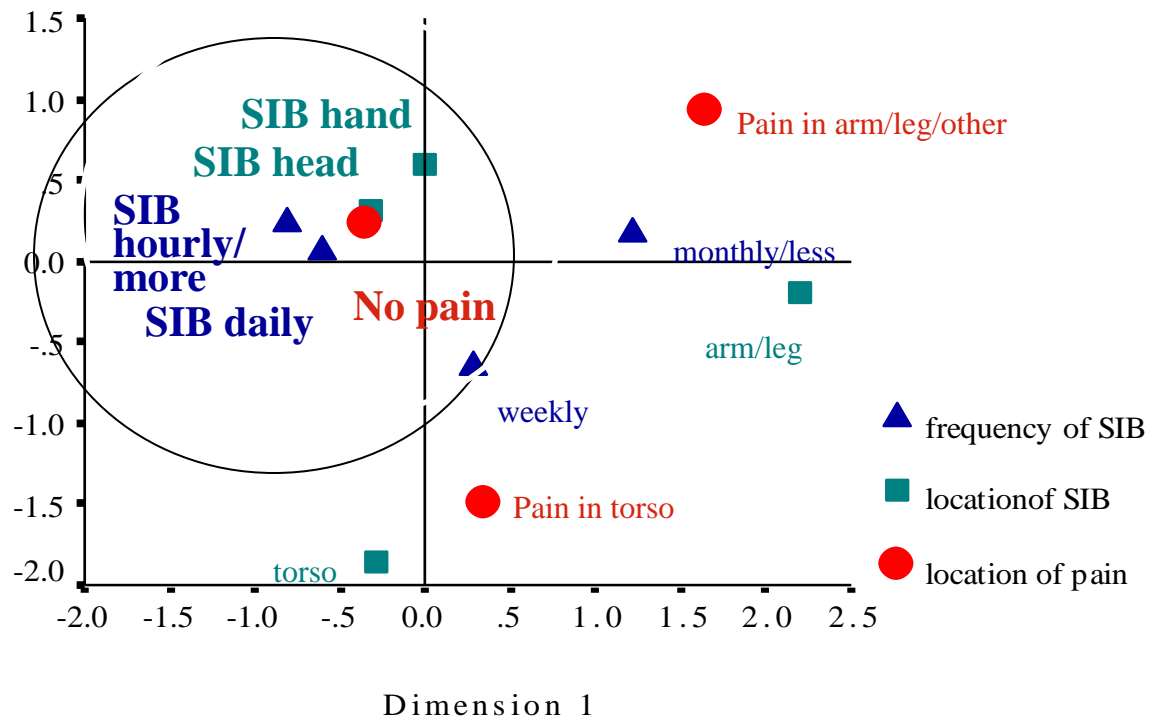
JM (24 YEARS): SUSPECTED ONGOING PAIN



When JM's scores on days he had sleep problems were separated from his "no pain" scores, it became apparent that he was probably having pain at those times that was not detected.

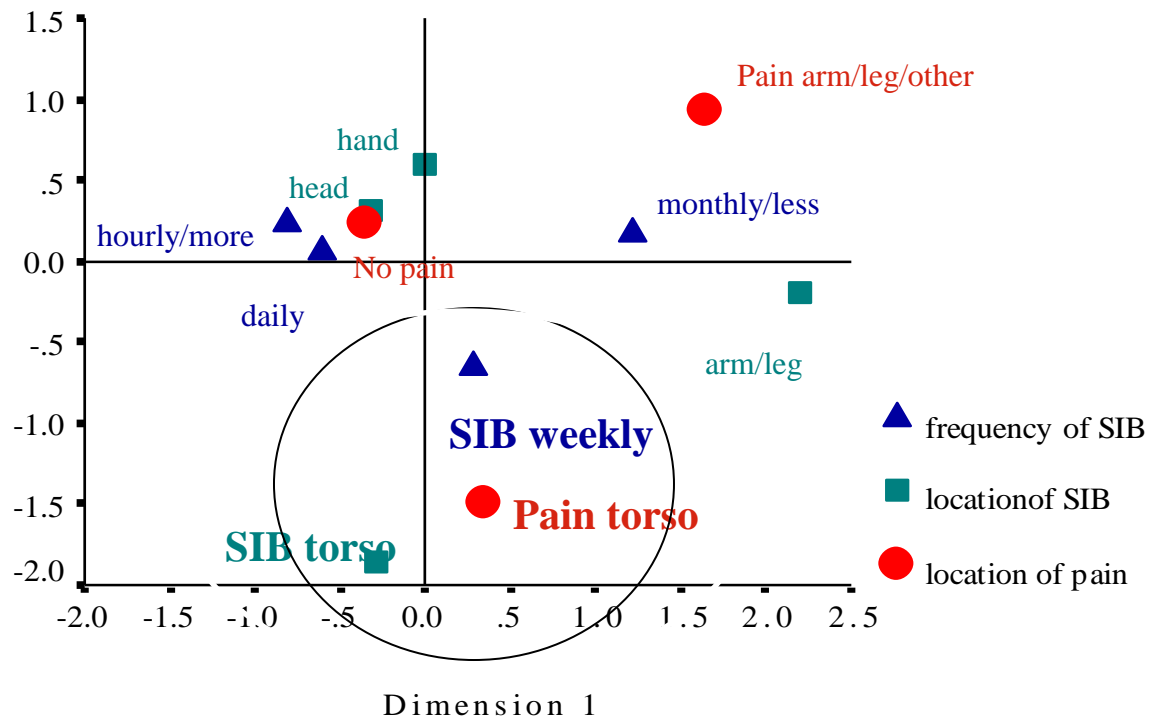
BECAUSE NOT EVERYONE IS
LOOKING FOR PAIN, IT OFTEN IS
NOT CONSIDERED A POSSIBLE
CAUSE FOR CHANGES IN
BEHAVIOUR, MOOD OR
FUNCTION.

