The Body Comes to Family Therapy: Utilising Research to Formulate Treatment Interventions with Somatising Children and their Families*

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Children and adolescents with functional somatic symptoms are challenging to understand and to treat. The challenges begin at the very outset of the intervention – with the neurological and psychiatric assessments. Patients presenting with functional somatic symptoms, as well as their families, frequently deny any emotional or family problem, and parents are often genuinely baffled as to why a child has suddenly become so ill and why no medical explanation is forthcoming. Families can be unwilling to engage in family assessment and therapy, and therapists may find that standard approaches to family therapy simply can end up alienating these families – the door to therapy is slammed shut. This article is the story of my struggle to understand somatising children and their families and to find a common language to enable us to co-construct formulations, to agree to a treatment plan, and to work together towards a pathway to health. It is also about the role of research and how knowledge from different system levels – and most specifically about the body – may need to be integrated into the therapy to help bring about change.

Keywords: functional neurological symptom disorder, conversion disorder, functional somatic symptoms, somatising, children, families

Key Points

1. Understanding the diagnosis of conversion disorder via a therapeutic assessment and conversation with a paediatrician, physician, or neurologist is a cornerstone of assessment and treatment.
2. Family assessment works best if the therapist takes a detailed, temporally ordered history of the symptom(s) and gathers information about other salient events – illness, family life events, events at school, family emotional processes – all in relation to the story of the symptom(s).
3. The aim of the family assessment is to establish a therapeutic relationship – without which treatment is unlikely to succeed. The conversation requires a body-focused language that the family understands and is comfortable with. Questions about psychological issues and processes should be left for later, after the relationship is established.
4. Understanding the stress system and the manner in which the body responds to stress – and particularly the stressors of a particular child or family – can help the family therapist co-construct a formulation that is consistent with the family story and experience.
5. A body-based formulation provides a rational for treatment – why a combination of physical and psychological (mind-body interventions) might be helpful.

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*This paper is based on a keynote presentation at the November, 2015, AAFT Family Therapy Conference in Melbourne.
Before we start this address, I would like to clarify a few preliminary points just to make sure we are on the same page. In a recent plenary address, Alan Carr (2016) reported that two in three families improve with systemic family therapy, one in three families improve with some other type of therapy, and one in 10 families gets worse. The starting point for my story is when systemic family therapy is not working. What does a therapist do when things are not working? How does a therapist work with families when the therapist him- or herself is struggling to understand what is going on? How does one maintain one’s own equilibrium in the face of ‘not knowing’ and ‘not understanding’?

The second point is about the meaning of the term ‘systemic therapies.’ My use of the term ‘systemic’ may be different to yours. As a doctor, I have in mind the idea of living systems, which have a tendency to form multileveled structures of systems within systems (Capra, 1997), and where each system structure varies in complexity and is governed by different laws (Checkland, 1981). This definition frees me up as a clinician, as a family therapist and as a researcher. It means that if one system level – the family system level – provides me with only some, but not all, the data I need, then I am free to move to other system levels to see whether this information broadens my understanding and provides me with new options for treatment.

The third point is that I will sometimes utilise the pronoun ‘I’ and sometimes the pronoun ‘we.’ The latter refers to myself as part of our consultation–liaison team at The Children’s Hospital at Westmead Hospital because the story I tell is both my story and the story of our team. We are a small team made up of three part-time psychologists, an intern psychologist, a clinical nurse consultant, a paediatric registrar, myself, a child and adolescent psychiatrist, and sometimes a child and adolescent psychiatry fellow. The team also works closely with a number of physiotherapists who are functionally members of the team. We also work very closely with the staff on the adolescent and neurology wards and with the Hospital School.

To begin a conversation about some of these very uncomfortable questions – the management of one’s own ignorance – I am going to tell you the story of my struggle to understand somatising children and their families and to find a common language to enable us to work together towards a pathway to health. I inherited the work with somatising children when our team took over the consultation–liaison cover to the neurology ward at The Children’s Hospital at Westmead some 13 years ago. The children and adolescents I had to see were very sick and they presented with parents who were very distressed by the child’s symptoms, who wanted to find an answer, and who were highly anxious that some awful medical condition had been missed.

My first discovery was that these families did not respond well to the normal family assessment that we routinely conducted with families. The families did not respond well to an interview that focused on emotional issues, emotional processes, the quality of family relationships, family functioning, and psychological issues or symptoms in the family. As far as they were concerned their children had grown up in good loving families and they resented and were sometimes hostile to the questions asked – especially when the questions were about relationships or emotional processes. This was a problem because if the team failed to engage a family, they went off to doctor shop – and their child’s symptoms were in jeopardy of becoming chronic. Because what we were doing was not working we had to change.

