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A Review of Pain Measures for Hospitalized Children with Cognitive Impairment

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Abstract

Purpose—The aim of this review is to examine pain measures for hospitalized children with cognitive impairment who are unable to self-report.

Design and Methods—Electronic searches to identify published evidence were conducted and studies reviewed. Reported psychometrics and feasibility of the NCCPC-PV, INRS, PPP, and r-FLACC were examined.

Conclusions—These four measures have established validity and reliability. However, clinical utility findings varied.

Practice Implications—The r-FLACC has demonstrated feasibility in acute care settings related to ease of use, time requirements, and flexibility regarding caregiver input.

Keywords

Cognitive impairment; communication disorder; developmental delay; developmental disability; intellectual disability; language disability; learning disability; non-verbal; pain assessment; pain measures; review

One in six children is diagnosed with a developmental disability in the United States, and the prevalence of developmental disability has increased by 17% over the last decade (Boyle et al., 2011). Cognitive impairment (CI) is the most common developmental disability and is defined as “the condition of a child whose intellectual functioning level and adaptive skills are significantly below the average for a child of his chronological age” (Siskin Children's Institute, n.d.). Among children with CI, those who are unable to self-report pain are particularly vulnerable to inaccurate pain assessment and subsequently inappropriate pain management (Oberlander & Symons, 2006). Additionally, children with severe CI are likely to have co-occurring physical disabilities further increasing their vulnerability.

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Background

Clinically it is important to distinguish children with CI who are able to report pain from those who are not. Whenever possible, self-report is the gold standard starting place for pain assessment. Therefore, healthcare providers should use standard pediatric pain measures appropriate to the child's developmental age for children with CI who are able to self-report (Dubois, Capdevila, Bringuier & Pry, 2009). Care should be taken to ensure that physical disability alone does not prohibit self-report as some children with physical disability and/or CI are unable to report pain verbally but able to report through augmented communication (i.e., adaptive devices, symbols). For example, a child with cerebral palsy may be unable to speak due to physical limitations but able to self-report pain through pictures. Children with CI who are unable to self-report require specialized observation pain measures to accurately assess their unique pain behaviors.

Observational pain measures intended for use in typically developing infants and toddlers (e.g., FLACC) are inadequate because pain behaviors in children with CI who are unable to self-report are often atypical (Fanurik, Koh, Schmitz, Harrison, & Conrad, 1999; Terstegen, Koot, de Boer, & Tibboel, 2003; Dubois et al., 2010). Additionally, pain behaviors in children with CI might be confounded by baseline behaviors (e.g., moaning, atypical facial expressions) and physical disabilities (e.g., spasticity, inability to pull away from painful stimuli). These variations in pain behaviors may lead to the false assumption that children with CI are insensitive or indifferent to pain (Oberlander & Symons, 2006). Despite these challenges, healthcare providers are ethically obligated to ensure competent pain assessments for children with CI, and the pain research community has recognized the need for better pain measures in this population. Since the 1990s numerous pain measures that capture levels of pain intensity for children with CI have been developed, tested, and in some cases implemented into practice. These pain measures contain similar content focused on pain behaviors but vary in format, parent or caregiver input, psychometric properties, and clinical utility, posing challenges for clinicians to determine the most appropriate measure to use in an acute care setting.

Significance

The prevalence of pain is higher in children with CI compared to typically developing children (Bottos & Chambers, 2006). In addition to usual pains of childhood (i.e., otitis media, dysmenorrhea), sources of pain for children with CI include invasive medical procedures and surgeries, medical equipment, and symptoms related to the underlying condition (e.g., spasticity with cerebral palsy). Stallard, Williams, Velleman, Lenton, and McGrath (2002) examined nonverbal children with severe CI and reported that 41% experienced pain on a daily basis, and 38% experienced pain lasting more than 24 hours. In a similar sample, Breau and colleagues (2003) reported that on average children with CI had pain weekly, lasting about 9 hours. Given this frequency of pain in this population, optimal assessment, including valid, reliable, and feasible pain measures, is critical to inform appropriate pain management for these children.

