

Problems with diagnosing Conversion Disorder in response to variable and unusual symptoms

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Abstract: Conversion Disorder (CD) is a diagnosis offered to explain signs and symptoms that do not correspond to recognized medical conditions. Pediatric patients with variable, vague, and multisystem complaints are at increased risk for being diagnosed with CD. Little is known about the impact of such a diagnosis. In making such diagnoses, it is likely that pediatric providers hope to encourage patients to access mental health care, but no basis exists to show that these diagnoses result in such access in any useful way. This article presents the case of a child with Ehlers-Danlos Syndrome, who had been previously (incorrectly) diagnosed with CD and referred for mental health care. It offers commentary based on interviews with other pediatric patients with similar experiences – conducted in collaboration with the Ehlers-Danlos National Foundation. These cases indicate that CD diagnoses can seriously undermine patients' trust in doctors, and can create such defensiveness that it may interfere with (especially) patients' abilities to engage with mental health services. Such interference is an important problem, if the diagnosis is accurate. But, in the (more likely) event that it is not accurate, this defensiveness can interfere with both important mental health care and further ongoing necessary medical care.

Keywords: somatoform disorders, dysautonomias, pain, collagen diseases, mitochondrial diseases, complex regional pain syndromes

Introduction

Pediatric primary care professionals and specialty providers sometimes find themselves unable to arrive at a clear diagnosis for patients with atypical symptom presentations. In such circumstances, providers may consider offering a diagnosis of Conversion Disorder (CD),¹⁻³ believing that, in the absence of a sound physical diagnosis, the child's symptoms are probably the result of some psychological process, and that such a diagnosis may help the child to get necessary psychiatric care.

As part of making an educational video regarding problems with making a diagnosis of CD in children with complex, obscure, multisystem physical complaints, the author (a practicing child and adolescent psychiatrist who works with a number of children and teens with persistent complex medical problems) interviewed about half a dozen children (and parents) attending a national meeting of the Ehlers-Danlos National Foundation. This article stems from those interviews, and offers commentary and opinion, based on the experiences that these patients reported.

CD is one of a number of conditions in which, it is thought, the child's symptoms are not the result of a physical process, but instead have a psychological cause. This is distinct from malingering, which is simply a deliberate process of faking or exaggerating symptoms, in order to achieve a specific, targeted goal (such as disability

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benefits, civil damage claim awards, or to be excused from certain responsibilities). CD is a diagnosis of exclusion, requiring that physical causes of symptoms have been ruled out. The key criterion is the following: "Clinical findings provide evidence of incompatibility between the symptom and recognized neurological or medical conditions."⁴

Until recently, the diagnosis of CD also required establishing that some unresolved and unconscious psychological conflict is present, providing the psychic energy for the development of symptoms. This requirement posed insurmountable problems for diagnostic validity, and has been dropped. However, an unconscious process is still implicit in CD, which is one factor distinguishing it from malingering. In CD, it is understood that the patient is not aware of the conversion of psychological difficulty into physical symptoms, and thus (perhaps) may not be considered responsible for the phenomenon, and may be (theoretically at least) amenable to psychological intervention.⁵

CD is most commonly (and properly) diagnosed when a patient presents with neurological symptoms that do not make sense in light of what is known about the anatomy and physiology of the nervous system.⁶ CD may be offered also as a diagnosis in other, less clearly-defined circumstances, in which a patient's symptoms may be hard to diagnose. Such circumstances often include pain as a significant aspect of the child's presentation. Pain is, of course, an entirely subjective symptom, typically reported by patients on a 1 to 10 scale of severity, along with subjective descriptions of pain quality, duration, and mitigating and exacerbating factors. Despite this subjectivity, pain does tend to be reported in relatively standard ways in typical conditions. Furthermore, pain is typically associated with certain objective signs (eg, guarding, facial expressions of distress, weeping, moaning), on which providers may tend to rely in forming their impressions of the severity and nature of the pain. When a child's report of pain characteristics and severity does not match the provider's expectations (based on how patients ordinarily experience pain in typical conditions), the provider may doubt the validity of the child's report. If a child who is sitting calmly in the doctor's office, with unremarkable behavior and facial expression, complains of pain rating 8 of out 10, this presentation may bring to mind the classic sign, "la belle indifference," which was ascribed to patients diagnosed with hysteria during the late nineteenth and early twentieth centuries.⁷ The provider may think that the child cannot possibly be experiencing as much pain as she is describing, and may tend to consider a diagnosis of CD on that basis.

In addition to neurological symptoms and pain, a number of complex medical conditions lend themselves to CD diagnoses; they may present with vague, non-specific, and unstable symptoms that do not conform to any widely-held understanding of any medical condition. Ehlers-Danlos Syndrome (EDS) and mitochondrial diseases are prominent among these problems.