My first intervention was to change the structure and process within the family assessment interview (Kozlowska, English, & Savage, 2013b). As before, I began the
interview with a family tree. Here I asked all sorts of medical questions first – taking a medical family history – making it clear the team and I were interested in medical issues. Then I also asked about emotional or mental health history, but almost as an aside. I would then begin the interview from the time period where the child was well, and track the story of the child and family via the physical symptoms, asking questions about the emotional part of the story as a side-line to the symptoms themselves. As I tracked the symptoms, I asked questions in a way that might help the family connect the symptoms to the life story of the child and family, and to the various cumulative adverse life events – loss, family conflict, illness, and so on that had happened along the way.

When the team and I used the child’s body and the child’s symptoms as a starting point – the symptoms as the beacon that started the journey we followed, and that which we ended with – the families seemed able to utilise the family interview. They were able to tell the family story with all the important components.

One very distressing piece of information we discovered as families told us their stories was about the quality of their interactions with the medical system. Many of the kids had been told that their symptoms were all in their head, that life sucks, to stop faking it, and so on. These experiences provided a huge block to engagement. The families were loath to trust anyone. Contrary to popular views, maltreatment issues in families were uncommon, but negative experiences in the medical system – which functioned to traumatised the child and family – were very common.

At the end of the family assessment we provided a formulation. This formulation was co-constructed in the sense that it emerged from the family story – it was a summary as to why the symptoms may have emerged in the context of the story. Then we outlined what we could offer the family as a team – via our mind–body inpatient rehabilitation program (Kozlowska, English, Savage, & Chudleigh, 2012; Kozlowska, English, Savage, et al., 2013c). We were very clear what we could do and what we could not do. We were very clear as to what was known and what was not known from a medical perspective. Despite the dearth of information regarding the mechanisms that underpinned the symptoms, having a treatment option helped, to some degree, settle the anxiety in the family system. Now, at this point in time, our treatment program was an inheritance of what had been done before. We admitted the child for daily physiotherapy to prevent medical complications and to maintain physical resilience, we provided daily individual therapy sessions to try to understand and address emotional processes, we had weekly family sessions to try to understand and address family processes, and the child attended the hospital school.

Now the sticking point here was the difficulty of providing formulations about a physical process that we did not understand. Why did distress trigger paralysis or non-epileptic seizures, or jerking limbs in a child? The overall idea was that stress or distress somehow unleashed these processes, but how? And the parents – even if they bought the stress hypothesis – still wanted to understand what was happening to their child.

So at this point in time it became clear to me that the answer to these questions, about somatising as such, did not lie on the family-systems level (Kozlowska, 2005). Others before me had examined the dynamics at the family system level (Seltzer, 1985a, 1985b; Taylor, 1986; Wood, 2001) – but this this not explain how these dynamics resulted in paralysed legs or non-epileptic events. What was the manner in which the body responded to the increase in interpersonal stress, unresolved issues...
from the past, and reactivity in the family system? It was also clear to me that my attempts to understand the problem as a clinician had come to a limit. I needed some alternate lens to better understand what was happening in the child’s relationships, the child’s mind, the child’s brain, and their body. How was stress and distress coming to be expressed through somatising?

To begin to find some answers to these questions, I enrolled in a PhD and structured it to look at different system levels: the attachment relationship, emotional and cognitive processes, and the child’s body and brain (Kozlowska & Williams, 2010). Although I completed my PhD in 2012, the process of analysing the studies is still ongoing.

**Exploring Attachment Issues**

The first study used an attachment methodology (Kozlowska, Scher, & Williams, 2011). I wanted to clarify whether the kids who presented with conversion symptoms had had non-problematic attachment relationships: had everything been fine as perceived by their parents – or whether there were issues within the attachment relationship that were not easily apparent but that put the child at risk of developing a somatic illness.

Here is a diagram of the Dynamic Maturational Model of Attachment (see Figure 1). In this model structured interviews are used to assess attachment with school-aged children and with adolescents (Farnfield, Hautamaki, Nørbech, & Sahar, 2010;
Kozlowska & Elliott, 2014; Landini, Kozlowska, Davies, & Chudleigh, 2012). The school-aged assessment of attachment (SAA) utilises picture cards that depict events of increasing stress ... the first card depicting the girl going out alone (see Figure 2) and the last card depicting the mother going to hospital. The child has to provide a made-up story about the child in the picture and then a real story about themselves. The Transition to Adulthood Attachment Interview (TAAI) is a modified Adult Attachment Interview, which probes the childhood relationship with parents more.
directly. The interviews are transcribed and coded using the DMM linguistic analysis method (Crittenden & Landini, 2011).