Compared to typically developing children, children with developmental disabilities (cognitive and/or physical) are two times more likely to visit the emergency room, four times more likely to be hospitalized, and have hospital stays that are eight times longer (Newacheck, Inkelas & Kim, 2004). Given the high rates of hospital utilization and the prevalence of CI, nurses' knowledge and appreciation of appropriate pain measures for children with CI is essential. The purpose of this review was to 1) examine valid and reliable pain measures for hospitalized children with CI who are unable to self-report pain, and 2) describe the best available evidence for their clinical utility in acute care settings.

Methods

Search Strategy

Electronic databases were searched for published articles on pain measures for children with CI who are unable to self-report pain. The key words intellectual disability, developmental disability, developmental delay, cognitive impairment, learning disability, language disability, communication disorder, non-verbal, pain assessment, and *pain measures* were used in searches of PubMed and Cumulative Index to Nurse and Allied Health Literature (CINAHL). In PubMed the term pain measurement was selected as a MeSH major topic and the age filter was set to "child: birth – 18 years." Searches were limited to articles published in English and human subjects. The search was not limited by date. The search resulted in articles published between 1994 and 2012. Studies included in this review examined the psychometric properties and/or the clinical utility of a pain tool specifically for children with CI in an acute care setting.

Pain Measure Criteria

Pain measures having established validity and reliability for children 3 to 18 years unable to self-report pain due to CI and conditions such as cerebral palsy, congenital or chromosomal syndromes, autism, seizure disorders, neurodegenerative diseases, and encephalopathy, were included. Studies conducted solely in home or residential settings were excluded. Pain measures not validated in English were also excluded.

Results

A total of 54 potentially relevant articles were retrieved and appraised. On review, 47 articles did not meet the inclusion criteria and thus were excluded. Seven articles, representing four different pain measures, met all the inclusion criteria: the Non-Communicating Child's Pain Checklist – Postoperative Version (NCCPC-PV), the Individualized Numeric Rating Scale (INRS), the Pediatric Pain Profile (PPP), and the revised Face, Leg, Activity, Cry and Consolability scale (r-FLACC; Figure 1). Four studies examined the psychometric properties of these measures in an acute care setting (Breau et al., 2002; Hunt et al., 2004; Malviya, Voepel-Lewis, Burke, Merkel, & Tait, 2006; Solodiuk et al., 2010), and three studies examined the clinical utility of these measures (Voepel-Lewis et al., 2008; Hunt & Franck, 2011; Chen-Lim et al., 2012). The following section describes each pain measure and discusses the validity, reliability, and clinical utility in acute care settings (Table 1).

Pain Assessment Measures

Non-Communicating Children's Pain Checklist – Postoperative Version

(NCCPC-PV)—The NCCPC-PV is a 27-item parent or clinician report of observed behaviors. Each item is scored from 0 to 3 based on six subscales (i.e., vocal, social, facial, activity, body and limb, physiological). It yields a total pain score ranging from 0 to 81. A score between 6 and 10 indicates mild pain; scores > 10 indicate moderate to severe pain. The NCCPC-PV requires the caregiver or clinician to observe the child for 10 minutes before assigning a pain score. It was adapted from the Non-Communicating Children's Pain Checklist- Revised, which includes the same items as the NCCPC-PV in addition to an “eating/sleeping” category.

The NCCPC-PV was validated in a post-operative inpatient setting with 24 children (3 to 10 years), with severe CI (Breau et al., 2002). The psychometric properties of the scale were evaluated among caregivers, researchers and nurses. All three groups rated pain intensity with the visual analog scale (VAS); only the caregivers and researchers also rated pain intensity with the NCCPC-PV. Internal reliability was adequate with Cronbach's alpha .71 for researchers and .91 for caregivers. Inter-rater reliability interclass correlation coefficients (ICC) were .78 and .82 between researchers and caregivers; inter-rater reliability for nurses was not assessed, as nurses did not use the NCCPC-PV. Parents and researchers rated pain higher using the NCCPC-PV post-operatively. Positive correlations with the VAS were found between the VAS and NCCPC-PV. However, the VAS scores assigned by the bedside nurses were not higher after surgery and did not correlate significantly with parents' or researchers' NCCPC-PV scores. Since nurses did not score the NCCPC-PV, reliability among healthcare providers was not fully assessed.

