**Title**: Caregiver Pain Catastrophizing and Pain Ratings of their Young Children with Developmental Delay During Venipuncture

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**Introduction**: Children with developmental disabilities (DD) experience more painful procedures and conditions than their typically-developing peers.1 Self-report of pain is often limited or absent in these populations due to cognitive and/or communication delays, forcing clinicians to rely primarily on caregivers to make healthcare decisions. Current literature suggests parents’ interpretation of their children’s pain is influenced, in part, by several psychosocial factors.2 For example, parents with higher levels of pain catastrophizing, defined as “*responding negatively toward pain as if it were a sign of an impending health catastrophe,*”3 had higher and more accurate ratings of their typically-developing child’s pain (relative to their child’s self-report) than parents with lower catastrophizing.4 It is unknown if this relationship holds for children with DDs. As part of a larger project, this study explored if parents’ pain catastrophizing were related to ratings of their child’s pain during a venipuncture, a known painful procedure, in a sample of young children with DD.

**Method**: Children with a diagnosis of a DD aged 18-83 months scheduled for a standard-of-care venipuncture (blood draw) and their primary caregivers were recruited for the study. Parents completed the *Parent Catastrophizing Scale for Parents* (PCS-P) immediately before their child’s blood draw. The PCS-P consists of thirteen statements of the parent’s thoughts and feelings when their child is in pain, each rated on a 5-point scale. 3 Total scores range from 0 to 52, with scores ≥ 30 indicating a clinically-significant level of catastrophizing. Parents also rated their child’s pain level during the blood draw on a scale of 0 to 10 (0 = no pain, 10 = worst pain ever). Analyses included Pearson correlations and an independent samples t-test of child pain ratings between parents with and without clinically-significant PCS-P scores. Alpha was set at 0.05.

**Results**: Thirty children and caregivers were recruited for this study, with a mean child age of 47.7 months (SD = 15). 63.3% of the children were male and 70.0% were Non-Hispanic White/Caucasian. The average PCS-P score was 23.07 (SD = 12.7). Parents rated their child’s pain during the blood draw a mean of 3.9/10 (SD=2.5). PCS-P scores and child pain ratings were not significantly correlated (r = -0.28, p = 0.14). Parents with clinically significant PCS-P scores (n = 9) rated their child’s pain lower, on average (mean= 2.7/10 [SD = 2.3] vs. 4.4/10 [SD = 2.5]), though this difference was not statistically significant (t = 1.81, p = 0.08).

**Discussion:** There was no correlation between parent catastrophizing and child pain ratings in this sample of young children with DD, contrary to the typically-developing literature. In fact, these results suggest it could be the opposite, as parents with clinically-significant pain catastrophizing scores rated their child’s pain lower than parents with non-clinical PCS-P scores. Additional research is needed to establish whether this relationship varies by child disability status or other relevant co-variates (e.g. child communication level). Future work will increase the sample size and compare parent pain ratings to observationally-coded child pain behaviors during the blood draw. This work is funded by the NICHD, grant no. 110981.

**References:**

1. Lotan, M., Elefant, C., & Merrick, J. (2016). Pain in people with intellectual and developmental disability: Focus on children. Journal of Pain Management, 9(2), 183-194.
2. Craig, K. D. (2009). The social communication model of pain. *Canadian Psychology/Psychologie Canadienne, 50*(1), 22.
3. Goubert, L., Eccleston, C., Vervoort, T., Jordan, A., & Crombez, G. (2006). Parental catastrophizing about their child’s pain. The parent version of the Pain Catastrophizing Scale (PCS-P): A preliminary validation. PAIN®, 123(3), 254-263.
4. Goubert, L., Vervoort, T., Cano, A., & Crombez, G. (2009). Catastrophizing about their children’s pain is related to higher parent–child congruency in pain ratings: an experimental investigation. *European Journal of Pain, 13*(2), 196-201.

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