The top part of the circle – the Type A1–2 strategies, the Type B strategies and the Type C1–2 strategies – depict the normative attachment strategies. The bottom parts of the circle – the Type A3–6 strategies (also known as Type A+) and the Type C3–6 strategies (also known as Type C+) depict the at-risk attachment strategies. And here is our data depicted over the DMM (see Figure 3). In this study we had 76 children and adolescents with conversion disorder aged 6–18 and the same number of sex-aged controls. The green dots are the controls and the red dots are the kids with conversion disorders.

Assessments of attachment also identify life events that – from a linguistic point of view, because of dysfluencies – reflect lack of resolution (Crittenden & Landini, 2011; Farnfield et al., 2010; Kozlowska & Elliott, 2014). The child may try to keep information about the endangering event out of mind (this is dismissed trauma), or alternatively, the child may be pre-occupied about the endangering events so they are recurrently brought up in the narrative (this is preoccupied trauma) (Crittenden, Kozlowska & Landini, 2010). Seventy-five percent of the children and adolescents with conversion disorder had unresolved loss and trauma vs. 12 percent of controls.

As depicted in Figure 3, the children and adolescents with conversion disorders fell into two main groups. Those on the left in the Type A+ categories (i.e., the Type A attachment strategies with higher subscripts) are good, compliant kids. Their parents have been uncomfortable with expression of negative affect – fear, anger, and desire for comfort – so these kids inhibit expressions of distress, and they do what their parents want them to do . . . they perform, they comply, and they please. By the school-

FIGURE 3
The attachment strategies used by children and adolescents with conversion disorders (red dots) and healthy controls (green dots). (Figure provided courtesy of Patricia Crittenden.)
age years this group of kids takes their parents’ perspective regarding what they should do, and they blame themselves for any problems. For a developmental description of how these attachment strategies develop, you can read Danger and Development, an article written by Patricia Crittenden (Crittenden, 1999).

So this subset of children can feel distressed on the inside, and look happy and smiley on the outside. Because this pattern of emotional functioning is now habitual, it can be very hard for the child to pick up if their body is signalling distress, to know how they are feeling, and to be aware when they are not OK on the inside. It can also be hard for their parents to tell from looking at them, how they are feeling on the inside.

Of course the Type A+ strategies are also challenging for professionals. Because the child is smiling and saying that ‘everything is fine,’ it is not uncommon for a psychological assessment to have a nil finding. They key is to look for discrepancies:

- Is the child not distressed when they should be distressed?
- Are they are not crying when they should be crying?
- Do they not report pain when pain is expected?
- Are they not seeking comfort when they should be?

If not, then something is wrong.

In Figure 3, the children and adolescents on the left in the Type C+ categories (i.e., the Type C strategies with higher subscripts) are the coercive kids. Their parents have been consistently inconsistent, so the children have learnt to use exaggerated affect, and to alternate it, for example by alternating displays of anger and disarming behaviours, to ensure that their parents attend to them. At the extreme end, these are the chronically angry kids, the whiny kids, the difficult kids. By the school-aged years they take a ‘me me me’ perspective and blame others for their problems. What was interesting in the conversion group was that coercive kids with conversion did not signal anger very much – anger was not acceptable in the family system. Instead they signalled desire for comfort or distress, or pain, or being sick. The expression of anger was indirect and hidden.

The data about attachment in our cohort made sense as to why parents of children and adolescents with conversion did not perceive any overt problems. They either had good compliant children or coercive kids, who utilised a softer coercive strategy, one that did not involve overt expression of anger. When the children and adolescents using the Type C+ strategies were being coercive, they were coercive in a passive and helpless sort of way. Their parents did not see this as problematic.

The information from the attachment study changed the way our team organised our treatment program and the overarching goals for the child’s individual therapy sessions. When we gave the Type A+ group a timetable, we could rely on the child to take responsibility and do what she needed to do. In individual therapy we learnt to focus on helping read her body, to take note of her emotions, to communicate her emotions, and to practice this with the therapist and with her mother and father. In the family work we learnt to focus on helping the child and parents to recognise potential stressors, to recognise and communicate distress, to take action to manage stress and distress, and so on.

By contrast, when we gave the Type C+ group a timetable, we could expect that the child would need very close supervision to follow the timetable. Anything that needed to be done would have to be timetabled in. When things went wrong it
would always be someone else’s fault. The individual therapy also required more limit setting, a very clear articulation of expectations, homework, and so on. We could expect passive resistance, which we needed to try to circumvent in creative ways. Rather than dwelling on body symptoms and emotions, we mapped and acknowledged these but focused on how to manage them in a better way, focusing on skills and putting the responsibility of using the skills back on the child. In family sessions, helping parents to respond to the child in clear and predictable ways, and to set clear and predictable expectations, were key interventions.

