A clinical approach to paediatric conversion disorder: VEER in the right direction

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Conversion disorder (CD) is an uncommon but highly disabling condition in the paediatric population. Affected children and adolescents are often severely impaired and at risk of serious long-term physical and psychosocial complications, including educational failure, social isolation, physical disability and psychiatric morbidity. The condition is typically associated with extensive use of paediatric and allied health resources. Despite the enormous personal suffering and health resource implications of CD, the epidemiology and clinical burden in children and adolescents in Canada have not been documented.

What are the diagnostic criteria for conversion disorder?

Conversion disorder (CD) is categorized within the group of disorders known as “Somatoform disorders” in the Diagnostic and Statistical Manual (DSM-IV).1 Children and adolescents presenting with CD describe symptoms that are suggestive of a medical illness but on further history, examination and investigation cannot be explained in terms of known pathology and pathophysiology. Most commonly, the symptoms suggest neurological disease. Frequently reported symptoms include seizures, paraesthesias, paresis, abnormal gait and other abnormal movements. The symptoms must cause the patient to experience clinically significant distress or impairment in social, occupational or other important areas of functioning. It is important to understand that the symptoms are not intentionally produced. According to the DSM-IV definition, there must be a recognized psychological stress that can be related to the onset of symptoms; however, this may not be immediately evident at presentation.1 Finally, the symptoms or deficits are not limited to pain or sexual dysfunction, do not occur exclusively during the course of a somatization disorder and are not better accounted for by another mental disorder.
Is the epidemiology of conversion disorder in paediatrics well described?

Most of what is known about CD originates from studies done in adult populations. The prevalence of CD is estimated at approximately 5%–14% of general hospitalized patients, 5–25% of psychiatric outpatients and up to one-third of neurology outpatients.²

There appears to be no specific estimates of the prevalence of CD in the paediatric population. Indeed, the literature has remained rather elusive in this regard. This may be partially due to the methodological challenges in the investigation of CD in children, notably the limited availability of valid diagnostic interviews and difficulties in obtaining information from multiple sources.³

The first published report of CD in children came out of the U.S. in 1898 by neurologist Herman B. Sheffield who reported a total of 98 cases. In 2000, a retrospective German study estimated a 12-month prevalence of 0.2% for CD in a large cohort including adolescents and young adults aged 14–24 years of age.⁴ A significant limitation of this study was that although a structured diagnostic interview was used, it included self-reported symptoms of conversion without medical opinion. In 2007, an Australian surveillance study of CD in children and adolescents was published.⁵ It estimates an annual incidence rate of 2.3–4.2/100,000 children, which probably represents the most accurate estimate of frequency to date. Estimates of prevalence in non-Western clinical settings have been reported in the literature as being as high as 31%. Low socio-economic status and low levels of psychological sophistication are reported as being associated with high prevalence.

In terms of the first North American preliminary epidemiological data gathered during the first months of the CPSP CD study, 49 cases have been confirmed (female to male ratio of 3:1) with an average age of 13.7 years (range 8–18). The majority (87.5%) of youth required hospitalization with an average length of stay of 15.6 days (range 3–104; SD=20.5 days). The average number of specialists seen per patient was 4.5.

What are the clinical clues on history indicating a conversion disorder?

There is no single pathognomonic feature upon which the diagnosis of CD rests. Like other clinical syndromes, it is a constellation of features that together points to the diagnosis.

Paediatric CD has been predominantly reported in pubertal and post-pubertal children, although systematic prospective surveillance has identified cases as young as three years; however, cases under five years old appear to be rare.⁷ Younger children present with negative symptoms (loss of function, such as weakness, imbalance, or vision loss). Positive symptoms such as non-epileptic seizures and psychogenic movement disorders are only encountered in pubertal-aged and older children.

There is a higher incidence of CD in girls than in boys. In younger children (<10 years of age) the sex difference is small (1.3 girls for every 1 boy), but in children ≥10 years of age, the ratio rises to 3.1 girls for every 1 boy.⁵

Almost any neurologic symptom can constitute the presenting complaint in CD. In the Australian paediatric surveillance study, the three most common presenting neurologic symptoms were weakness, ataxia and non-epileptic seizures.⁵ Of note, more than half (55%) of the children in that study had multiple neurologic complaints at presentation. An equal proportion (56%) also had concomitant complaints of chronic pain.
Irrespective of the specific neurological symptom, there are qualitative features of the presenting complaint that tend to indicate a high likelihood of CD. For instance, there may be biologically implausible aspects to the symptoms, such as apparent generalized seizures with preserved awareness and subsequent memory for the event, or there may be weakness or sensory loss in a non-neuroanatomic distribution (often delimited by a circumferential band halfway up a limb).