CHILDREN WITH NO CHRONIC PAIN SELF-INJURE THE HEAD OR HANDS DAILY OR MORE...



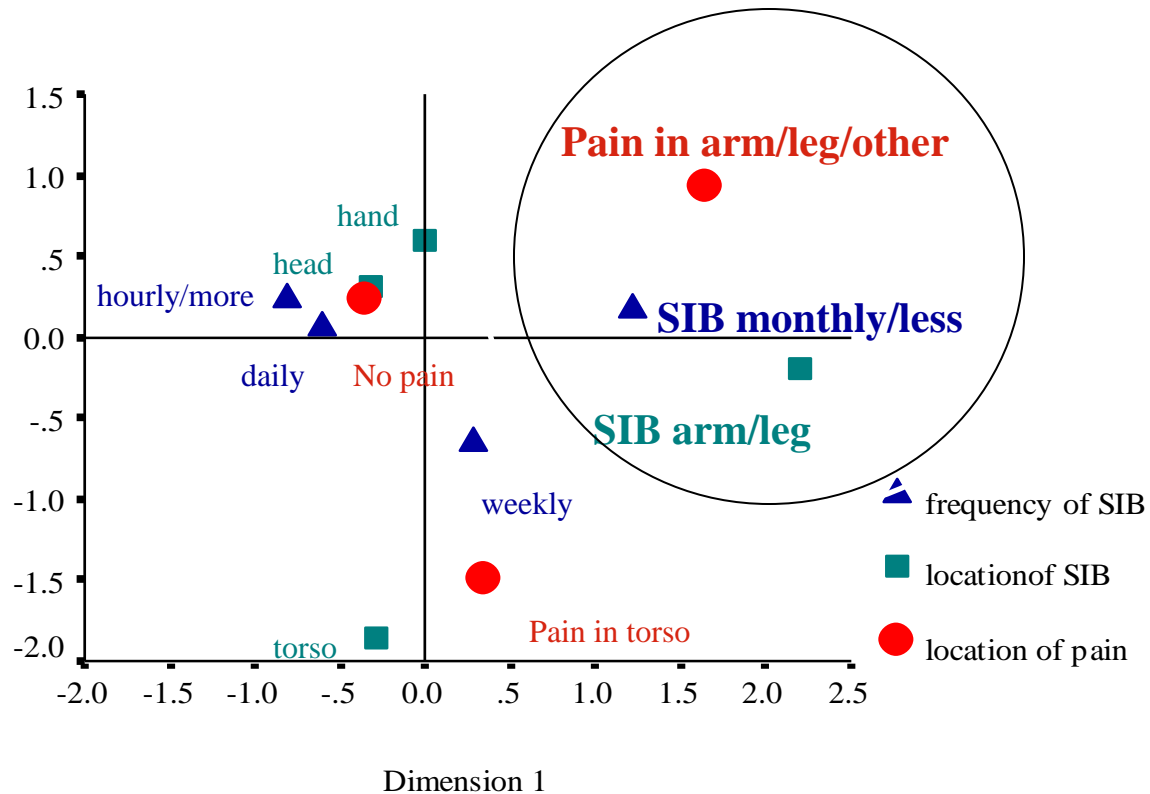
Categorical PCA. Variance accounted for: Dimension 1: 53%; Dimension 2: 44%

CHILDREN WITH CHRONIC PAIN IN THEIR TORSO SELF-INJURE THEIR TORSO WEEKLY...



Categorical PCA. Variance accounted for: Dimension 1: 53%; Dimension 2: 44%

CHILDREN WITH CHRONIC PAIN IN THEIR LIMBS SELF-INJURE THEIR LIMBS MONTHLY OR LESS...