Mitochondrial diseases include a broad range of (primarily genetic) abnormalities that were formerly thought to be mostly fatal in early childhood, but which are now understood to lead to a variety of metabolic abnormalities, which may not present early, and which persist into adulthood.⁸⁻¹⁰ All body systems may be affected; problems with pain, fatigue, and multiple dysautonomias are especially troublesome.

EDS is best known for presenting problems with joint hypermobility and skin abnormalities. However, as a profound disorder of connective tissue, EDS can present with symptoms relating to any organ system. Especially prominent are gastrointestinal symptoms,¹¹ which can contribute to overall poor nutrition and general ill-health, and neurological problems, including spinal abnormalities with significant pain,¹² and dysfunction of the autonomic nervous system.¹³ Dysautonomias manifest especially as wild fluctuations in heart rate and blood pressure associated with postural changes (postural orthostatic tachycardia syndrome [POTS]), as well as low body temperature, generally poor temperature regulation, and vulnerability to heat stroke. Other neurological problems include headaches, disturbed sleep architecture with unrestful sleep,¹⁴ profound fatigue, and pain.¹⁵ When children with EDS experience pain, it can often be quite severe; but these children tend to be accustomed to it, and to be functioning at a level higher than one might ordinarily expect. As a result, the pain may appear to be less severe than it truly is.

When these symptoms present without the cardinal signs of joint hypermobility, they can be difficult to diagnose specifically. Patients are often treated purely symptomatically, without definitive success. Symptoms may tend to be seen either as "functional" or as explicit psychiatric symptoms – especially POTS symptoms (which can mimic panic attacks) and fatigue (often seen as a sign of depression).

When patients' problems persist, or clearly relate to multiple body systems in ways that do not make obvious sense, medical providers may be challenged to arrive at a specific diagnosis. When no diagnosis is apparent, providers may hope that offering a diagnosis of CD will reassure both patient and family that the problem is not medically more serious, also that it will facilitate the patient's access

to psychiatric care. In fact, making a diagnosis of CD usually accomplishes neither of these goals. Instead, it leads to many new and more serious problems, including stigmatization, undermining of personal identity, and worsening of symptoms.¹⁶ In general, a useful rule is: “If you are thinking about CD, think harder.”

Case example

Emily was a third grade girl who had been suffering from pain that was consistent with Complex Regional Pain Syndrome. She also had unstable joints, which was consistent with EDS (although, initially, she did not have that diagnosis). For a period of a year or longer, her medical providers were suspicious that she was purposely dislocating her joints, demonstrating an atypical spasmodic tremor, and altering her gait (as manifestations of CD). Over time, she also developed POTS and some other dysautonomias, and was referred as an outpatient to a local hospital for cognitive behavioral therapy with a psychologist. It was hoped that this treatment could help her to develop improvements in her ability to cope with stress, and thereby to have fewer symptoms. The psychologist was clearly a bright and sophisticated clinician, who made the point that some of Emily's symptoms were not what one might expect, medically. Emily experienced this effort at treatment as the therapist accusing her of “having it all in her head,” and was trying to hypnotize her, to “fix something”. Emily proved to be very guarded, and unresponsive to this treatment.

Later, during one of multiple medical hospitalizations, Emily developed seizures. Since there was no electroencephalographic evidence of epilepsy, she was more seriously considered as having CD. Hospital medical and psychiatric staff recommended she be transferred to their inpatient psychiatric service for treatment. Her mother was very upset at this recommendation. It did not feel right; but she did not want to deny her daughter any treatment that might help. The mother was unable to gain explanation, from anyone who recommended this plan, as to how it would help Emily to get over her CD, to spend time in an inpatient psychiatric unit, with depressed and suicidal teenagers. As a result of this, Emily did not enter the psychiatric unit.

The psychiatrist responsible for Emily's outpatient care (the author) wrote a long, detailed, carefully-reasoned assessment report, reviewing Emily's symptoms and addressing explicitly the issue of whether she should be understood to suffer from CD. At that point, there was no medical explanation for the seizures. The report acknowledged that CD was a possibility, though it did not offer that diagnosis conclusively.

The psychiatrist continued to be curious, and supportive, in meeting with Emily and learning about her symptoms.

Even though Emily enjoyed these meetings, and was generally comfortable with the psychiatrist, she remained very defensive about any suggestion that she might have any kind of psychological problems; she agreed to meet only a few times a year. The psychiatrist's rationale for this treatment was, essentially, to protect Emily from the effects of medical professionals, disregarding her symptoms by accusing her of having CD; she was comfortable with this formulation, and grateful to receive this help. In fact, the psychiatrist had many phone conversations, and went to more than a few meetings, in order to make it clear to others on her treatment team that Emily's psychological health was being taken care of. Although others on the team continued to have doubts about Emily's symptoms, they continued to look for a physical diagnosis and to provide her with appropriate medical care.

