

Research papers

Validation of the Individualized Numeric Rating Scale (INRS): A pain assessment tool for nonverbal children with intellectual disability

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ABSTRACT

Clinical observations suggest that nonverbal children with severe intellectual disability exhibit pain in a wide variety yet uniquely individual ways. Here, we investigate the feasibility and describe the initial psychometrics properties of the Individualized Numeric Rating Scale (INRS), a personalized pain assessment tool for nonverbal children with intellectual disability based on the parent's knowledge of the child. Parents of 50 nonverbal children with severe intellectual disability scheduled for surgery were able to complete the task of describing then rank ordering their child's usual and pain indicators. The parent, bedside nurse and research assistant (RA) triad then simultaneously yet independently scored the patient's post-operative pain using the INRS for a maximum of two sets of pre/post paired observations. A total of 170 triad assessments were completed before ($n = 85$) and after ($n = 85$) an intervention to manage the child's pain. INRS inter-rater agreement between the parents and research nurse was high (ICC 0.82–0.87) across all ratings. Parent and bedside nurse agreement (ICC 0.65–0.74) and bedside nurse and research nurse agreement (ICC 0.74–0.80) also suggest good reliability. A moderate to strong correlation (0.63–0.73) between INRS ratings and NCCPC-PV total scores provides evidence of convergent validity. These results provide preliminary data that the INRS is a valid and reliable tool for assessing pain in nonverbal children with severe intellectual disability in an acute care setting.

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1. Introduction

Pain is a complex, subjective experience best understood through self-report using words. Children with profound intellectual disability, who are unable to use words to express pain, are dependent on others to recognize pain indicators and intervene. Nonverbal children with intellectual disability often have pain that is not easily recognized because of subtle or idiosyncratic pain behaviors [7,13,18] and a wide variation in physical and expressive abilities. In addition, they have several possible sources for pain [1,5,17].

One of the first steps towards standardizing pain assessment for this population was the creation of the Noncommunicating Children's Pain Checklist (NCCPC). The checklist with behavioral and physiologic measures has been shown to be internally consistent

with good inter-rater reliability [2–5]. However, the current length of the checklist (27 items) limits its clinical utility in an acute care setting where pain assessments are considered the 5th vital sign and completed every 4 h around the clock. Recently, the popular behavioral observational pain scale, the FLACC (Face, Legs, Activity, Cry and Consolability), was revised as a measure of pain in children with intellectual disability [11,20,21]. While initial findings support the validity and reliability of the Revised FLACC, the instrument's equally scored 5 categories limits the significance that can be placed on unique pain descriptors. In addition, the 5 categories of the Revised FLACC do not accommodate salient pain descriptors such as physiologic indicators or changes in patterns of sleeping and eating.

A strategy that may be useful in assessing pain in this population is the individualization of pain assessment tools based on the unique pain indicators described by the family and or caregivers [1]. Several studies have demonstrated that parents of children with intellectual disabilities can describe their child's pain indicators [6,7,10,13,18,20]. Using the parental knowledge of child pain

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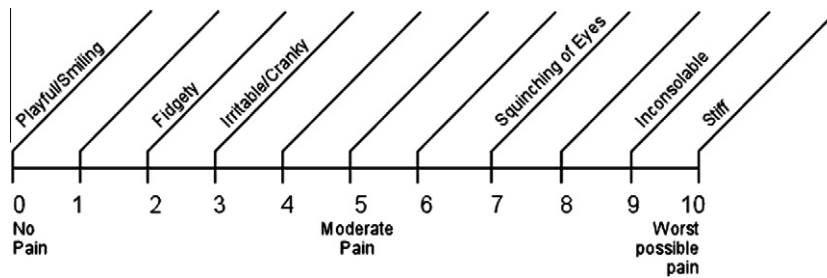


Fig. 1. Example of populated INRS.

indicators is common in clinical practice and consistent with the statement on Surrogate Reporting in Pain Assessment in the Nonverbal Patients [9].