The Role of Family and Life Stressors in Conversion

Before we leave the family-system level, I just want to show you the types of stressors that families reported antecedent to the child’s conversion disorder. When I say ‘reported’ I mean that these were the stressors that were elicited via the family story in the interview technique we had developed. These stressors also include any stressors reported by the child during the intervention or any disclosures of sexual abuse made later on.

So here is a table of antecedent life events reported by families from the laboratory cohort of 57 children aged 8–18 with functional neurological symptoms (see Table 1). Although this table was originally published in *Psychosomatic Medicine* in a paper called ‘Specific biases for identifying facial expression of emotion in children and adolescents with conversion disorders’ (Kozlowska, Brown, Palmer, & Williams, 2013a), the table shown here is an updated version that includes information provided by families or abuse disclosed by patients subsequent to the publication date.

| Antecedent Life Events Reported by 57 Children and Adolescents with Conversion Disorders and Their Families (copyright Kasia Kozlowska 2016) |

<table>
<thead>
<tr>
<th>Antecedent life events (range 1–10, mean 5.3)</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family conflict</td>
<td>38</td>
<td>67%</td>
</tr>
<tr>
<td>Child physical illness</td>
<td>27</td>
<td>47%</td>
</tr>
<tr>
<td>Bullying</td>
<td>27</td>
<td>47%</td>
</tr>
<tr>
<td>Loss via separation from a loved one or a friend</td>
<td>23</td>
<td>40%</td>
</tr>
<tr>
<td>Loss via death of a loved one</td>
<td>19</td>
<td>33%</td>
</tr>
<tr>
<td>Maternal mental illness</td>
<td>19</td>
<td>33%</td>
</tr>
<tr>
<td>Paternal mental illness</td>
<td>17</td>
<td>30%</td>
</tr>
<tr>
<td>Maternal physical illness</td>
<td>15</td>
<td>26%</td>
</tr>
<tr>
<td>Moving house</td>
<td>13</td>
<td>23%</td>
</tr>
<tr>
<td>Domestic violence events</td>
<td>12</td>
<td>21%</td>
</tr>
<tr>
<td>Father physical illness</td>
<td>9</td>
<td>16%</td>
</tr>
<tr>
<td>Physical abuse</td>
<td>9</td>
<td>14%</td>
</tr>
<tr>
<td>Sexual abuse</td>
<td>6</td>
<td>12%</td>
</tr>
<tr>
<td>Neglect</td>
<td>7</td>
<td>11%</td>
</tr>
</tbody>
</table>
As the table shows, maltreatment and sexual abuse were not very common. But an accumulation of life events – life event after life event was common. The typical story was that ‘X’ had happened, and the child had coped with that. Then ‘Y’ had happened and the child coped with that. Then ‘Z’ happened and the child became sick. Please notice that antecedent physical illness (including injuries of various sorts) was common – almost half the children in our study had an antecedent illness as a life event. High levels of physical injury have also been reported in adult cohorts (Stone et al., 2009).

So what this data tell us is that there are a lot of different types of stressors. For some children emotional or relational stressors will have activated conversion symptoms and for others it will be an illness; for other children it will be a combination of both. So you need to remember that for the body, illness is a stressor and will activate the body stress response just like an emotional stressor (Kozlowska, 2013a, 2013b). And activation of the stress response – arousal and emotion-processing areas in the brain – seems to be important in conversion disorder (Aybek et al., 2015; Bakvis, et al., 2009a, 2009b; Kozlowska, et al., 2013a, 2015a, 2015b; Perez et al., 2015; Voon et al., 2010a, 2011).

What makes a stressor important is how it is interpreted by the individual. It has been found in the adult literature that patients with conversion disorders perceive adverse life events as more stressful than controls (Roelofs et al., 2005; Uliaszek, Pressky, & Baslet, 2012).

Gianaros and Wager (2015) illustrate the areas in the frontal lobe that are involved in the appraisal of psychological stressors and the areas in the frontal lobe that activate the body’s arousal machinery: heart rate, blood pressure, baroreflex, and so on (Gianaros & Wager, 2015). So if you appraise the threat to be mild, you will have a mild brain-body response; if you appraise the threat to be significant, you will have a more intense brain-body response.

