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Can pain assessment tools accurately measure pain experience of disabled individuals?

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Identifying the best method for assessing pain is perhaps most challenging for individuals with cognitive impairment or physical disability, given differences in verbal and body language capabilities. Pain assessment tools meant to most closely reveal the degree of pain experienced by these individuals have been developed to include behaviors commonly associated with pain. The most common observable pain responses include vocalization, social behaviors and facial expression, and (less so) bodily activity and This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/dmcn.14033

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movements. 1,2 These behaviors become exaggerated when pain is severe and lessen as pain is relieved, thus permitting the scoring of pain severity. Importantly, observable behaviors become less reliable as pain persists over time and as children age and can dampen their distress responses. Additionally, observable pain behaviors are often present in children even when there is no evidence of a pain stimulus, indicating other sources of distress. Similarly, children often report some degree of pain intensity even during 'no-pain' conditions. Together, these data suggest that interpreting pain behaviors and self-reported pain intensity scores is fraught with potential confounders.

Findings from the study by Fox et al. describe some of the problems with behavioral observation that have been previously demonstrated, as well as new considerations. Specifically, their data suggest that scores derived from the validated r-FLACC instrument⁴ correlate only moderately with self-reported pain intensity scores of adults with cerebral palsy (CP). Fox et al. also found only moderate reliability of r-FLACC scores between raters who viewed videotapes stripped of all verbal content, and thus not likely to have included the important 'Cry' or verbal category. These investigators describe confounders (including spasticity) that likely impact reliability and interpretability of observed behaviors in individuals with CP.

Similarly, in their original work, Malviya et al. found lower interrater agreement for the r-FLACC categories of Legs and Activity in children with spasticity, but also found highest agreement for the Face and Cry categories and good overall interrater reliability. Others have also found excellent interrater reliability in younger children with CP (intraclass correlation coefficient 0.75). Additionally, r-FLACC scores have been found to be very responsive to procedural pain and treatment conditions (i.e. scores increased on average by 2.23 points after surgery and decreased 4.2 points after analgesia). Together with data regarding other similar observational

scales, such findings suggest that observed distress behaviors can provide an indication of pain severity and response to treatment.

The r-FLACC and other measures¹ have been adapted to address individual variations in pain expression. These individualized scales have higher reliability between parents and nurses, and excellent responsiveness to analgesic intervention compared to observational scales, including the original FLACC that do not address the child's personal expressions.² Still, these scales are not perfect and are not necessarily specific to pain states.

It is now well-recognized that pain intensity scales cannot capture the complexity of the pain experience. Single scores taken out of context have no clinical meaning – particularly observational scores obtained in children whose baseline behaviors are considered abnormal (e.g. spasticity). Changes in pain scores may have more meaning but must still be considered as only one aspect of pain assessment. Behavioral pain intensity scores can provide an indication of distress which may or may not be pain and are thus insufficient to diagnose or guide care. Pain assessment is an imperfect science and scores derived from *any* pain scale must be interpreted with caution and in the context of many other factors. The search for a perfect tool is thus a search in vain.

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