The Individualized Numeric Rating Scale (INRS) is based solely on the child's individual pain indicators as described by parents and caregivers. An example of a populated INRS is presented in Fig. 1. The INRS is an adaptation of the numeric rating scale that incorporates the parents' (and/or caregivers) descriptions of their individual child's past and current responses to pain. Once described, the responses are then stratified on a scale from 0 to 10. The INRS was initially developed at Children's Hospital Boston to help intensive care nurses observe, consistently document and communicate (shift-to-shift) the unique pain indicators of nonverbal critically ill children after major surgical procedures [17]. In April 2000, hospital-wide practice guidelines recommended the use of the INRS in all clinical areas. The purpose of this study was to (1) assess the feasibility of creating a usable parent-guided INRS for nonverbal children with intellectual disability; (2) test the inter-rater reliability of a completed INRS across multiple raters, and (3) examine the criterion and construct validity of the INRS.

2. Materials and methods

2.1. Study population

This prospective cohort study was approved through our Institutional Review Board and written informed consent was obtained from the parent or legal guardian of each subject. A convenience sample of nonverbal children with intellectual disability and their parents was recruited from the pre-operative and the orthopedic clinics. All subjects were between ages 6–18 years. The following inclusion criteria were used: (1) documented intellectual disability; (2) inability to communicate verbally even with one word; (3) scheduled for an elective surgery necessitating a post-operative overnight hospital stay. The inclusion criteria for the parents were (1) the parents were the primary caregivers who have lived with the child for at least the last 6 months; (2) planned parental presence during a surgical admission.

2.2. INRS completion

As per current practice, a pre-operative nurse assisted the parent(s) in completing the INRS through a face to face interview conducted in a private room within the hospital. Specifically, the parents were given a blank INRS. The nurse first invited the parent(s) to describe their child's behaviors on a usual day, when not in pain. These behaviors were then recorded under "0". The parent(s) were then asked to recall a time when they knew their child had pain whether from past surgeries, painful procedures and/or experiences. The parents were requested to describe the changes in their child's behavior, vocalization, expression and other physical changes and to stratify and link them with a number from "1–10" with one being mild pain and 10 being the worst

imaginable pain. To help parents recall past pain indicators, nurses informally used the FLACC (Face, Legs, Activity, Cry and Consolability) acronym [12]. For example, the nurses would tell parents that pain cues of some children include changes in facial expression, changes in legs or limbs, changes in activity, cry or consolability. The FLACC acronym was used since it was familiar to the nurses, being the pain assessment tool used for infant and preverbal children in the hospital. After the form was populated, the parents were asked to review the populated INRS and to make any changes to the tool. During subsequent post-operative meetings with the parents, the parents were once again asked to review their child's INRS and to either confirm or make any changes to the tool.

2.3. Pain assessments

The pain assessments were collected in the following manner. After surgery, the bedside nurse would contact the research team when the child began to exhibit signs of pain. Prior to and one hour after an intervention to decrease pain, the triad simultaneously yet independently observed the patient for one minute, then scored the patient's pain using the INRS for a maximum of two sets of pre/post paired observations. Each set of observations included the same participants (same parent, nurse, and RA). The scores were documented on separate report forms then folded and given to the research nurse. Data collection did not alter current practice nor delay the administration of pain medication. When the research team was not able to be quickly assembled, then the child would receive the analgesic ordered and the scoring for the research study would occur at a later time.

