

How bad does it hurt? New research helps children suffering from chronic pain conditions

December 9 2015, by Dawn Fuller

A new study describes the development of pediatric pain measures for a National Institutes of Health Initiative aimed at helping doctors better evaluate and therefore better treat children who cope with chronic pain. Based on face-to-face interviews with pediatric patients, the study better captured the young patient's perspective of living with chronic pain.

An article by researchers in the University of Cincinnati's Department of Anthropology, UC College of Medicine Department of Pediatrics, Cincinnati Children's Hospital Medical Center and Emory University School of Medicine is published in the current issue of the *Journal of Pain*.

Lead author Jeffrey Jacobson, a UC associate professor of anthropology, says the interdisciplinary study was based on individual and focus group interviews with 32 children and with parents of children with chronic pain, including children affected by juvenile arthritis, sickle-cell anemia and cerebral palsy.

The study was conducted to evaluate pain measures developed by the Patient Reported Outcomes Measurement Information System (PROMIS) under the National Institutes of Health. PROMIS is an initiative to create a set of freely available, broadly applicable and high-quality patient-reported outcomes - measures that can be used within and across disease conditions throughout a patient's lifetime.



"Pain is not something that can be objectively measured, and patient-reported measures are therefore essential for research and clinical assessment," explains Jacobson. "Our study focused on how children aged 8-to-18 experience and talk about their pain and on the kinds of language and vocabulary they like to use. "For example," he added, " We found that many questions or items from pain measures used with adults, describing pain as 'gnawing or suffocating,' made younger children uncomfortable. They appeared to relate that to a monster or someone doing something to them. They also have a more limited vocabulary than adults, particularly in relation to the more abstract language of pain quality."

The paper describes the different categories of <u>pain experience</u> and language used by children when they talk about chronic pain, and the fit of these categories with those used by PROMIS:

- Pain behavior The child indicates he or she becomes irritable or suffers a lack of appetite (or other behavior) when in pain.
- Pain interference The child describes slower movement, such as walking, or lack of energy due to pain interference.
- Pain quality The child describes pain as sharp, cutting, dull or achy.

"The fit between PROMIS domains and those used by children was very good," says Jacobson. "However, we also found that among some children, they would say something like, 'I did better when the teacher gave me permission to be a little late for class, because it takes me so long to get there.' So, they're describing how they're managing or coping with pain," says Jacobson.

Other pain-coping strategies included self-distraction and exercise as well as cognitive coping strategies, such as "keep going, save it for another day," states the paper.



The study recommended 13 revisions to the PROMIS pain assessment framework for further study based on <u>children</u>'s feedback, including dividing pain quality into two categories - pain sensory quality (punching, twisting, electrical) and affective pain quality, including the question, 'In the past 7 days, did your pain ever feel weird?'

The study also recommended additions to describing pain behavior including:

- I took breaks
- I asked for someone to help me
- I told people I couldn't do things with them
- I told people I couldn't do my usual chores
- I tried to think of something nice/fun
- I went to sleep
- I had to stop what I was doing
- I got angry at people

The authors add that their findings on pain coping warrants further study for adding to the PROMIS network.

Provided by University of Cincinnati

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