There is often also an unusual time course to the symptoms. Common patterns include either (i) chronic symptoms that began with a sudden onset at maximal intensity and have remained present and undiminished since onset, or (ii) paroxysmal symptoms that have occurred exclusively in the presence of trusted family members or friends.

Finally, and perhaps most important overall in identifying CD, the impact of the neurologic symptoms on the patient’s life is typically out of proportion to the apparent severity of the symptoms. It is helpful in this respect to bear in mind that emotionally healthy children and teens who develop neurological diseases (such as epilepsy, neuropathies, or movement disorders) continue to attend school and participate in social activities, and generally seek to maintain their previous level of involvement and contact with their peers despite the presence of new neurologic symptoms.

By contrast, children and teens with CD usually withdraw from school and/or other activities (especially performance-athletic activities, such as dance, gymnastics, or figure skating). The young person will often verbally state a desire to be able to attend school and participate in activities, but in this situation ‘actions speak louder than words’. Despite protestations of disappointment, youths with CD typically appear to complacently accept reductions in their participation as an unavoidable consequence of their symptoms.

In addition to these features relating to the presenting complaint, there are also frequently additional clues in the past medical and family histories that suggest CD.

Patients with CD often have a history of previous medically unexplained symptoms, or possibly symptoms that were given a specific diagnosis but which caused an impact on life that was markedly greater than what one would normally have expected for someone with that condition. There is also frequently a history of having sought medical opinions from multiple different specialists for the same symptom.

Behaviourally, youths with CD tend to have a history of being well behaved at home and at school (and often being academic high achievers). There is typically no history of conflict with authority figures and most typically will deny the presence of any significant current life stressors.

In the family history, there is often a parent experiencing chronic health problems with frequently unexplained symptoms medically. Other commonly encountered traits seen in parents of children with CD include: familiarity with medical terminology and/or the health care system; a firm belief that the child’s symptoms are biological in nature; and a strong reluctance to endorse the contribution of psychosocial factors to the child’s current symptoms (in fact more reluctance toward this idea than is encountered in parents of children who have organic neurological conditions).

As stated at the outset, there is no single clinical feature that cements the diagnosis of CD. Almost invariably children with CD have a constellation of many of the above
features, making the diagnosis clinically apparent even before the physical examination.

**Are there any specific findings on physical examination that indicate a conversion disorder?**

A general theme regarding physical examination findings in patients with CD is inconsistency of the findings over time and with repeated examination. Often the most revealing moments occur during ‘non-exam’ portions of the clinical encounter. Bearing this in mind, the examination should really be an ongoing evaluation throughout the encounter, beginning in the waiting room or hallway and continuing past the end of the formal examination sequence.6

Some particular findings indicative of CD are discussed below. Again, as with the individual features of the clinical history, these clinical signs can serve to reinforce the clinical impression, but are not diagnostic when encountered in isolation.

**Focal weakness:**
- Typically the whole limb is affected, with all muscle groups being equally weak, rather than the weakness being present in specific neuroanatomic patterns (as is seen with myopathies, neuropathies, and corticospinal tract disorders).
- Quality of the weakness is often a collapsing or ‘give-way’ weakness, rather than the smooth weakness normally encountered with neuromuscular diseases.
- Deep tendon reflexes are preserved in the involved limb, and no atrophy is present.

**Ataxia / abnormal gait:**
- Often unusual patterns of gait occur, such as walking as though on ice, or appearing to be continuously on the verge of falling but not actually doing so.
- Sudden knee-buckling when near bed or trusted family member.
- Inconsistent difficulty, often improving when the examination seems to be over.

**Tremor:**
- Inconsistently present, or varying in direction, amplitude and frequency.
- Subsides with distraction and amplifies with attention.
- Frequency is altered or entrained by rhythmic tapping of another body part.

**Myoclonus:**
- Exaggerated startle response occurring with long or variable latency from stimulus.
- Anticipatory jerk seen by stopping reflex hammer just short of contact.