Over time, Emily's problems with EDS and dysautonomia became somewhat worse, as they tend to do; her diagnoses were no longer in doubt. Her seizures were understood to be secondary to dysautonomia. Recurrence was prevented by maintaining adequate hydration and electrolyte balance. As the unfortunate reality of her medical problems became better recognized, she began to feel less vulnerable to possibly being mislabeled. However, she began to feel increasingly angry about how hurt she had felt in the past at being mislabeled, and by her subsequent involvement in psychological treatments that did not help her, which were provided by people who did not believe her.

As it happened, her increasing POTS symptoms suggested that she might benefit from taking stimulant medication, to help stabilize her hemodynamic function. She did have a history of psychological test results that were consistent with a diagnosis of ADHD and nonverbal learning disorder and so she began a careful trial of slowly increasing doses of short-acting mixed amphetamine salts (Adderall), to see what effect it might have on her POTS symptoms of dizziness and fainting. The amphetamine worked very well for those symptoms, and also brought enormous benefit for her school functioning, helping her to go from being a slightly-above-average student, to being a truly outstanding one.

Emily is now an early adolescent, and is successful in school and with friends. She continues to meet with the psychiatrist every month, to renew her amphetamine prescription and to talk about her life. Unfortunately, her life continues to include a lot of difficult medical and surgical problems associated with EDS, but she has been strong and resilient in

coping with these problems; she has a good time talking about the unfairness of it all, how angry she is, and how she copes. It appears that she benefits from this support and has been maintaining an overall positive adaptation to her illness.

Discussion

The most obvious problem with making a diagnosis of CD is that doing so leaves unrecognized and untreated whatever underlying medical conditions may exist. As a result, the presenting symptoms persist and (usually) get worse, often with significant morbidity and deterioration in overall function. Another problem is that once the child has a diagnosis of CD in his or her medical record, it can be hard to expunge it, even after a more accurate physical diagnosis may have been established. A lingering CD diagnosis still further compromises the child's chances of getting good medical care – even for genuine physical problems – by engendering doubt in the minds of successive providers as to the reality of the child's continuing (or new) symptoms.

More profoundly, the diagnosis represents (especially to children) an accusation by the diagnosing doctor of either dishonesty or craziness. Children tend to be naïve and trusting of “authority figures” (including doctors); many children who have the types of complex, multisystem medical problems described here also tend to be concrete, literal, and “black and white” in their psychological functioning.^{6,17} This characteristic contributes to children's intense distress at having their own very real experience of being sick undermined. They feel a truly traumatic sense of unhappiness at the disruption of trust between doctor and patient, in response to the accusation of their “making up” an illness. Many children do not easily get over this trauma, and become intensely defensive with doctors generally. It can then be especially challenging to engage them in any kind of mental health care. As a result, not only does the CD diagnosis leave the child without treatment for whatever may be the underlying medical problem, it also makes it much harder for them to get the psychiatric treatment that the medical care provider, in making the diagnosis, presumably intended for them to receive.

Providers may try to soften the “making it up” diagnosis by underscoring the unconscious nature of CD. Telling children and families that the child's “brain is playing tricks”, that it is “not the child's fault”, or that it is “out of the child's control” are some common efforts in this regard. Although in some respects, this approach seems more forgiving, and might be expected to lead to less defensiveness, it is not actually comforting to most patients. Most of the children interviewed for this project said that they “just knew” they had a

genuine illness that was not recognized; they responded with compelling anger and skepticism to such blandishments.

Conclusion

In summary, it is important for pediatric providers to understand how destructive making a CD diagnosis can be, especially for those mental health problems for which making this diagnosis is presumably meant to be helpful. The following suggestions are offered:

1. Providers should take care to become familiar with the wide range of medical conditions that are known to cause elusive and difficult-to-diagnose symptoms, and should consider screening for them in working-up such symptoms. Obviously, if a patient is suffering with symptoms for which a clear diagnosis cannot be found, the first step should be to consult with other knowledgeable providers.
2. Most doctors do not enjoy being stumped diagnostically; awarding a diagnosis of CD (as a last resort) does not usually feel like success. It would be ideal to respond to this frustration not by closing out the patient (with a casual diagnosis and referral for mental health care) but instead by acknowledging the frustration of not having a satisfying answer; sharing the burden of uncertainty with the patient and family; promising to keep seeking a sound diagnosis; helping the patient to find more expert specialists; and referring the patient for mental health support, to help with the stresses associated with being sick from a mysterious condition.
3. In this process, there is probably no value in suggesting to either the patient or the mental health practitioner that the patient has CD. Doing so would engender defensiveness in the patient, and could tend to undermine the ability of the mental health practitioner to offer the patient sincere support.
4. Even if there is no diagnosis for the patient's symptom (as yet), it is good practice to refer the patient for rehabilitative care, to address the patient's impaired functioning.¹⁸

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