In addition to the INRS, the RA scored the patient's pain using the Noncommunicating Children's Pain Checklist – Postoperative Version (NCCPC-PV). The NCCPC-PV is a 27-item checklist of common pain indicators in noncommunicating children [2]. Each indicator is rated on a 4-point scale (0 = not at all, 1 = just a little, 2 = fairly often, 3 = very often) and is summed to create a total score (0–81). The checklist has six subscales: vocal, social/personality, facial expression of pain, activity, body/limbs and physiological signs. The scale has been shown to be internally consistent (Cronbach's alpha = 0.91) with good reliability (intra-class correlation coefficients 0.77 for vocal subscale, 0.48 for social, 0.81 for facial, 0.61 for activity, 0.45 for body and limbs, 0.63 for physiologic signs, and 0.82 for total score) [2–5,13]. Before the start of data collection for the current study, all RAs performed reliability testing on the NCCPC-PV using three videotapes of patients with pain post-operative pain until 90% agreement was reached.

2.4. Vineland Adaptive Behavioral Scale

The Vineland Adaptive Behavioral Scale (VABS) was used to describe the developmental level of functioning for the study population. The VABS was chosen because communication and socialization are important factors in communicating pain to oth-

ers. Also to minimize burden to the families, an assessment of developmental level via caretaker interview was chosen over direct examination of the patient. After discharge, the VABS was administered by a trained interviewer by telephone at the convenience of the parent. The VABS is designed to assess levels of personal and social abilities of individuals with and without disabilities from birth to adulthood. The VABS is administered by a semi structured interview with a caregiver who knows the patient well. The VABS measures adaptive behaviors in four domains (1) communication (both expressive and receptive language); (2) daily living skills (practical skills needed to take care of oneself); (3) socialization (how the child gets along with others and uses leisure time); (4) motor skills (physical movements and coordination necessary for daily activities) [15,19]. Internal consistency for the four domains ranged from 0.76 to 0.99 [15]. Test–retest reliability for the four domains ranged from 0.76 to 0.93. The range of inter-rater reliability values for the VABS was 0.62–0.78 [15,19]. With the exception of a moderate inter-rater reliability correlation of 0.62 for the domain of socialization, the overall reliability of the VABS is considered good for an interview instrument. For this study, motor skills were not assessed because participants were extremely limited in their independent motor skills.

2.5. Data analysis

We calculated descriptive statistics (e.g., frequencies, proportions, mean and standard deviations, medians and interquartile ranges) on all patient's demographic and clinical characteristics, and on parent, nurse, and RA pain ratings. To assess inter-rater reliability between bedside nurse and research nurse INRS ratings, we calculated intra-class correlation coefficients (ICC, two-way random effects model) [14,16] which is a measure not only of the agreement in the ordering of ratings but also in the magnitude of ratings. Although the weighted kappa would have been the best reliability statistic for the INRS due to the INRS having ordinal rather than interval properties, we could not calculate kappas due to some zero-case cells which resulted in non-symmetric two-way tables. As the intra-class correlation coefficient has been shown to be equivalent to the weighted kappa when applied to ordered response scales and where varying levels of disagreement are differentially weighted [8], we opted to calculate and report intra-class coefficients. To examine criterion validity, we calculated intra-class correlation coefficients (two-way fixed effects model) for agreement between the nurse ratings (bedside and research) and parent ratings, with parent ratings as the gold standard. We assessed construct validity by (1) calculating a Pearson's correlation coefficient between INRS and NCCPC-PV scores (convergent validity), and (2) comparing the INRS ratings taken before an imminent pain intervention (when pain should be higher) and shortly after its implementation (when pain should be lower) using mixed-effects modeling to account for multiple rating occurrences for a single patient. We conducted all psychometric analyses using all available paired ratings, which included multiple rating occurrences for a patient. Due to possible inter-correlation among multiple ratings of the same patient, we also conducted these analyses using only the pre-pain-intervention rating for a patient, only the post-intervention rating, and only a single randomly selected rating per patient. The single patient ratings were randomly selected using a random number generator in SPSS[™] 15.0 to assign a random number containing up to six digits to each individual rating occurrence for a patient. The record with the lowest random number for each patient was then selected for analyses of one rating occurrence for each patient. We used Bonferroni correction for multiple comparisons to reduce the likelihood of a Type I error. We conducted all analyses using SPSS[™] 15.0 statistical software.