**Paresthesia / sensory loss:**
- Non-anatomic distribution (often delimited by a circumferential border around a limb).
- There may be discrete borders reported to loss of vibration sense over the same bony structure.
- Affected area changes over time.

**Visual symptoms:**
- Diplopia that persists with one eye closed.
- Blindness with normal pupillary responses, preserved optokinetic nystagmus, and flinching to bright light.
A clinical approach to paediatric conversion disorder (continued)

Non-epileptic seizures:
- Onset tends to be more gradual than occurs with epileptic seizures.
- Prominent involvement of truncal muscles (arching and pelvic thrusting, as well as lateral rolling of head and body).
- Non-rhythmic thrashing movements of limbs. Movements tend to increase if restraint applied.
- Closed eyelids. Attempts to manually open the eyes typically produce more forceful closure.
- Moaning vocalisations.
- Response to noxious stimuli (such as nasal tickle).
- Rapid post-ictal re-orientation.

What are the barriers to making the diagnosis of conversion disorder?

There are several barriers to making the diagnosis of CD, including the anticipation of confusion and possible anger from the family and young person, the amount of time it can take to properly communicate the diagnosis, the potential misperception that a young person may be malingering, lack of knowledge or expertise in making a diagnosis and, finally, medico-legal concerns, given the confounding clinical presentations. Previously, CD was considered a diagnosis of exclusion based on the belief that clinical data were insufficiently reliable and that extensive investigation was therefore necessary. Influential in espousing this school of thought was British psychiatrist Eliot Slater who wrote that true CD was extremely rare and estimated the misdiagnosis rate at >60%. Thankfully, subsequent longitudinal studies have shown that the clinical diagnosis of CD tends to be impressively accurate based on long-term follow-up. Beginning in the 1950s when the misdiagnosis rate of CD was approximately 30%, diagnostic accuracy of CD improved quickly, likely due to expanding knowledge in clinical neurology and advancements in diagnostic technology. From the mid-1970s onward (even prior to the era of MRI), the misdiagnosis rate has remained at approximately 4%. Interestingly, there are many diseases in medicine which have much higher rates of misdiagnosis; for example, misdiagnosis of epilepsy has been reported to range from 23% to 30% in adult and paediatric epilepsy clinics.

CD is a positive diagnosis and should not be considered a diagnosis of last resort following exhaustive negative tests. In fact, protracted investigations may only further medicalize the problem and can delay appropriate treatment. Further, there is indeed risk of harm to the patient if an erroneous medical diagnosis is provided. One study examining adult cases found that inappropriate medication was prescribed in 80% of cases and unnecessary surgeries in 20% of cases. In addition, excessive investigations and inappropriate diagnostic labels may serve to reinforce the ‘sick role’ and this may result in even greater difficulty addressing psychological issues in the future.

Approach to disclosing the diagnosis of conversion disorder to paediatric patients and families?

The diagnosing physician must explain CD to the family, as effective treatment is available and otherwise maladaptive coping may be prolonged. With diagnosis comes the opportunity to evaluate for common comorbidities, such as anxiety and mood disorders, as well as to avoid or minimize sequelae, such as lengthy absences from school and potential physical complications including contractures and osteopenia. A clearly stated diagnosis is the first step in returning the young person to health.
It can be useful to explain to the patient and family that CD is a term for an illness that, while physically ‘real’ to the patient, is in fact rooted in complex interactions between mind and body, and therefore has psychological origins. Providing examples of biologic reactions to stress, such as sweaty palms, shaky legs or flushed cheeks, can be helpful. These common examples can help establish that, indeed, emotions do affect our physical state. The key difference is that unlike the person who blushes speaking in front of a crowd, the young person with CD typically is not consciously aware of the triggering stressor. This is in fact a cardinal feature of the disorder, as the emotional response is ‘converted’ into a physical symptom with the result that the emotional trigger no longer ‘exists’ on a conscious level.

Conveying belief that the patient has subjectively ‘real’ symptoms, and that these symptoms are not feigned or intentionally amplified, is pivotal in building trust.12 The need for a mental health assessment must be addressed, preferably early on in the evaluation while other tests are being conducted, rather than bringing it up only after all of the ‘medical’ avenues have yielded negative results. A referral to a mental health provider ensures that the young person will receive detailed assessment of psychosocial functioning, psychiatric comorbidities, and unrecognized stressors. Mental health providers should not be asked to ‘confirm’ the CD diagnosis as they typically will not have expertise in clinical neurological phenomenology.