It is important to recognise the breadth of potential stressors: otherwise therapists may find themselves chasing ghosts. For example, a therapist who has heard of Freud’s early work during his or her training and who associates conversion disorder with sexual abuse (Masson, 1985) may look for abuse when none is to be found. So when the family tell the story, and there is no abuse, the therapist might keep probing for abuse, or might perceive the family as being uncooperative or of providing an incomplete story. This is unlikely to facilitate the engagement process or to lead to a helpful formulation.

That said, it is important to acknowledge, that in line with Freud’s original findings – before he dismissed the idea of sexual abuse and began to explain somatic symptoms as the result of intrapsychic conflicts vs. real life events (Masson, 1985) – a large number of adults with conversion symptoms, and in particular with non-epileptic seizure report a childhood history of sexual abuse or maltreatment in the family system (Bowman & Markand, 1999). Another interesting aside is that the word ‘conversion’ came from Freud’s later work, the conversion of anxiety (psychic conflicts) into neurological symptoms. The first 1952 edition of the DSM used the term ‘conversion reaction.’ The second 1968 edition DSM-II called the disorder ‘hysterical neurosis (conversion type).’ Subsequent editions DSM-III (1980), DSM-IV (1994), and DSM-V (2013) have used the term ‘conversion disorder.’

So we need to keep in mind that an illness/injury can also function as a stressor that activates the stress system (see Figure 4). It is not uncommon to get a family story where...
an illness has ‘turned on’ the child’s stress system and then the child had been unable to turn it off (Kozlowska, 2013b). In this context the child will present with fatigue, pain, sleep disturbance, and sometimes develop conversion symptoms as part of his or her presentation. Interestingly approximately two-thirds of our cohort reported pain alongside their conversion symptoms, and approximately half had a variety of other non-specific somatic symptoms (nausea, dizziness, breathlessness, and fatigue).

Likewise it is important to remember that female sex hormones are important (Kozlowska, 2013b). Whereas male stress hormones downregulate the stress system, female stress hormones upregulate it. This is because women need a really robust stress system to fight infection when they are pregnant – they have to protect the foetus from infection. So being female immediately puts you at greater risk of activating the stress system and of suffering from stress-related disorders, including conversion symptoms. It is not unusual for a stressed girl to present with conversion symptoms around the time of puberty. Post-pubertally the frequency of conversion – previously called hysteria – is greater in females than males. This is true with all other disorders that include activation of the stress-system, previously considered neurotic disorders.

One exception to this female preponderance are post-war periods where men who had been exposed to the atrocities of war present with conversion disorders in large numbers. Of course, in the case of men, military doctors did not call the disorder...
‘hysteria.’ In World War I, for example, Myers (1873–1946) – who tried to save traumatised soldiers from execution – wrote about war-induced hysteria in men using the term ‘veteran’s shell shock’ (Myers, 1915). Shell-shock was manlier, and distanced the disorder from the supposed feebleness of the female mind. It was also an attempt to have the condition accepted by the military. What it also did however was to dismiss the idea that human beings could be injured by adverse life events.

Body Arousal and the Stress System

Here is a picture depicting how different components of the stress system are interrelated (See Figure 4). When one component is activated or deregulated, all other components will also be activated or deregulated. The body’s stress system is like a fortress, designed to activate all defence systems – the HPA axis, stress hormones, the autonomic nervous system, the immune response, and brain systems mediating defensive arousal and anxiety – to maximise protection. The alarm is raised at every battle station.

Our clinical impression was children and adolescents with conversion disorders were presenting with somatic symptoms because their body stress system had been activated. But was this really so or was it a figment of our imagination? The next research question was whether their bodies also showed activation of the stress system.

Here I need to do another detour. Figure 5 is a functional diagram of the autonomic system, which controls heart rate (HR) and other visceral functions on a second-by-second basis (Kozlowska, 2013b). The system is a complex feedback loop. Afferent signals from the body to the brain provide the body with information about the state of the body. This is depicted in the figure on the left. Efferent signals from the brain to the body provide second-by-second fine tuning of body state. This is depicted in the figure on the right. The red sympathetic nerves ‘up’ body arousal, they increase HR, respiration, vascular tone, and so on. The blue parasympathetic nerve – also known as the vagal nerve – ‘downs’ body arousal, it decreases HR, and so on. The blue parasympathetic nerve is involved in states of calm and states of restoration. The purple parasympathetic nerves are the defensive component of the parasympathetic system and work alongside the red sympathetic system. The purple parasympathetic nerves activate defensive programs in the gut (nausea, vomiting, and diarrhoea), and defensive programs in the heart (sudden drops in heart rate which can sometimes result in fainting, also known as fear-induced fainting or collapsed immobility). The key researcher who has differentiated the functions of the blue and purple components of the parasympathetic nerve is Stephen Porges (Porges, 2011).

