

## Commentary

# Conversion Disorder and pediatric chronic pain – talking through the challenges

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There is increasing interest in Conversion Disorder in pediatric chronic pain and while there is much to say on this topic, there is little previous research, and no consensus exists regarding best treatment practices. Our aim is to call attention to several key communication challenges and demonstrate the need for more research on this important topic. This commentary offers suggestions on working through these challenges, integrating existing research and clinical experience. A case example is provided at the conclusion.

### Introduction

In our clinical experience, youth presenting with chronic pain and/or Conversion Disorder (also known as Functional Neurologic Disorder) symptoms often experience a lengthy and complicated diagnostic process. Often, this protracted diagnostic process yields an emphasis on medical explanations and interventions for symptoms (referred to as medicalization), which delays treatment and complicates engagement in a self-management approach to their symptoms. The DSM-5 distinguishes between pain and conversion disorders (American Psychiatric Association, 2013); however, there is increasing discussion that the two are not necessarily mutually-exclusive, and youth with comorbid chronic pain and conversion symptoms may experience even greater delays and medicalization than those with either alone. Recent research suggests that conversion symptoms in youth can be triggered by relatively routine stressors (de Gusmão et al., 2014), and given the

high level of stress experienced by youth and families with chronic pain (Hunfeld, et al., 2001), it is possible that youth with chronic pain could be at increased risk of developing conversion symptoms as a result of their pain condition. However, the prevalence of conversion symptoms in pediatric chronic pain populations is not known and there is a clear need for more research regarding symptom comorbidity.

### Patient-family communication

*Enhancing treatment engagement – the need to demedicalize without delegitimizing.* Youth presenting with pain and conversion symptoms have often experienced a long and frustrating trail of diagnostic procedures and specialty referrals, as well as a baffling amount and variety of feedback regarding what was and was not found. Often the most specific feedback patients are given is that their symptoms are medically unexplained. While the goal of using this terminology may be demedicalization, many patients have told us they interpret this as: (1) being told “it’s all in your head,” or (2) the symptoms are very unique or severe, and thus very difficult to treat. In our experience, lack of an adequate diagnosis increases diagnosis-searching, delegitimizes a patient’s struggle, and increases reluctance to engage in well-validated cognitive-behavioral and rehabilitative approaches to improving function (which may be deemed by patients as giving up on finding a cure). Families we work with who are still seeking medical resolution typically struggle to recognize a

psychological component to apparently physiological symptoms, resulting in unique challenges in forming an effective therapeutic alliance.

**Talking with families about the conversion label.** Providers, in turn, can be uniquely hesitant to apply the Conversion Disorder label due to fear of alienating the families. Not fully discussing a somatic disorder may limit a patient and family's ability to fully engage and participate in the appropriate treatment (Cole et al., 2014). Research suggests that parent reactions are affected by the diagnosis given and, in the case of a non-organic diagnosis such as Conversion Disorder, using a biopsychosocial framework may reduce parental distress (Williams et al., 2009). This framework can help families understand how the mind and body work together, and that experiences such as chronic pain typically involve contributions from both the body and the brain. Anecdotally, this framework may be especially important when discussing psychological interventions for physiological symptoms. Failing to do so can unintentionally delegitimize the symptoms, communicating: "It's all your head." Previous research suggests using clear, non-pathologizing language (Morgan et al., 2013) and emphasizing the realness of the symptoms (independent of their etiology). Legitimizing the body's response to stress (Silber, 2011) can be helpful in understanding and accepting somatic diagnoses. However, to date no empirical investigations have been published on strategies to provide feedback regarding conversion symptoms, and more research is clearly needed to provide direction in this area.

### **Guidelines for effective interprofessional communication**

**Consistency, consistency, consistency.** Patients with pain and conversion symptoms often present with an array of symptoms that fluctuate in severity and type throughout treatment. If teams are not in agreement on the best approach to framing and treating symptoms, interventions will be inconsistently implemented, potentially causing intermittent reinforcement of the symptoms and behaviors that impair functioning. When suggesting that a Conversion Disorder accounts for some of a

youth's symptoms, it is very valuable to have physicians involved in the child's care present for discussions of this diagnosis and related treatment recommendations. Otherwise, families may be inclined to dismiss the psychological interpretation and continue to search for medical answers. In the treatment context, maintaining team cohesion can be especially challenging since treatment of pediatric chronic pain is typically provided in a multi- or interdisciplinary format, and additional strategies may be needed including: (a) routine sharing of progress notes, (b) cross-specialty, collaborative treatment planning, (c) scheduled conference calls, and (d) an identified point person to reduce the potential for confusion and/or splitting among providers. Even within a unified team, use of information sharing strategies such as written protocols and patient memory books may prove essential, along with frequent communication and careful monitoring of the team's progress in following its own plan.