3. Results

3.1. Demographics

We collected complete data on 50 children aged 6–18 years and who were nonverbal with profound intellectual disability between July 2004 and April 2008. The mean level of functioning was measured by the VABS in three domain scores; Communication (mean = 16.0 months, S.D. 6.5), Daily Living Skills (mean 15.1 months, S.D. 4.9); Socialization (mean 18.7 months, S.D. 8.4). Motor skills were not assessed as participants were extremely limited in their independent motor skills. Patient and parent demographics are presented in Tables 1–3. The most common cause of intellectual disability reported by the parents included prenatal or perinatal events ($n = 30$) and seizure disorders ($n = 4$). The children underwent the following surgeries: spinal fusion ($n = 16$, 32%); other orthopedic surgeries ($n = 26$, 52%); general surgeries ($n = 6$, 12%); ENT surgeries ($n = 2$, 4%). There were no significant demographics differences between consented patients who provided assessment and those who could not provide assessments (see Table 4).

3.2. Parental descriptions of pain indicators

All parents were able to complete the task of describing their child's pain indicators (when in pain and when not). All parents were able to rank order these descriptors and link them to the numeric rating scale for pain. A parent of an autistic child verbalized more difficulty than other parents in filling out the INRS and had fewer pain descriptors. This parent reported that the child did not always respond consistently to similar painful stimuli such as receiving immunizations at the pediatrician's office.

Parents filled out the INRS using an average of 8.4 different descriptors (total of 421 descriptors), 21% of the descriptors depicted the child's usual behavior when not in pain. The parent identified descriptors showed a wide variety including 22 variations of eye descriptors (examples: "avoiding eye contact"; "eye squinting"; pulling on eyelids) and 27 variations of arm descriptors (examples: "bites hands"; "clapping hands"; "extending tense arms").

3.3. Assessments

A total of 170 triad assessments ($n = 50$) were completed 3 days after surgery (median; range 0–8 days). The triad assessments were completed before ($n = 85$) and 1 h after ($n = 85$) an administration of pain medications ($n = 83$) or a change in the patient's position to alleviate pain ($n = 2$). The 42 bedside nurses, assigned to care for the patients, were primarily white ($n = 39$; 93%), female ($n = 38$; 90%), and prepared with a bachelor's degree in nursing ($n = 34$; 81%). All five RAs were white, females with at least a master's degree and, on average, 20 years of nursing experience. Four of the five RAs were nurse practitioners working for the Pain Treatment Service.

Table 1
Patient demographics.

	Results (N = 50)
Gender (N;% female)	21; 42%
Age (mean in years)	10.4
Ethnicity (N; %)	
Hispanic/Latino	13; 26%
Race (N; %)**	
White	43; 86%
Other	7; 14%

** Race was grouped into two categories due to low numbers.

Table 2
Parent demographics.

Gender (N, % female)	44; 88%
Age (mean; range)	40 years; 27–59 years
Ethnic group (N, %)	
Hispanic/Latino	6; 12%
Race (N; %)	
White	40; 80%
Black/African American	4; 8%
Other	2; 4%
Primary language	
English	42; 84%
Spanish	4; 8%
Other	2; 2.4%
Highest education	
Less than high school	2; 4%
High school graduate	26; 52%
College graduate	15; 30%
Graduate education	6; 12%

Table 5 presents the summary statistics for INRS ratings (range, mean, median) overall, and before and after a pain intervention. Ratings covered the full range possible (no pain = 0 through severe pain ≥ 8) and did not differ by patient's gender, age, surgical category or parent education level. In paired *t*-tests, ratings by the bedside nurse were significantly lower than parent ratings across all types of ratings (pre-intervention 3.2 vs. 4.0, *t*-statistic = 3.71, $p < .001$; post-intervention 1.2 vs. 1.7, *t*-statistic = 3.85, $p < .001$). Bedside nurse ratings were also lower than research nurse ratings at pre-intervention (3.2 vs. 4.0, *t*-statistic = 4.29, $p < .001$), but did not differ post-intervention. Research nurse ratings did not differ from parent ratings.