Heart measures are useful because they provide a window into the autonomic system – sympathetic and parasympathetic function – and the degree to which a person is calm versus aroused. So now we will now look at the results of our study looking at resting heart measures in our cohort of 57 children and adolescents with conversion disorders and 57 controls (Kozlowska et al., 2015b). After being wired up, the child would sit quietly with eyes open in front a computer screen for a period of three minutes. After that they did a number of other tasks – some of which you will hear about.

The measure of heart rate variability (HRV) – showing the beat-to-beat changes in heart rate – is an approximation of blue parasympathetic activity – the degree to which the relaxation response is activated. Greater HRV reflects a greater degree of calmness. The measure of HR is an approximation of both blue parasympathetic
activity – the degree to which there is a withdrawal of blue parasympathetic activity – and activation of red sympathetic activity. Our results are presented in Figure 6. The HRV is significantly lower in the conversion group and the HR is significantly higher. The children’s bodies are signalling a state of increased arousal. HRV is represented in two different ways in the diagram (the time domain of HRV and the frequency domain of HRV respectively).

What is really interesting here is the difference in HR and HRV between the Type A+ and Type C+ attachment groups (see Figure 7). This figure shows that healthy controls show the best degree of regulation (lowest HR and highest HRV), followed by the good compliant Type A+ group and the coercive, Type C+ group (highest HR and lowest HRV).

This data are very helpful because they helped our clinical team understand that our difficulties in engaging the children and families from the Type C+ group was not just a function of the parents being inconsistent and the patients being coercive; it was also related to these children’s very compromised regulation. Physiologically this group of children was so compromised that they found body interventions designed to help regulation more difficult.
Arousal and emotions

Now let us look at the issue of arousal from a different perspective; a study looking at emotional recognition and reaction time – how quickly kids recognise an emotion from a face – in a study of emotion faces (Kozlowska et al., 2013a). In this study the participants were presented with pictures of people’s faces depicting a basic emotion: fear, happy, sad, angry, disgust, and neutral and they were asked to press the button, identifying the correct expression as fast as possible. Both the percentage of correct identifications and the reaction time were measured.

Our results showed no differences between the conversion and control groups with regard to identification of emotions – both groups performed just as well. However, the conversion group were much faster in identifying all emotions, suggesting increased vigilance and motor readiness to emotional signals (see Figure 8). So once again, here the body is telling us that these children and adolescents have an activated stress system that is processing and responding to emotional stimuli much faster than that of controls. There were no differences in results between the Type A+ and the Type C+ groups on either measure.

Arousal and cognition

When people are emotionally aroused, there is disruption and a narrowing of cognitive activities, and prefrontal cortex (PFC) functions can be compromised. So we also assessed PFC function in our conversion sample using a standardised cognitive test.
battery (Kozlowska et al., 2015b). The kids with conversion performed worse on all tests which involved the prefrontal cortex. For example, in the executive function domain, the children and adolescents with conversion disorder had an increased number of errors, increased number of false alarms – hitting the button when you should not – and slower reaction times. So the children with conversion disorders were faster on the emotion processing task and slower on the cognitive tasks, which were dependent on PFC function. Their brain resources were funnelled into emotion processing – ‘I am protecting myself mode’ – thereby decreasing the resources available for reflective functioning.

**Interventions Program**

The data from these studies had further implications for our clinical work and in particular our mind–body inpatient rehabilitation program. What was really clear was that if we wanted our talking therapies and any cognitive interventions to have an effect, we needed to attend to the body first – we needed to help our patients settle their body. The body comes to therapy.
Body maps

Below (see Figure 9) is a representation of a body map. We routinely use body maps with the child as a means of identifying what the body is saying about arousal and weaving this into the therapy (Kozlowska & Khan, 2011).

Slow breathing

Because our patients are not in a calm state – they are in a state of arousal – we teach them a slow-breathing exercise to help them shift body state. The breath training is a key part of their treatment program. When you slow your breathing to as slow as you can – for most children and adolescents this is 5–10 breaths per minute – you upregulate the blue parasympathetic system (Kozlowska, 2013b). The breath rate which gives you the best HRV is also called the resonant frequency (Gevirtz, 2000). This means that the body, at this breath rate, is in a better state of resonance, physiological integration, and maximal calmness (Gevirtz, 2000; McCraty & Childre, 2010; McCraty & Shaffer, 2015; McCraty & Zayas, 2014).