Voepel-Lewis and colleagues (2008) compared the clinical utility of NCCPC-PV to the r-FLACC and the Nurses Assessment of Pain Inventory (NAPI) post-operatively in 15 children with mild to profound CI. Clinicians rated the NCCPC-PV as the least desirable based on complexity and length, compatibility with tools already in practice and patient population, relative advantage compared to other tools, ease of use and incorporation into practice (Voepel-Lewis et al., 2008). However, the sample size was small ($n = 20$), and 95% of the physicians and nurses who participated were familiar with FLACC, which may have contributed to the positive ratings of the r-FLACC. This study is the only one published that addresses the clinical utility of the NCCPC-PV, and further study is warranted.

Individualized Numeric Rating Scale (INRS)—The INRS defines pain intensity by parents' reports of their children's unique pain behaviors. Healthcare professionals interview parents and/or caregivers to describe their children's pain behaviors ranging from 0 to 10 with word anchors (i.e., 0 = *no pain*, 5 = *moderate pain*, and 10 = *worst possible pain*) (Solodiuk et al., 2010). For example, according to the parent report, squirming may describe behavior with pain intensity of “3,” moaning with pain intensity of “7,” and crying with pain intensity of “10.” The INRS is uniquely created for each patient according to parents' or caregivers' interpretations of the child's pain behaviors. Instructions for the INRS do not specify a required observation time, but an observation time of 1 minute was used to validate the scale (Solodiuk et al., 2010).

Validity and reliability of the INRS were investigated in 50 nonverbal children with CI, 6 to 18 years (Solodiuk et al., 2010). Solodiuk and colleagues (2010) compared the INRS to the NCCPC-PV following surgery, with ratings provided by parents, nurses and research assistants. Modest correlations were found between the INRS and NCCPC-PV (Pearson's $r = .63-.73$). Construct validity was supported by a significant decrease in INRS scores 1 hour after a pain management intervention. Inter-rater reliability among nurse researchers and parents was strong (ICC .82 – .87). However, bedside nurses consistently scored pain lower than parents and research nurses (ICC .65– .80). Evidence regarding the clinical utility of the INRS is limited; Solodiuk and colleagues (2010) reported that nearly all parents were able to complete the INRS for their children without difficulty, but the time required by parents and nurses was not measured.

Pediatric Pain Profile (PPP)—The PPP includes the child's pain history, baseline and ongoing pain assessments, interventions and outcomes, and discussion with clinicians about the child's pain. The pain measure includes 20 items rated on a 4-point Likert scale (i.e., 0 = *not at all*, 3 = *a great deal*) with total scores ranging 0 – 60. Generally, scores greater than 14 indicate moderate to severe pain, although this may vary for individual children. Parents or caregivers first complete the tool to establish baseline scores on “a good day,” as well as when the child experiences pain. These scores become the benchmark against which ongoing ratings are compared. A 5-minute observation period is recommended before assigning a score.

Validity and reliability for the PPP have been established in multiple studies; however, only one included an acute care setting (Hunt et al., 2004; Hunt et al., 2007). Hunt and colleagues (2004) assessed the reliability and validity of the PPP among 141 children with severe CI, 1 to 18 years; 30 of those children were hospitalized post-operatively. Data for face validity, concurrent validity and internal consistency were reported in aggregate, combining inpatient and residential groups. Parent ratings of pain using the PPP increased from baseline scores on “a good day,” supporting face validity. These scores correlated with parents' evaluation of pain on the verbal rating scale, supporting concurrent validity. Validity was further supported by a significant decrease in PPP scores following analgesic administration in a residential setting. Internal consistency was good (Cronbach's alpha .75–.89). Inter-rater reliability was also good (ICC .70 – .87) between parents and healthcare professionals, but this was not assessed in an acute care setting. Parents of the 30 children undergoing surgery rated pain with the PPP pre-operatively and then post-operatively over 5 days. In this subgroup, validity and sensitivity were not supported as PPP scores were not highest on the first post-operative day as expected, did not differ across post-operative days, and did not indicate a conclusive change in relation to analgesic administration. Use of epidurals and around-the-clock analgesic dosing may have contributed to this finding, but this could also suggest decreased sensitivity of the PPP with postsurgical pain. Additionally, since acute care nurses did not utilize the PPP, the reliability and validity of this measure in an acute care setting is not fully understood.

