Children's Hospital of Orange County (CHOC)
Best Evidence and Recommendations (BEaR)

Developmentally Delayed Pediatric Patients: Detecting Changes in Neurological and Pain Status in the Acute Care Setting

Stephanie Griego, APRN, RN
sgriego@choc.org

Abstract

Children with intellectual disability disorders (IDD) or global developmental delay (GDD) are unique when it comes to addressing acute neurological changes or identifying pain. Their inability to communicate verbally makes using the standardized assessment tools difficult. The Glasgow Coma Scale (GCS) used as part of the assessment of acute neurological changes relies heavily on the ability to verbalize and, therefore, presents as a challenge to children with IDD or GDD, making their scores inaccurate and, therefore, unreliable. Generic pain scales struggle to include the individual features of children with IDD or GDD. Caregivers and/or parents become their voice for pain, and when they are not present, nursing and ancillary staff must use the appropriate pain tools to assess pain. The pain tools available do not always capture the unique pain features of those children with IDD and GDD display.

This nurse-led project aims to evaluate and consolidate the best evidence for practice in assessing acute neurological changes and pain in children with developmental delay.

Based on recommendations from the literature, interventions both short and long-term include evaluating the use of a coma score that could be a better fit for children with IDD and GDD and adding an addendum to the current pain scoring tool that would include the ability to record the unique behaviors displayed by children with IDD and pain. Outcome measures include evaluating results from patient satisfaction surveys, REDCap data, and associate surveys.

Keywords

Global developmental delayed, pediatric, intellectual disability disorder, r-FLACC, NPASS pain scale, full outline of unresponsiveness score, and Glasgow coma scale

PICO(T)

In developmentally delayed pediatric patients, what are the best practices for neurological and pain assessment compared to current practice to detect changes in neurological and pain status during hospitalization?

Background and Significance

Assessing neurologic status in children with neurodevelopmental conditions presents unique challenges due to the complex nature of their conditions and their limited ability to communicate (Hadders-Algra, 2021).

Key challenges include:

- Communication difficulties: Limited verbal skills make it challenging to identify child's needs or assess their neurological status accurately.
- Limited self-reporting: The child may lack the cognitive and linguistic abilities to report pain accurately.
- Non-specific behavioral cues: Some children exhibit challenging behaviors even when they are not in pain, making it difficult to interpret their actions.
- Complex medical comorbidities: Other conditions can mask or complicate the assessment of neurological status and pain.
- Pain expression variations: The child may have atypical responses to pain (including pain hypersensitivity), which can further complicate the assessment process.
- Lack of standard assessment tools: Existing tools may not account for the unique characteristics and needs of the population.

Addressing these challenges requires a multidisciplinary approach involving healthcare providers, caregivers, and specialists in neurodevelopmental disorders. The purpose of the evidence-based project is to enhance the assessment of neurological and pain status in developmentally delayed pediatric patients during hospitalization by identifying and implementing best practices that improve the accuracy and efficacy of detection compared to current practices.

Framework

This EBP project utilizes the "Translating Evidence into Practice: CHOC's Approach to EBP" model, adapted from the EBPI Model © 2007 Brown & Ecoff (Ecoff, Stichler & Davidson, 2020).

Search for the Evidence

Databases searched for this review included CINAHL (and Medline in EBSCO. Key search words: Global developmental delayed, pediatric, intellectual disability disorder, r-FLACC, NPASS pain scale, full outline of unresponsiveness score, and Glasgow coma scale. This search yielded 20 articles for coma scales and 47 articles for pain. Yielded 20 articles for coma scales and 47 articles for pain. Of those articles, 11 were applicable to the project.

Critical Appraisal and Synthesis of the Evidence

Neurological Assessment

- The Glasgow Coma Scale (GCS) is a widely used tool for assessing the level of consciousness and neurological status (Jain & Iverson, 2023; Ramazani & Hosseini, 2019).
- The scale's components such as eye-opening, verbal response, and motor response, may not be as applicable or informative in this population (Jain & Iverson, 2023; Ramazani & Hosseini, 2019).
- FOUR Score (Full Outline of UnResponsiveness Score) is a proposed replacement for GCS in specific clinical settings, particularly for patients with complex conditions, including pediatric patients and those with neurodevelopmental issues (Almojuela at al., 2019; Anestis et al., 2020; Cohen, 2009; Wijdicks et al., 2005).
- FOUR Score addresses the limitations of GCS and offers a more comprehensive assessment (Almojuela at al., 2019; Anestis et al., 2020; Cohen, 2009; Wijdicks et al., 2005).

Pain Assessment

- The FLACC scale is specifically designed to assess pain in non-verbal or pre-verbal children and adults with neurodevelopmental conditions (Cascella et al., 2019; Crellin et al., 2015).
- The revised FLACC (r-FLACC) scale was found to have the highest and most consistent validity and specificity of the pain scales reviewed (Malviya et al., 2006).
- The FLACC scale allows for individualized scoring based on the patient's unique behaviors and responses Cascella et al., 2019; Crellin et al., 2015).
- The scale should be adapted to the specific characteristics and needs of the patient, considering their developmental stage and any known sensitivities or triggers (Malviya et al., 2006).

Practice Recommendations

- Meet with neurosurgery to discuss the appropriateness of FOUR Score use on the neuroscience unit. If deemed appropriate, I would like to explore its use on NSU/MSU
- Edit the r-FLACC in Powerchart to remove the r-FLACC changes table.
- Edit the pain assessment documentation in Powerchart to allow caregivers to be specific in what pain looks like for their child.
- Add Pain to Admission history and have it be reflected in SummaryM.