INRS inter-rater agreement between the parents and RAs was high (ICC 0.82–0.87) as shown in Table 6 across all types of ratings. Bedside nurse agreement with parents was (ICC = 0.65) for ratings immediately before a pain intervention and (ICC = 0.74) post-intervention. Interestingly, in patient subgroup analyses, patient gender appeared to influence the level of agreement between nurse and parent ratings conducted prior to a pain intervention. There was higher agreement between nurse and parent ratings for male patients than for female patients. The ICC between bedside nurse and parent pre-intervention ratings was 0.76 (95% CI 0.60–0.86) for male patients compared to 0.56 (95% CI 0.29–0.75) for female patients. Similarly, the ICC between research nurse and parent pre-intervention ratings was 0.90 (95% CI 0.82–0.94) for male patients compared to 0.72 (95% CI 0.52–0.84) for female patients. This gender effect on the level of agreement was not seen for post-intervention ratings nor for agreement between the two types of nurses.

We found a strong correlation (Pearson's $r > .60$) between INRS ratings and NCCPC-PV total scores (see Table 6), indicating convergent validity. We also found that INRS ratings, regardless of the type of rater, were significantly higher just prior to a pain intervention compared to immediately after, as expected, further supporting construct validity of the INRS.

Table 3
Results of the Vineland Adaptive Behavioral Scale (VABS).

Domain	Mean score (n = 50)
Communication	16.0 months, S.D. 6.5
Daily living skills	15.1 months, S.D. 4.9
Socialization	18.7 months, S.D. 8.4
Motor skills	Not assessed*

* Motor skills were not assessed as participants were extremely limited in their independent motor skills.

Table 4
Reasons patients did not complete study (N = 32).

11	Remained ventilated and sedated for >72 h after surgery
7	Surgery cancelled
4	Parent unavailable for assessments
3	Not assessed to be in pain by the parent
3	Discharged after surgery without an overnight stay
1	Found to use words for pain and therefore did not meet the study criteria
1	Parent withdrew child from the study
1	Assessment aborted when child had respiratory depression during the assessment
1	Study personnel unavailable

4. Discussion

These results provide preliminary evidence that the INRS is a valid and reliable method to assess pain in nonverbal children with profound intellectual disabilities. INRS scores from the research nurse, the bedside nurse and parent were significantly correlated. The moderate to strong correlation (0.63–0.73) between INRS ratings and NCCPC-PV total scores indicates convergent validity. This is important because it shows that the INRS and the NCCPC-PV (a well studied pain assessment tool) are measuring a similar construct.

Correlations between research nurses and parents were higher than those between bedside nurses and parents. Interestingly, often the bedside nurses had more direct patient knowledge than the research nurses. Both reviewed the same child-specific INRS before and throughout the scoring. Since most of the research nurses were nurse practitioners working in pain management, the higher correlation between research nurses and parent scores are likely explained by the research nurses having a greater number of years of experience with a focus on pain management than the bedside nurses. It may be that this experience allows for better pain assessment skills. Another explanation is that research nurses' familiarity with the literature on pain assessment may have given them a better appreciation of parental knowledge of a child with intellectual disability. Several studies of pain assessment in children with intellectual disability have found that parents can identify their child's pain indicators and can provide reasonable estimates of pain [6,7,10,13,18,21]. Being familiar with these studies, the research nurses may have focused more attention on the parent-described pain descriptors than the bedside nurses. Further education of nurses about these research findings may be needed.