The clinical utility of the PPP in acute care is questionable due to the length of time required to complete the profile. Two recent studies trialed the PPP with bedside nurses in acute care settings (post-anesthesia care unit, in-patient surgical unit, in-patient rehab unit). The length

of time to complete the measure (2–3 minutes) and the teaching requirements were reported as limitations to this measure (Chen-Lim et al., 2012; Hunt & Franck, 2011). Parents perceived the PPP as more accurate than the r-FLACC due to the detailed descriptors but not as helpful or useful (Chen-Lim et al., 2012).

Revised Face, Legs, Activity, Cry and Consolability Scale (r-FLACC)—The r-FLACC is an observational pain measure based on the Face, Legs, Activity, Cry and Consolability scale (FLACC), a well-established pain measure for young, pre-verbal children (Merkel, Voepel-Lewis, Shayevitz, & Malviya, 1997). Similar to the FLACC, pain intensity is measured on a 3-point ordinal scale (0–2) for five categories. Each category includes a description of behaviors to guide scoring the category from 0 to 2 (i.e., *no cry* = 0, *moans* = 1, and *screams* = 2). For each category (Face, Legs, Activity, Cry and Consolability), parents or caregivers can add unique, descriptive behaviors that represent moderate to severe pain in their children. These added descriptions are scored as “2” within the 0–2 scoring range. Total scores range from 0 to 10, higher scores indicating more pain. Observation time before scoring the r-FLACC has not been established. However, Malviya and colleagues (2006) established validity and reliability using an observation time of five minutes.

Voepel-Lewis and colleagues (2002) examined the validity and reliability of the FLACC in 79 children post-operatively, 4 to 18 years, with varying degrees of CI. The “Legs” and “Activity” categories had poor reliability and validity, which was likely related to the physical limitations that are common in this population of children. The scale was then revised to include additional pain behaviors characteristic of children with CI and parent report of individualized behavior within each category. Within the “Legs” category, descriptors such as “marked increase in spasticity” and “constant tremors or jerking” were added. Additions to the “Activity” category included behaviors such as head-banging, shivering, and breath-holding. The r-FLACC showed improved validity and reliability in 52 children post-operatively, 4 to 21 years, with varying degrees of CI (Malviya et al., 2006). Of the 52 children who participated in the study, 12 children were able to self-report their pain. Content validity was supported by physicians and nurses with expertise in pain assessment for children with CI. Construct validity was supported by a significant decrease in pain scores 30 minutes after analgesic administration. Moderate to strong criterion validity was reported between r-FLACC scores and Nursing Assessment of Pain Intensity (NAPI) scores, parents' global rating scores, and child self-report (0.65–0.87). Test-retest reliability (ICC .97), and inter-rater reliability (ICC0.90) were strong among nurses. Reliability and validity of the “Legs” and “Activity” categories improved with the revised FLACC scale.

Two studies examined the clinical utility of the r-FLACC (Voepel-Lewis et al., 2008; Chen-Lim et al., 2012). Clinicians from three major medical centers compared the r-FLACC, NAPI, and NCCPC-PV for post-operative pain assessment using the Clinical Utility Attributes Questionnaire. The r-FLACC was rated as having better clinical utility than the NCCPC-PV and better compatibility and advantage than the NAPI (Voepel-Lewis et al., 2008). Chen-Lim and colleagues (2012) reported that 74% (93/126) of bedside nurses preferred the r-FLACC to the PPP, and nurses were able to complete the r-FLACC in less

than 1 minute compared to 2–3 minutes for the PPP. Both nurses and parents rated the r-FLACC more helpful and useful than the PPP, but parents viewed the PPP as more accurate. The primary challenge for nurses in using the r-FLACC was deciding which children should be assessed using this measure. These studies support the utility and feasibility of the r-FLACC in an acute care environment.

Discussion

The INRS, NCCPC-PV, PPP and r-FLACC have established validity and reliability for children with CI who cannot report pain. Of the four pain measures, the clinical utility of the r-FLACC has been the most studied, and findings suggest feasibility in acute care settings. Several studies highlight the importance of time, teaching and parental input requirements, yet only three studies incorporated these variables (Voepel-Lewis et al., 2008; Hunt & Franck, 2011; Chen-Lim et al., 2012). Time and clinician resources in acute care settings are often limited but important variables to consider for pain assessment and management.