**VEER (validate, educate, empathize, rehabilitate) in the right direction: managing conversion disorder in paediatrics**

Engaging the patient and family in understanding and accepting the diagnosis is the first step in management of paediatric CD. Validation is achieved through communicating that you, as the health professional, believe the symptoms are ‘real’ to the patient, not feigned or ‘faked’ and that at some level the symptoms and the diagnosis are distressing. Educating the patient about the natural history of CD is an important intervention. For the majority of paediatric patients, the symptoms often subside and go away within weeks to a few months. The family and patient need to be reassured that the medical professional will still be available for follow-up and medical reassessment in the future. Families can be at risk of feeling ‘abandoned’ by the medical team once a psychiatric diagnosis has been given. Empathizing with families about the stigma of mental health issues and problem solving with them about how they are going to explain the illness to friends and family can also be very helpful.

Rehabilitation is the mainstay of management of paediatric CD. This starts with the basics of getting back to a regular routine with respect to eating, sleeping and exercise/activity. It is vitally important to enlist the assistance of the parents and to have the young person start returning to school and normal activities. The initial goals are very modest with progression thereafter.

A key role of parents and family is to actively distract their child from the symptoms and focus instead on leisure activities that the young person enjoys and that are developmentally appropriate.

There is a paucity of literature on paediatric CD, but by extrapolating from the adult literature, we know that cognitive behavioural therapy (CBT) is effective and a referral should be provided. Involvement of a wider circle of health care professionals (physiotherapy, occupational therapy, and speech and language therapy) can be helpful depending on the symptoms, especially if all health care providers are working towards a return to normal function. Psychiatric referral for assessment and treatment of protracted symptoms or severe comorbidity is also recommended.13
A clinical approach to paediatric conversion disorder (continued)

What is the outcome of paediatric conversion disorder?

Much of the outcome data published on CD are based on adult studies, which indicate that 50–90% of patients with CD will exhibit short-term resolution of symptoms after diagnosis and reassurance.2, 14-17 Unfortunately, 25% of these responders will relapse or subsequently develop new conversion or somatic symptoms in the future. Psychiatric comorbidity, longer duration of symptoms, psychogenic seizures and tremors, all herald worse prognoses in adults. However, in cases where onset of symptoms occurs immediately following a stressor, or when a stressor is easily identifiable and removable, prognosis is very good. In general, childhood CD is believed to be associated with a good outcome due partially to the relative lack of chronicity of symptoms and potential increase in suggestibility when compared to adults. As such, early intervention as outlined above may provide an important opportunity for prevention of further symptoms in this population.

References

Quiz

1. Conversion disorder involves:
   a. a history of complaints about pain that appears to have no physical cause
   b. excessive preoccupation with some part of the body the person believes is defective
   c. loss of functioning in some part of the body for psychological rather than physical reasons
   d. chronic worry that one has a physical disease in the absence of obvious symptoms

2. The most important skill in the assessment and management of the adolescent with conversion disorder is:
   a. attempting to ‘engage’ the patient in treatment
   b. titrating psychotropic drugs against somatic symptoms
   c. dealing with transference
   d. ending treatment

3. Which is not a hallmark feature on history for conversion disorder:
   a. symptoms or deficits affecting voluntary motor or sensory function suggesting an underlying medical or neurological condition
   b. model of illness in the family
   c. impairment in social, occupational or other functioning
   d. symptoms must cause the individual significant distress
   e. an obvious emotional stressor may not always be present

4. All of the following are considered potential barriers to making a diagnosis of conversion disorder, except:
   a. anticipation of lack of acceptance of the diagnosis by the family
   b. the fact that CD has typically been considered a diagnosis of exclusion
   c. medico-legal concerns regarding confounding clinical presentations
   d. la Belle Indifference
   e. a perception that a young person may be malingering

5. The prevalence of conversion disorder in community studies of children and adolescents in North America is estimated to be:
   a. unknown
   b. 2.3–4.2%
   c. 0.2%
   d. 10%
   e. 0.001%

6. Clinical clues on presentation indicating the possibility of a conversion disorder may include all of the following, except:
   a. inconsistent findings/disappearance of symptoms with distraction
   b. give-away weakness on examination of strength
   c. la Belle Indifference
   d. overt secondary gain
   e. giving way of legs with prevention of a fall

Answers: 1-c, 2-a, 3-d, 4-d, 5-a, 6-d