

## Book review

### Challenging the stigma of pediatric pain: A graphic novel for pain education

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**Dakoji KD (2022).** *Pain: It's all in your head. Just like everything else.* Peace Out Press, 20 pp. ISBN 979-8-9866090-0-3 (Paperback: \$13.99 USD). [www.peaceoutpain.com/press](http://www.peaceoutpain.com/press)

Pain neuroscience education is a major component of effective treatments for pediatric ongoing pain (Harrison et al., 2019). Kavita Desai Dakoji, PhD, is a pediatric psychologist with 10 years of experience working within the Children's Minnesota Pediatric Pain Clinic. More recently, she has created Peace Out Pain, her private practice and educational platform to change the way the lay public and medical providers speak with people about their pain. She brings this experience to tackling the stigma young people experience when they encounter providers that doubt the veracity of their pain. The authors of this review work in tertiary pediatric hospital systems with experience using interdisciplinary approaches to rehabilitative services for youth with ongoing pain and have encountered individuals who have experienced this stigma. The book has been reviewed through the lens of clinical experience, where pain education is a significant component of the rehabilitation model.

*Pain: It's all in your head. Just like everything else* is a 20-page graphic story for middle grade readers. It was written by Kavita Desai Kakoji, PhD, and illustrated by Kate Eolina and features a conversation between two young people after one had a confusing and distressing conversation with a provider about the nature of their stomach pain. The

common experience of attributing one's pain to psychological causes and the accompanying sense of being accused of faking and exaggeration is the central theme in the story and one that is commonly encountered by youth and their families when seeking care. Stigma often leads individuals to avoid professionals, and the resulting marginalization can cause individuals to doubt their own experience of symptoms. It ultimately erodes trust in the medical profession at a crucial time of need for youth - as they encounter pain and pain-related interference.

The dialogue in the graphic story starts straight away with the main character pronouncing profound frustration with adults, specifically the adult provider who marginalized the young person's pain. The character makes the immediate connection between the physician's comment that the pain was "all in my head" to asking, "Why would I be making this up?" The nearly universally derogatory term "all in your head" usually communicates to an individual, "I don't believe what you are telling me," and instead, "believe you imagined, invented, exaggerated or fabricated what you told me was true." Researchers have investigated the impact of provider beliefs about their patient's pain. Providers tend to underrate patients' pain intensity relative to patients' own ratings (Prkachin et al., 2007), are influenced by implicit bias, and attribute pain behaviors to drug-seeking or secondary gain (Sabin & Greenwald, 2012). These doubts influence pain treatment strategies (Boring et al., 2021; Nicola et

al., 2021) and can negatively impact pain treatment (Sabin & Greenwald, 2012). The character is correct to question the provider's attribution and the meaning of the comment.

The response of the friend is direct and challenges the interpretation of the meaning of "all in your head." The friend introduces a physiological explanation for why someone may say, "pain is all in your head" by explaining the function of the brain in interpreting incoming nervous system messages. Reclaiming this term is a bold strategy to empower youth and their parents to diffuse the power of the phrase. The dialogue continues to include both aspects of the experience – the affective response to hearing the term (i.e. frustration) and the scientific content of the explanation. The friend's response is consistent with the International Association for the Study of Pain (IASP; Raja et al., 2020) definition of pain as a "sensory and emotional experience." Through continued dialogue, examples and illustrations, the authors educate youth on how the peripheral and central nervous system work together, without ever naming them outright. The turning point comes when the character states, "I think I get it," then proceeds to teach back the concept of peripheral to central nervous system transmission of nervous system signals.

Clinicians will immediately recognize this aha moment as a signal that the character in the book understood the concept clearly enough to repeat it and then teach it back (Kornburger et al., 2013). Importantly, the character goes from feeling blamed and stigmatized to feeling understood and validated when having pain. Once that occurs, it facilitates the confidence to generate the statement, "I wish they would have used ALL of those words. That would have made more sense and I wouldn't have felt so hurt." This statement highlights the importance of providers offering effective pain neuroscience education, which can help patients feel understood and improve participation in treatment recommendations (Locher et al., 2023). *Pain: It's all in your head* illustrates the power of language and education in reducing the stigmatization of youth with ongoing pain. The dialogue between the two young people acknowledges the degree of distress that conversations with providers can cause

and importantly models different coping strategies by interpreting the literal content of the phrase in a more positive way. The book remains developmentally appropriate for youth, straightforward, and concise. It normalizes the experience of pain, distress over having pain, and frustration over not being heard or taken seriously. These are all themes that may resonate with youth and their caregivers and are accomplished through cheerful illustrations and colorful schemes. Although the book was written for all ages, the content might be most effective in illustrating an interaction for children with ongoing pain and can be used as a helpful guide for parents and caregivers.

The value of this short, visually engaging story comes in the conversation that it can spark among individuals, parents and caregivers, patients, and providers who are impacted by, care for, and interact with youth with ongoing pain - beyond just disorders of gut brain interactions. The afterword of the book urges readers and healthcare professionals to challenge the stigma that exists for individuals experiencing ongoing pain. It is a call for all of us to check, monitor, and correct our language around the explanation of ongoing pain and continue developing and disseminating effective pediatric pain neuroscience education for youth and their families.

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