Clinical Utility of Pain Measures

Clinical utility of the NCCPC-PV may vary depending on clinical setting because of the defined 10-minute observation time. For example, in a post-anesthesia care unit or an intensive care unit where the nurse-patient ratio is low and the nurse remains at the patient's bedside, implementing this measure may be realistic. However, in acute care units where nurse-patient ratios are higher, a 10-minute observation period may be unrealistic for every pain intensity rating. The length of the NCCPC-PV and wide scoring range of 0 to 81 may also limit clinical utility. Breau and colleagues (2002) found low inter-rater reliability when the visual analog scores of bedside nurses were compared to parent and researcher scores on the VAS and NCCPC-PV. Unlike the parents' and researchers' VAS scores, the nurses' VAS scores did not change significantly before or after surgery, suggesting that some nurses may not be familiar with pain behaviors in children with CI. Additional study of utilization of the NCCPC-PV by healthcare providers is needed to fully understand the NCCPC-PV's clinical utility and reliability in an acute care setting.

Characteristics of the INRS, including limited number of items (10 or less), scoring range (0–10), and a short observation time of 1 minute, may translate to clinical practice more readily, and therefore increase feasibility in an acute care setting. However, there is a paucity of knowledge about the time and quality of the interview required by the nurse and parent to create an INRS for each patient, and it is unknown if parents could create the scale independently. Solodiuk and colleagues (2010) found that bedside nurses scored the INRS significantly lower than parents and researchers. This finding suggests that prior or additional knowledge of behaviors in children with CI may be necessary to improve this measure's sensitivity; this finding also suggests that the INRS might be better suited to chronic care or residential settings. Further research on the implementation and utilization of the INRS in acute care settings is necessary to support consistent application to practice.

The PPP was designed under the fundamental assumption that optimal pain assessment for children with CI who are unable to self-report requires the assessor be familiar with the child. While this has obvious patient care benefits in any setting, clinical utility may be less

appealing in acute care due to the lengthy format and required parent or caregiver involvement to establish baseline. Recent studies reported that completing the PPP is feasible but the length of the measure limits its efficiency in acute care settings, and parents also report the measure to be cumbersome (Chen-Lim et al., 2012; Hunt & Franck, 2011). Chen-Lim and colleagues (2012) report nurses needed 2 to 3 minutes to score the ongoing pain assessment, but time to complete the profile in entirety is unknown. The scoring of 20 items, with a score total ranging from 0 to 60 may also require additional teaching compared to a scale scored 0 to 10, and it has potential to create confusion among clinicians in the interpretation of the score's meaning.

Clinical benefits reported for the r-FLACC include clinician preference, ease of use, flexibility in acute care settings, and brief completion time. Compared to the PPP, the majority of acute care nurses preferred the r-FLACC due to ease of use in a variety of inpatient settings (e.g., post-anesthesia care unit, a medical/surgical unit, and in-patient rehab unit), inclusion of parent report, time to complete, and scoring of the instrument (Chen-Lim et al., 2012; Malviya et al., 2006). Additionally, the r-FLACC's format offers flexibility as it can be used with or without parental input. Since the format of the r-FLACC is similar to the well-established FLACC, it would likely require less teaching and result in quicker adoption because of its familiarity. Conversely, familiarity could be a limitation as clinicians may mistakenly use the r-FLACC to replace the FLACC for all patients. The familiarity of the scale may also discourage clinicians from fully understanding the unique pain behaviors that children with developmental and language disabilities display.

Commonalities Among Pain Measures

Each of the scales in this review has similar descriptions of behaviors that indicate pain in hospitalized children with CI who are unable to report pain. Scale content for each measure was developed using several methods. The NCCPC-PV obtained information through parent interviews, and the PPP obtained information from both parents and healthcare providers. Compared to the NCCPC-PV and the PPP, the r-FLACC added content to an established observational pain scale based on findings in the literature, expert opinion and videotaped segments of children with CI post-operatively. Despite variation in information gathering, each measure examines facial expression, body activity, vocalizations and consolability/sociability. For example, vocalizations such as moaning, whimpering, crying, and screaming are all represented in the NCCPC-PV, PPP, and r-FLACC. Solodiuk and colleagues (2010) found that the parents' descriptions of pain used to create an INRS for their children were similar descriptions in the NCCPC-PV. The finding suggests that parents and healthcare providers have similar perspectives and descriptions of behaviors that indicate pain. This finding also highlights the challenge of validating pain scales for children with CI in that scale development includes secondary reports of pain, which introduces observer bias.