**Team functioning.** Although case studies have been published on conversion symptoms in medically complex youth (Gooch et al., 1997; Campo & Negrini, 2000), no research has examined best strategies to enhance team functioning and communication in this area. More research is urgently needed. The variable course and progression of symptoms and symptom-related impairment that characterize conversion can be particularly challenging. For example, physical and occupational therapists providing direct services may be at increased risk of frustration or burnout when spending 3+ hours a day with a patient who fails to improve as expected based on their primary pain condition. As frustration increases, team members may begin to see confronting the patient as the most direct and effective way to resolve the difficulty. In these circumstances, attention to team communication and support will be important. Strategies may include: (a) reassurance that variability in progress and functioning is expected, (b) support and encouragement on managing setbacks or relapses, (c) education and working with providers to enhance their communication with the patient and family through role play or scripts, and (d) team support to prevent and address issues related to caregiver fatigue.

## Conclusion

There is increasing recognition of the importance of addressing comorbid conversion symptoms in youth with chronic pain, a topic that has historically been somewhat avoided. One potential reason for the failure to discuss conversion symptoms relates to communication challenges surrounding the diagnosis and lack of research on best practices for intervention. In this commentary

we have sought to draw attention to these issues and demonstrate the need for more research on strategies to address them. As is clear, much more work is needed to understand key aspects of conversion symptoms in youth with chronic pain including prevalence rates as well as best practices for diagnosis, treatment, and communication about the diagnosis with patients and families.

## Case Example

Megan is a 16-year-old Caucasian female with a significant history of chronic headache and autonomic dysfunction following concussion over one year ago. She has struggled to reduce headache symptoms despite multiple medication trials, physical therapy, reiki, and psychological interventions. Recently she fell and hit her head on the floor, creating a second concussion incident. She was stable but sought follow up with neurology within a few days. Due to peculiar eye movement during the exam, she was sent for an EEG. She experienced a seizure episode during the EEG (which was confirmed as non-epileptic) and again 30 minutes later while still in the hospital. Over the next week she became progressively weaker in her lower extremities, eventually requiring assistance from her mother to walk and using a wheelchair when possible. Her gait is very unsteady and her balance is compromised by poor posture and excessive muscle tension, as if bracing for a fall.

Megan has recently experienced multiple stressful life events including a family member with dementia and a parent receiving cancer treatment, which was identified following surgery for an injury. In her previous sessions, Megan has demonstrated a strong desire to avoid emotional distress, often denying feelings in response to stress-provoking situations. Although she describes being terrified of life-limiting sequelae resulting from her second concussion (death, dementia, depression), she states that her current physical symptoms are not stressful.

**Patient-family communication.** After evaluating Megan's symptoms, we first spoke with Megan's mother. We described the symptoms and empathized with her concern for her daughter's health and safety. After detailing symptoms and underscoring that a physical cause for the seizures (epilepsy) was ruled out, we introduced the role psychological distress can play in physical symptoms. We introduced the term Conversion Disorder, demystifying the term and directing her to psychological treatments. At this time, Megan's mother still had questions about neck injury, swelling or damage to the spine influencing pain and gait. Since clear physical cause had not been ruled out for this symptom, we encouraged her to clarify the diagnosis with neurology (this was later ruled out).

With Megan herself, we slowly introduced the concept of conversion. This began with a discussion of the power the brain has to alter our sensations and perceptions, even at a subconscious level. We discussed the blind spot created by the optic nerve as an example, which she understood. We then moved to discuss how the brain may subconsciously create sensations/perceptions or blocks in movement in an effort to protect the body, using the example of fainting. We described how, at times, this does not work in the expected way and we call this conversion. Her brain's effort to avoid the stress caused by various life events and her current mental state likely was the primary cause of her symptoms. Checking in with Megan throughout the discussion, she initially understood and was receptive. She later noted doubts, which were normalized and

we validated the ambiguity that she was feeling.