There are also other interventions that can be used to decrease the red sympathetic system and to increase the blue parasympathetic system. We also integrate these into
the program. I am listing them here, so you can get a sense of how research drives changes in clinical practice (for a review of these interventions see Ogden & Fischer, 2015 and Kozlowska et al., 2015c).

- Breathing interventions
- Grounding interventions (somatic interventions that help the individual stay present and calm, with a particular focus on directing somatic energy toward the ground and bringing awareness to legs and feet in order to increase the sense of felt support)(Ogden & Fisher, 2015)
- Somatic resources for centering yourself (Ogden & Fisher, 2015)
- Somatic tracking or sensorimotor sequencing (Levine, 1997, 2010; Ogden & Fisher, 2015)
- Acupuncture
- Movement and voluntary regular exercise
- Mindfulness exercises
- Trauma processing interventions – like tapping (Radical Exposure Tapping, RET) (Greenwald, 2013; MacKinnon, 2014) – to address specific areas of unresolved loss, unresolved trauma, or emotional trigger points

This is not to say that we don’t continue to do talking therapy both in terms of individual therapy and family work, we do, but we attend to the body first.

**Sleep–Wake cycle**

So you, the reader, might now be asking why it is so important to decrease body arousal. First, as we mentioned before, because the sleep-wake cycle is intimately connected to the stress system, and because good sleep is associated with blue parasympathetic activity, which mediates states of calm and restoration, maximising sleep and parasympathetic activity is important for healing and to prepare the stage for other work (Kozlowska, 2013b). Second, because the prefrontal cortex does not function at its best in states of high arousal - it gets switched off or is overridden by emotion processing, which happens lower down in the brain - decreasing arousal puts the prefrontal cortex back on line (Kozlowska et al., 2015b). The prefrontal cortex is needed for reflection and for good outcomes in talking therapies. And then there is a third reason, still hypothetical, which I will briefly cover now.

**Emotion processing and brain connectivity**

One of the research findings from the adult literature, from brain imaging studies with patients with conversion disorders, is that the strength of connection between different parts of the brain is altered during conversion (Aybek et al., 2015; Voon et al., 2010a, 2010b, 2011; Vuilleumier, 2014; Vuilleumier & Cojan, 2011). In normal circumstances, in a healthy individual, different components of the motor system – the supplementary motor area (SMA), the motor cortex, and the basal ganglia – are all high connected. That is, they have a high connectivity because they relate to each other all the time.

When conversion symptoms occur, this pattern of connectivity or relationship between parts is disrupted. Emotion processing areas of the brain – the insula, medial prefrontal cortex, the precuneus, and the temporo-parietal junction (TPJ) – disrupt or hijack normal motor connections. These motor areas show decreased connectivity
between themselves and increased connectivity with emotion-processing regions. This hijacking of the motor system appears to be responsible for the disruption of motor function seen in conversion and it can result in a broad variety of functional neurological symptoms.

Thus, a systemic view of the brain is not so different to the systemic view of the family. In the same way as changes in relationships between family members change the family system, changes in relationships between brain regions change the brain system, and result in functional neurological symptoms.

And of course increased arousal involves emotion-processing areas in the brain. It is highly likely then that high states of arousal may be a precondition for generating conversion symptoms – for tipping the system into a different state of connectivity that undercuts normal functioning. Just in the same way as stress can tip a family into a state of crisis, so, theoretically, shifting arousal back to normal levels, using physiotherapy to address motor dysfunction, and using other psychological interventions to address emotional factors both within the individual and in the family, may all add up to help shift the brain system back to its typical patterns of connectivity.

If we think systemically, the treatment of conversion disorders involves the use of arousal-related, motor-related, and emotion-related interventions to break aberrant patterns of functional activation and connectivity and to help them shift back to healthy patterns of functional activation and connectivity. All these components make up our mind–body program.

**Integrating the Data for Children and Adolescents with Conversion Symptoms**

As a way of pulling the data together, I will present a story about children and adolescents with conversion symptoms. The story tries to weave in the different system levels that make up the conversion story. Understanding it enables us as therapists to make sense of the child’s and family’s story, and to provide them with a formulation that resonates with their experience. When this happens the family’s anxiety will be contained and the family will find it much easier to engage in the treatment process.