Facial expression is another common, critical construct found in these pain measures. "Facial expression" was the only subscale of the researchers' NCCPC-PV scores that correlated with nurses' VAS scores (Breau et al., 2002), and this may be secondary to nurses using facial expression as a primary indicator of pain. When the original FLACC was evaluated in children with cognitive impairment, the strongest correlations to total score

were the “Face” and “Cry” categories (Voepel-Lewis, Merkel, Tait, Trzeinka, & Malviya, 2002). In the r-FLACC, of all the subscales, the “Face” category had the highest inter-rater reliability (Malviya et al., 2006). This finding supports the importance of examining facial expression during pain assessments, while understanding that some children with CI, especially those with co-occurring physical disability, may not exhibit pain through facial expressions. In typically developing infants and children, facial expression is a reliable indicator of pain often associated with other behaviors including verbalizing “ouch” or pulling away from a stimulus. However, in children with CI who are unable to verbalize and/or have physical limitations, facial expression is not always reliable due to the potential for diminished facial expression, lack of muscle tone, nerve damage, or paradoxical pain behaviors. Messmer, Nader, and Craig (2008) examined visual analog scores in children with autism undergoing venipuncture and reported that facial expression had the most impact on the assessors' rating of pain intensity, regardless of information given regarding the child's level of pain sensitivity. These findings highlight that providers may be prone to rely on facial expression as a primary pain indicator, in spite of known evidence and/or parent provided information. Heightened awareness of the complexities of pain assessment and conversations with parents about how their children express pain is critical for adequate pain management in children with CI unable to self-report. Some children with CI may require individualized pain assessment, and this is a contentious issue discussed in the following section.

Standardization versus Individualization of Pain Measures

Pediatric clinicians often consult with parents about a child's behavior and expression of pain. Individualized pain scales support the practice of healthcare providers partnering with parents and thereby promote trust, relationship-based care, and improved pain assessments. Voepel-Lewis, Malviya, and Tait (2005) reported strong correlation between parent and nurse assessments of a child's pain behavior, demonstrating the validity of parent report. Findings from several studies support that when given the opportunity parents have additional descriptors to aid healthcare providers in assessing their children's pain. In the validation of the INRS, 17% of the pain behavior items were unique and did not correspond to behaviors described in FLACC (Solodiuk et al., 2010). With the validation of the r-FLACC, 40% of children (21/54) in the study had behaviors added by parents (Malviya et al., 2006). Similarly, when the r-FLACC was trialed in an acute care hospital, 60% of children had supplementary content provided by caregivers (Chen-Lim et al., 2012). In these situations, parents provided unique pain behaviors that captured the intensity of pain in their children; a valuable opportunity to improve patient care would have been lost had parents not been included in their children's pain assessments. Findings from Hunt and Franck (2011) show that parents are motivated to share knowledge about their children's pain. Hunt and Franck pilot tested the PPP, and parents were asked to complete the pain history and baseline assessment before hospital admission; despite the inconvenience and lengthy time requirement, parents reported that they prioritized the paperwork as it pertained to better care for their children.

A pain measure incorporating elements of standardization and individualization is ideal. Some standardization in a pain measure is necessary for acute care settings since parents or

primary caregivers may not always be accessible. Furthermore, standardization is also necessary as some parents, particularly those of a young child or a child with newly acquired disabilities, might not yet be knowledgeable of pain behaviors in the child. For parents with limited knowledge of pain behaviors in children with CI, a pain measure such as the NCCPC-PV or r-FLACC could be a helpful teaching tool and provide necessary assistance. A scale that solely relies on parent or caregiver input, like the INRS, is not a dependable pain measure method for all situations. Caregiver involvement in pain assessments for children with CI is preferred because it encourages family-centered care, and evidence indicates that a level of individualization is needed to fully capture behaviors indicating pain (Chen-Lim et al., 2012; Hunt et al., 2004; Malviya et al., 2006; Solodiuk et al., 2010). Additionally, caregivers are valuable partners in conducting a complete pain assessment beyond the quantification of pain. The goal of pain measures is to rate the degree or quantity of pain, but they provide limited information without considering the significance or context of the child's pain experience. Caregivers have an important role to accurately measure pain intensity and partner to conduct a comprehensive pain assessment for children with CI who are unable to self-report pain.