Outcome Measures

Neurological Assessment

- Evaluate the training sessions of the RNs on the unit how to use FOUR Score.
- Track patient outcomes based on incorporation of FOUR Score.
    - Was FOUR Score helpful in detecting neurological changes prior to calling a rapid response or code white?
    - Were there any changes made to the plan of care based in part on the use of FOUR Score?

Pain Assessment

- Assess patient satisfaction to determine if the tool improved pain management.
- Determine if the changes made in the documentation were useful in identifying pain levels when parents were unavailable.
- Evaluate the indicators of the usefulness of the new tools:
    - Was there improved communication between nursing staff and physicians?
    - Was there improved communication between families and medical staff?
    - Were changes made to r-FLACC useful where pain was a factor in calling a rapid response?
    - Was there an incorporation of a pain team consult or a palliative consult?

Acknowledgements

- The Evidence-Based Scholars Program was supported by a grant from the Walden W. and Jean Young Shaw Foundation
- Jennifer Hayakawa, DNP, PCNS-BC, CNRN, CCRN, Nurse Scientist and Director of Nursing Research and Innovation, CHOC
- Vicky R. Bowden, DNSc, RN, Nurse Scientist, CHOC
- Lisa Catanese, EBP Scholar Mentor

References

Albani, E., Petsios, K., Saridi, M., Fradelos, E., Tzenalis, A., Toska, A. (2022). Pain assessment in children with cognitive disabilities: Critical review and clinical implications. *International Journal of Caring Sciences 15*(3). 1784-1791.

Almojuela, A., Hasen, M., & Zeiler, F.A. (2019). The full outline of unresponsiveness (FOUR) score and its use in outcome prediction: A scoping review of the pediatric literature. *Child Neurology 34*(4), 189-198. doi:10.1177/0883073818822359

Anestis, D.M., Tsitsopoulos, P.P., Tsonidis, C.A., & Foroglou, N. (2020). The current significance of FOUR score: A systematic review and critical analysis of the literature. *Journal of Neurological Sciences 409*. https:// doi.org/10. 1016/jns.2019. 116600

Cascella, M., Bimonte, S., Saettini, F., Muzio, M.R. (2019). The challenge of pain assessment in children with cognitive disabilities: Features and clinical applicability of different observational tools. *Journal of Paediatric Child Health 55*(2), 129-135. doi:10.1111/jpc.14230

Cohen, Jennifer. (2009). Interrater reliability and predictive validity of the FOUR score coma scale in a pediatric population. *American Association of Neuroscience Nurses 41*(5), 261-267. (CLASSIC)

Crellin, D.J., Harrison, D., Santamaria, N., & Babl, F.E. (2015). Systematic review of face, legs, activity, cry, and consolability scale for assessing pain in infants and children: is it reliable, valid, and feasible for use? *International Association for the Study of Pain 156*(11), 2132-2151.

Ecoff, L., Stichler, J.F., & Davidson, J.E. (2020). Design, implementation, and evaluation of a regional evidence-based practice institute. *Applied Nursing Research, 55*(2), 151300. doi: 10.1016/j.apnr.2020.151300

Fabio, R.A., Chiarini, L., & Canegallo, V. (2022). Pain in Rett syndrome: A pilot study and a single case study on the assessment of pain and the construction of a suitable measuring scale. *Orphanet Journal of Rare Diseases 17*(1), 356. https:// doi.org/10.1186/s 13023-022-02519-y

Hadders-Algra M. (2021). Early diagnostics and early intervention in neurodevelopmental disorders-age-dependent challenges and opportunities. *Journal of Clinical Medicine*, *10*(4), 861. https://doi.org/10.3390/jcm10040861

Hauer, J., & Houtrow, A.J. (2017). Pain assessment and treatment in children with significant impairment of central nervous system. *American Academy of Pediatrics 139*(6). E20171002

Jain, S., Iverson, L.M. (2023). *Glasgow coma scale*. StatPearls. StatPearls Publishing LLC.

Malviya, S., Voepel-Lewis, T., Burke, C., Merkel, S., & Tait, A.R. (2006). The revised FLACC observational pain tool: improved reliability and validity for pain assessment in children with cognitive impairment. *Pediatric Anesthesia 16*(3), 258-265. doi: 10.1111/j.1460-9592.2005.01773. x.

Mithyantha, R., Kneen, R., McCann, E., & Gladstone, M. (2017). Current evidence-based recommendations on investigating children with global developmental delay. *Archives of Disease in Childhood 102*(11), 1071-1076. doi:10.1136/archdischild-2016-311271

Ramazani, J., & Hosseini, M. (2019). Comparison of full outline of unresponsiveness score and Glasgow coma scale in medical intensive care unit. *Annals of Cardiac Anesthesia 22*(2). Doi: 10.4103/ aca_ACA_25_18

Pizzinato, A., Liguoro, I., Pusiol, A., Cogo, P., Palese, A., & Vidal, E. (2022). Detection and assessment of postoperative pain in children with cognitive impairment: A systematic literature review and meta-analysis. *European Journal of Pain 26*(5), 965-979. https://doi.org/10.1002/ejp.1936

Wijdicks, E.F.M., Bamlet, W.R., Maramattom, B.V., Manno, E.M., & McClelland, R.L. (2005). Validation of a new coma scale: The FOUR score. *Annals of Neurology 58*(4), 585-593. doi:10.1002/ana.20611