During this study, the pre-operative clinic nurses assisted families in populating the INRS. The amount of time to populate the INRS for parents and nurses was not measured during this study. As mentioned previously, all the parents were able to describe their child's pain indicators and rank order them. Many parents expressed gratitude for the opportunity to document their child's pain indicators. All but one parent of an autistic child was able to describe their child's pain indicators with ease. Although parents were offered the chance to change their child's INRS before each set of pre/post assessments, not one parent revised their child's scale. This is consistent with the literature that parents do know their child's pain [6,7,10,13,18,21]. Further study is needed to assess if the scale could be filled out by parents independently.

Another important consideration is how this tool can be used when parents speak a different language compared with the clinicians caring for the child. The ability to speak English did not exclude patients from this study. However, we did not have the opportunity to enroll a child with non English speaking parents. When parents and clinicians are unable to speak the same language, configuring the child's INRS will require a translator. However, once the INRS is configured, the INRS may ease pain assessment especially if the translator documents the INRS in both

Table 5

Descriptive statistics (range, mean and standard deviation, median and interquartile range) for pain ratings made by each rater, and paired *t*-test comparison of pre-pain intervention ratings and post-pain intervention ratings.

	All ratings (N = 170)			Pre-intervention only (N = 85)			Post-intervention only (N = 85)			Pre/post <i>p</i> -value ^c
	Range	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	
<i>Individualized Numeric Rating Scale</i>										
Parent	0–9	2.9 (2.6)	2.0 (0.0–5.0)	0–9	4.0 (2.5)	4.0 (2.0–6.0)	0–9	1.7 (2.1)	1.0 (0.0–3.0)	<.001
Research nurse	0–10	2.7 (2.6)	2.0 (0.0–4.0)	0–10	4.0 (2.5)	4.0 (2.0–6.0)	0–8	1.4 (2.0)	1.0 (0.0–2.0)	<.001
Bedside nurse	0–10	2.2 (2.3)	2.0 (0.0–4.0)	0–10	3.2 (2.4)	3.0 (1.5–5.0)	0–10	1.2 (1.7)	0.0 (0.0–2.0)	<.001
NCCPC-PV ^{a,b} total score	0–59	11.4 (11.3)	7.5 (4.0–15.0)	0–59	15.4 (12.7)	11.0 (6.0–24.0)	0–37	7.4 (7.8)	5.0 (2.5–9.5)	<.001

^a Completed by research nurse.

^b Noncommunicating Children’s Pain Checklist – post-operative version.

^c Results of mixed-effects regression analyses comparing pre-pain-intervention and post-intervention ratings for each patient, adjusting for multiple pre- and post-intervention observations on a single patient.

languages so parents can still be actively involved in their child’s pain assessment. Further investigation is needed to look at the use of the INRS when parents and clinicians do not speak the same language.

The use of parent-described pain indicators to individualize pain assessment tools has been used to individualize a pain tool originally created for children without intellectual disabilities, the Face-Legs-Activity-Cry and Consolability (FLACC). Initial findings support the reliability and validity of the individualized, revised FLACC as a measure of pain in children with intellectual disability [11]. However, the study sample had a wide variety of ID (only 46% (24 children) with significant ID and 23% (12 children) able to self report) [11]. It is likely that researchers studying the FLACC chose a diverse sample of children with a range of intellectual disability in order to increase the generalizability of the FLACC to apply to a wide range of children. However, this choice of sample may skew the results by assessing children with a high level of expressive and physical abilities. Although the FLACC was used in this study as a guide to help parents recall pain indicators, 17.1% (*n* = 72) of the total 421 descriptors did not fit into the FLACC categories. When adjusted by eliminating the baseline “no pain” indicators, this increased to 19.5% (*n* = 65) of the 333 pain cues were unable to fit into the FLACC categories. Examples of pain cues that did not fit into the FLACC categories were physiologic changes such as “heavy breathing”, “breath holding”, increased seizure activity”, “increased sleep”, “sweats”, “turns red”; changes in behavior such as “decreased eye contact”, “tries to make eye contact”, “bites hand”, “makes fists”; and changes in sleep and eating patterns such as “stops eating”, and “increased time sleeping”. Based on these findings, the six subscales from the NCCPC, vocal, social/personality, facial expression of pain, activity, body/limbs and physiological signs, may be a better guide for parents when personalizing the INRS.