Limitations

Current evidence in the literature on pain measure criteria for hospitalized children with CI guided this review. Limitations include age, setting, and language. The age limit of 3 to 18 years excluded studies that exclusively focused on infants and toddlers. Infants and toddlers with developmental disabilities may also need specialized pain measures, as traditional infant and toddler pain measures may not be sensitive to behaviors that indicate pain in this population. For example, infants and toddlers with Down syndrome often have diminished tone and this may cause the clinician to under-appreciate a pain response. This review was also limited by setting, as only studies that *included* acute care settings were included. It is also possible that pain measures evaluated *solely* in home or residential settings may be clinically relevant to acute care settings.

Due to time and resource constraints, language requirements were another limitation of this review. Specifically, a Dutch pain scale (Pain Behavior Checklist) with established reliability and validity in post-operative children with intellectual and language disabilities was excluded because it was not validated in English (Duivenvoorden, Tibboel, Koot, van Dijk & Peters, 2006). Additionally, the PPP has been translated and validated in Portuguese (Pasin, Avila, de Cavata, Hunt, & Heldt, 2012), and the NCCPC-PV has been translated and validated in French and Swedish but these studies were not included for review (Johansson, Carlberg & Jylli, 2010; Zabalia et al., 2011).

How Might This Information Affect Nursing Practice?

Nurses have critical responsibilities for assessing and managing pain in hospitalized children. For hospitalized children with CI who are unable to self-report pain intensity, nurses must be more vigilant in assessing pain, communicate with parents and caregivers about how the child expresses pain, and use an appropriate pain measure for this vulnerable population. In the hospital setting, nurses are also charged with the important task of selecting which pain measure to use based on the child's cognitive and communication

abilities. Knowledge and application of valid and reliable pain measures for children with CI could assist nurses in providing appropriate pain assessments, directing pain management, and improving patient outcomes. Pain measures that include caregiver input such as the INRS, the PPP and the r-FLACC promote communication and are likely to facilitate family-centered care and trust. In situations where parental input is not feasible, the r-FLACC and the NCCPC-PV may be more appropriate. Nurses also have the arduous task of time management so a measure with demonstrated clinical utility in acute care settings, like the r-FLACC, is key. If pain measures specific to children with CI who cannot report pain are not currently utilized in acute care settings, nurses should advocate for implementation of an appropriate pain measure. It is the ethical obligation of all healthcare providers to minimize pain and suffering, and it starts with recognition and assessment.

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Figure 1.

Table 1**Pain Measures for Hospitalized Children with Cognitive Impairment**

	NCCPC-PV	INRS	PPP	r-FLACC
Reference	Breau et al., 2002	Solodiuk et al., 2010	Hunt et al., 2004	Malviya et al., 2006
Description	27 items, 6 categories (vocal, social, facial, activity, body, physiological), scored 0–3	Parents recall past pain behaviors and rate them 0–10. Word anchors “no pain” and “worst possible pain”	20 items scored 0–3. Profile includes pain history, parent description of child “at their best,” and “at their worst”	Five behavioral categories scored 0–2 with option for caregiver to add behaviors
Scoring	0–81; score 11 indicate moderate to severe pain	0–10; higher scores indicate more pain	0–54; scores 14 indicate moderate to severe pain	0–10; higher scores indicate more pain
Parent/Caregiver Input	No	Yes; required	Yes; required	Yes; not required
Observation Time	10 minutes	1 minute	5 minutes	5 minutes
Sample description	Nonverbal children with severe cognitive impairment, ages 3–19	Nonverbal children with cognitive impairment, ages 6–18	Nonverbal children with cognitive impairment, ages 1–18	Children with mild to severe cognitive impairment, 12 children could self-report, ages 4–21
Setting & Sample	Post-op <i>N</i> = 24	Post-op <i>N</i> = 50	Multi-setting; home, post-op, in-patient <i>N</i> = 141	Post-op <i>N</i> = 52
Validity Established	Construct	Construct and concurrent	Content, construct and concurrent	Content, construct and concurrent
Reliability Established	Inter-rater and internal	Inter-rater	Inter-rater and internal	Inter-rater and test-retest

Note. NCCPC-PV - Non-communicating Children's Pain Checklist – Postoperative Version, INRS - Individualized Numeric Rating Scale, PPP - Pediatric Pain Profile, r-FLACC - Revised Face, Legs, Activity, Cry and Consolability