**Interprofessional communication.** It was important to have the same conversation with all staff involved with Megan's care, as care was being provided through multiple specialty services in different physical locations. Providers included physicians, nurses, physical and occupational therapists, and the recreational therapy staff and teachers working with Megan. It was very important that all staff had a consistent understanding of the symptoms as well as a consistent message to Megan and her family. The initial treatment plan focused on pain related to concussion (now classified as chronic daily headache), specifically on increasing endurance, strengthening, and daily functioning, using appropriate accommodations but not avoiding life activities. However, as a result of her response to the second concussion, we became aware of the need for a plan to manage acute pain or new physical symptoms that may occur during rehabilitation. We therefore devised a specific plan to avoid over-responding to the symptoms, guard Megan for medical safety, and encourage daily functioning. She was provided a helmet and noted that given her fall risk, she would have to wear the helmet for her own protection until the episodes were resolved. This served a dual purpose of guarding her against potential injury and providing negative reinforcement for improved coping and functioning (i.e., if she went a week without conversion symptoms, we could remove the helmet). Behavioral modalities were used to reinforce functioning (verbal praise, access to desirable activities, social attention/interaction) that depended upon staying in physical/occupational therapy sessions. Staff reported precipitating events for all seizure episodes to psychology, which enabled her primary therapist to better identify the triggers, understand the function of the symptoms, and modify the treatment plan as needed.

Psychology then worked directly with Megan, identifying the situations that seemed most important in improving functioning, avoiding excessive attention and medicalization of symptoms, and addressing the emotional/psychological underpinnings of her condition. Given her strong desire to avoid emotional distress, she has been slow to progress in this domain. However, the hope is that by reducing any potential secondary gain of symptoms (with a focus on functioning), the frequency and intensity will diminish over time. As her emotional distress emerges without eliciting conversion symptoms, she and her psychologist will be able to work directly on her emotional distress, leading not just to resolution of her symptoms but improvement in the underlying causal factors.

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## References

American Psychiatric Association. Diagnostic and statistical manual of mental disorders (5th ed.). Washington, DC: Author, 2013.  
[www.worldcat.org/oclc/830807378](http://www.worldcat.org/oclc/830807378)

Campo JV, Negrini BJ. Case study: negative reinforcement and behavioral management of conversion disorder. J Am Acad Child Adolesc Psychiatry 2000;39:787-790. [www.pubmed.gov/10846314](http://www.pubmed.gov/10846314)

Cole CM, Falcone T, Caplan R, Timmons-Mitchell J, Jares K Ford PJ. Ethical dilemmas in pediatric and adolescent psychogenic nonepileptic seizures. *Epilepsy Behav* 2014;37:145-150. [www.pubmed.gov/25022823](http://www.pubmed.gov/25022823)

de Gusmão CM, Guerriero RM, Bernson-Leung ME, Pier D, Ibeziako PI, Bujoreanu S, et al. Functional neurological symptom disorders in a pediatric emergency room: diagnostic accuracy, features, and outcome. *Pediatr Neurol* 2014;51:233-238. [www.pubmed.gov/25079572](http://www.pubmed.gov/25079572)

Gooch JL, Wolcott R, Speed J. Behavioral management of conversion disorder in children. *Arch Phys Med Rehabil* 1997;78:264-268. [www.pubmed.gov/9084347](http://www.pubmed.gov/9084347)

Hunfeld JA, Perquin CW, Duivenvoorden HJ, Hazebroek-Kampschreur AA, Passchier J, van Suijlekom-Smit LW, et al. Chronic pain and its impact on quality of life in adolescents and their families. *J Pediatr Psychol* 2001;26:145-153. [www.pubmed.gov/11259516](http://www.pubmed.gov/11259516)

Morgan LA, Dvorchik I, Williams KL, Jarrar RG, Buchhalter JR. Parental ranking of terms describing nonepileptic events. *Pediatr Neurol* 2013;48:378-382. [www.pubmed.gov/23583055](http://www.pubmed.gov/23583055)

Silber TJ. Somatization disorders: diagnosis, treatment, and prognosis. *Pediatr Rev* 2011;32:56-64.

Williams SE, Smith CA, Bruehl SP, Gigante J, Walker LS. Medical evaluation of children with chronic abdominal pain: impact of diagnosis, physician practice orientation, and maternal trait anxiety on mothers' responses to the evaluation. *Pain* 2009;146:283-292. [www.pubmed.gov/19767148](http://www.pubmed.gov/19767148)