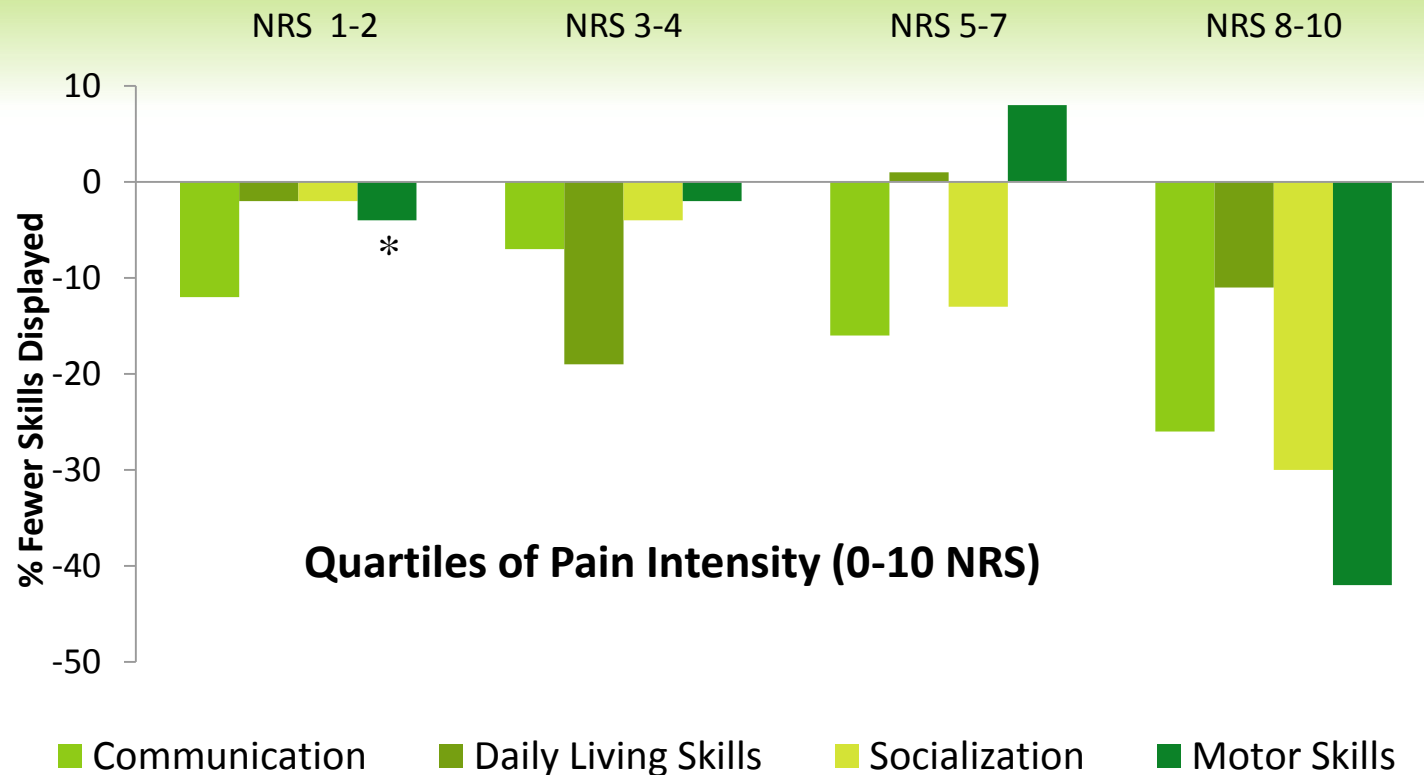


Intermittent, location-specific SIB may be due to pain

Categorical PCA. Variance accounted for: Dimension 1: 53%; Dimension 2: 44%

IMPACT OF PAIN ON FUNCTIONING: BY INTENSITY

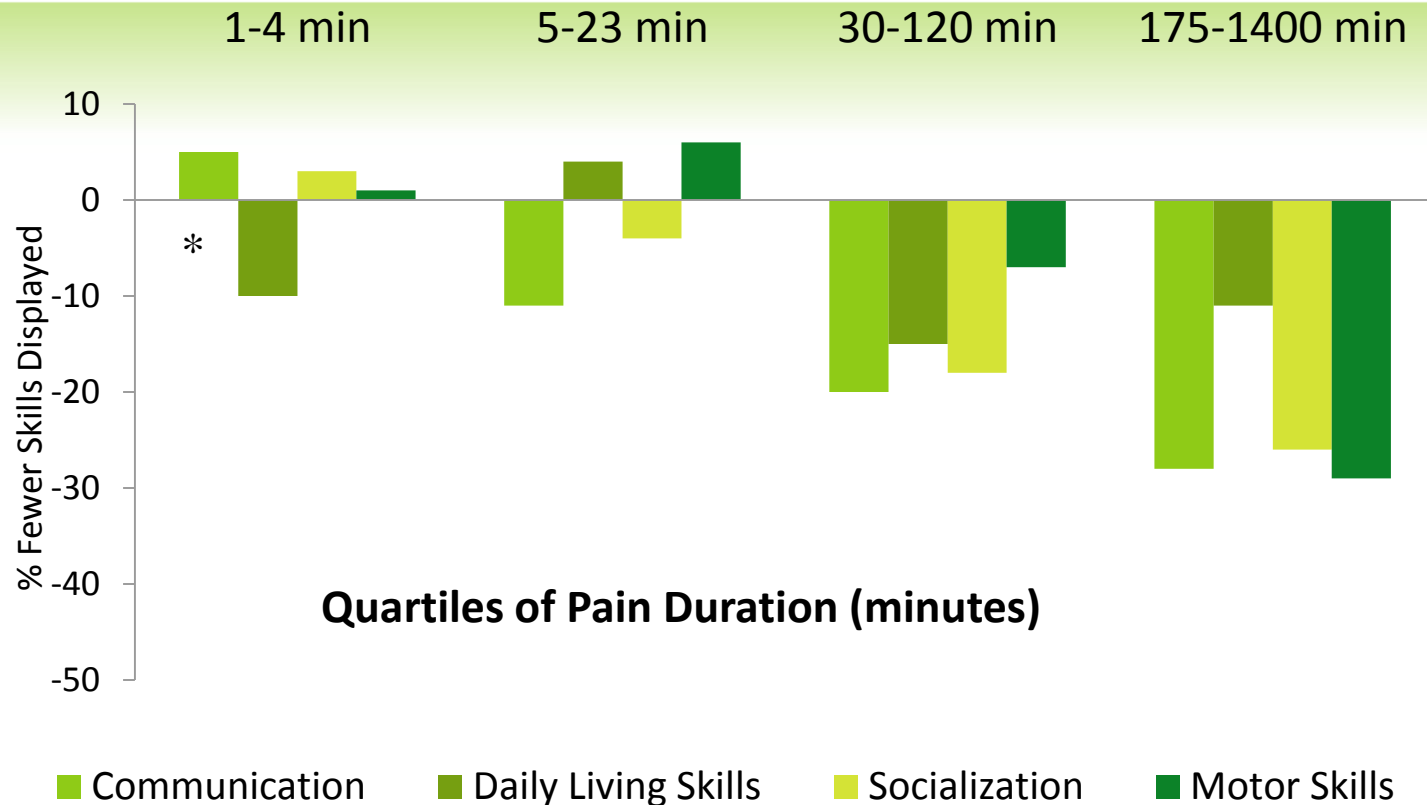
BREAU, CAMFIELD, MCGRATH & FINLEY (2006): *JOURNAL OF INTELLECTUAL DISABILITY RESEARCH*



$N = 70$. Domains of VABS, Sparrow et al. (1984). Intensity: $F(12, 145.8) = 2.3, p = .01$, Duration (covariate): $F(4, 55) = 2.4, p = .06$. Intensity univariate effects: Motor Skills ($F(3, 58) = 6.5, p = .001$).

IMPACT OF PAIN ON FUNCTIONING: BY DURATION

BREAU, CAMFIELD, MCGRATH & FINLEY (2006): *JOURNAL OF INTELLECTUAL DISABILITY RESEARCH*



$N = 70$. Domains of VABS, Sparrow et al. (1984). Duration: $F(12, 145.8) = 1.6, p = .10$, Intensity (covariate): $F(4,55) = 1.4, p = .24$. Duration univariate effects: Communication ($F(3,58) = 2.0, p = .05$).

LESS THAN OBVIOUS

- ◎ Multiple sources of pain possible
- ◎ Some are not often considered
 - ◎ Neuropathic
 - ◎ Dental
 - ◎ Positioning
 - ◎ Headaches
 - ◎ ENT
 - ◎ Arthritis
- ◎ Be aware of the fact that people with ID are as likely or more to suffer from the same pain sources as others.

TAKE HOME MESSAGE

- ② Use the most sound tool for the specific group you are working with
- ② Consider long-term changes in behaviour and function as possible signs of pain
 - ② Self-injury
 - ② Regression, loss of skills
 - ② Sleep problems
- ② Consider ALL possible sources of pain

SCIENCE IS THE GREAT ANTIDOTE TO THE POISON OF ENTHUSIASM AND SUPERSTITION.

ADAM SMITH, *THE WEALTH OF NATIONS*, 1776

No single scale or tool is the answer.
If we are to call what we do “**science**”
we must be open,
not only to new facts,
but also to new ways.... Lynn

Thank you!