The INRS offers several advantages for assessing pain in this population. The INRS allows weighting of pain indicators based on past observations. For example, if a parent identifies that their child exhibited severe pain primarily by complete social withdrawal, social withdrawal would be heavily weighted as 10/10

on the INRS. In comparison, the five-part structure of the FLACC-REV limits the weight that parental knowledge has on the final pain score so social withdrawal would be only 20% of the total pain tool. The same child being assessed with the NCCPC-PV may score high values in the social subscale; however, the social subscale is only 16% of the total score of the NCCPC-PV. In addition, baseline physical abilities, including neuromuscular function and expressive behaviors have been found to be helpful in order to recognize a deviation from usual behavior [6,10].

Another strength of the INRS is that it expands upon the knowledge of parents and caretakers by assisting them in organizing and recording their past observations of pain cues. The INRS relies heavily upon the parents’ ability to articulate their child’s pain cues. This method of pain assessment is congruent with family-centered-care as it invites parents to participate in the care process. Parents may also be reassured that clinicians will use their input when assessing pain especially when the parent cannot be present. This strength of the tool may also be a weakness in the wrong situation. In rare situations, reliance on parents’ knowledge may be inappropriate if parents are unable to objectively describe their child’s pain indicators. For example, in the case of a child being evaluated for Munchhausen by Proxy, a standardized pain assessment tool or observation by clinicians and caretakers other than the parents would provide a greater measure of safety to this rare but serious situation.

The higher agreement between nurse and parent ratings for male patients requires further investigation. Males may demonstrate more pain indicators or perhaps female raters evaluate signs of pain differently in males.

This study had several limitations. The study sample size did not allow extensive sub group analysis. For example the VABS was only used to describe the range in functioning of the sample. Further study with a larger sample is needed to compare the INRS descriptors across different levels of functioning. Another limitation was that the data were collected over a period of several years, during which time the literature about pain assessment in this population was published. This information may have influenced the later assessments. However, a strength of the study is that

Table 6

INRS inter-rater agreement and convergent validity.

	N	INRS inter-rater agreement			Convergent validity
		Research nurse and bedside nurse ICC ^a	Parents and bedside nurse ICC ^a	Parents and research nurse ICC ^a	INRS and NCCPC-PV Pearson’s <i>r</i>
All rating occurrences	170	.80**	.74**	.87**	.73**
Pre-intervention only	85	.74**	.65**	.82**	.71**
Post-intervention only	85	.74**	.74**	.85**	.63**
Randomly-selected single rating per patient	50	.80**	.73**	.86**	.72**

^a Intra-class correlation coefficient.

** Significance level *p*.

the sampling included only those who were nonverbal with profound intellectual disabilities. Further study is needed to replicate these findings in different settings, including critical care units, and with a larger group of children. One of the next steps is a content analysis of the parent-identified pain cues to identify themes and to compare parent descriptors to other pain tools described in the literature. It is hoped that this type of analysis may help us to understand the range of the pain descriptors in this population and how these descriptions fit into the current pain tools described in the literature for this population. Further research is also needed on practical aspects of the scale such as the burden on families and staff.

For this population of children with a diverse range of pain responses, baseline behaviors and physical abilities, a standardized approach to pain assessment is needed. The standardized approach must include a three-way comparison of the child's baseline behaviors, observed responses to a known pain source and assessment of the child's current behavior. The structure of the INRS is set up to guide the clinicians to assess pain in this way. In this study, the scores of bedside nurses with little prior knowledge of the child correlated with parental assessments of pain. This gives initial evidence that the INRS is a valid and reliable pain assessment tool for nonverbal children with intellectual disability and can be used by a bedside nurses in a hospital setting.

Conflicts of interest

The authors have no conflicts of interest in regards to this study.

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