Here is the story in bullet points:

- We know that children and adolescents presenting with conversion have histories of relational stress and disrupted attachments.
- We know that attachment figures act as psychobiological regulators and help their offspring learn emotional regulation in the face of stress (Belsky & de Haan, 2011; Hofer, 1994; Kozlowska, 2013a). So if the child’s attachment figure was compromised and struggled to function as the child’s psychobiological regulator, then the child’s regulation skills – both physiological and emotional – will also be compromised.
- In the face of illness, pain, or emotional stress the child will evaluate the threats to the self as being very significant.
- The child will then activate all her body and brain stress systems and suffer from a broad range of non-specific somatic symptoms – the child’s body will signal stress and distress.
- Once the child activates the stress system he/she will find it difficult to turn it off.
And if the child has a susceptibility to conversion symptoms – aberrant connectivity patterns between emotion-processing and motor-processing areas – he/she will present with one of more conversion symptoms.

Outcomes

Now let us move onto outcomes. Table 2 presents our outcome data. Most of the children and adolescents do reasonably well. But even though 61% of our cohort of 57 children recovered, and did not suffer from any relapses, some of these children and adolescents took a long time to get well. Whereas most children were symptom-free in a six-month period, outliers took 36, 43, 48, 58, and 60 months to reach symptom-free status. For example, two adolescents with hemiparesis and hemi-sensory loss recovered motor function (and returned to school) in three and nine months respectively, but full (sensory) recovery occurred at 18 and 58 months respectively.

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fully recovered</td>
<td>35</td>
<td>61%</td>
</tr>
<tr>
<td>Time to recovery (median) = six months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time to recovery (mean) = 11.42 months (mean value is inflated by five outliers whose recovered times were 36, 43, 48, 58, and 60 months respectively). Two children with hemiparesis and hemi-sensory loss recovered motor function (and returned to school) in three and nine months respectively, but full (sensory) recovery occurred at 18 and 58 months respectively</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relapsing in the context of new stress but well in between (attending school or working)</td>
<td>10</td>
<td>17.5%</td>
</tr>
<tr>
<td>Relapses became shorter over time as the children/adolescents and their families got better at managing stress and at managing the episodes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic conversion symptoms (non-epileptic events)</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Conversion disorder transformed into a different chronic illness</td>
<td>9</td>
<td>16%</td>
</tr>
<tr>
<td>Chronic pain (n=2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic pain, fatigue, anxiety, and depression (n=1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic and debilitating anxiety (n=1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating disorder (n=1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Factitious presentations (n=2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Borderline personality disorder and severe family conflict (n=1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lost to follow up</td>
<td>2</td>
<td>3.5%</td>
</tr>
<tr>
<td>Discharge against medical advice following a child protection notification (n=1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family not contactable (n=1)</td>
<td></td>
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</tr>
</tbody>
</table>

TABLE 2
Clinical outcomes of the 57 children/adolescents with conversion disorders following the multimodal treatment intervention (Kozlowska, English, Savage, & Chudleigh, 2012; Kozlowska, English, Savage, et al., 2013c) (follow-up for a minimum of four years). Reproduced from Psychosomatic medicine with permission of Wolters Kluver (Kozlowska et al., 2015a)
respectively, but full (sensory) recovery occurred at 18 and 58 months respectively. There was also another group of children and adolescents – 17.5% of the group – who recovered with the team intervention, but who subsequently relapsed, one or multiple times, in the context of subsequent stress (physical or psychological).

What was interesting with these families, especially those that were well engaged with the team, was that they got better and better at identifying when the family or child was under stress, and at utilising the strategies they had learnt to manage any anxiety or conversion symptoms in a very proactive way, so that the subsequent episodes resolved over shorter periods of time.

Then there was a group where the conversion symptoms resolved but the child or adolescent went on to develop a chronic somatic (pain or fatigue) or psychological disorder (depression, anxiety) and so on. Years later, when she was an adult, one of the girls from the chronic group – one of our most challenging patients – contacted the team wanting to discuss her ongoing psychological and somatic difficulties. For me this highlighted the strength of the therapeutic alliance. The importance of the therapeutic relationship and a therapeutic conversation – and the consequences of their absence – is emphasised by neurologists and psychiatrists alike (Carson, Lehn, Ludwig, & Stone, 2015; Kanaan, Armstrong, Barnes, & Wessely, 2009a; Kanaan, Armstrong, & Wessely, 2009b; Kozlowska, 2013b; Kozlowska et al., 2013b; Stone, 2014; Stone & Carson, 2013).

And finally there is always a small group of patients who remain physically disabled by chronic conversion symptoms. This group is much larger in adults and results in a significant burden of care for adult neurologists, psychiatrists, and health services, as well as for the families of these patients.

**Thoughts for Family Therapists Working with Children and Adolescents with Conversion Disorders**

There are many recurring themes in the literature with regard to what is helpful when working with patients with conversion disorders (Kozlowska et al., 2013b; Stone, 2014). First, it is important that the patient has been seen by a paediatrician, physician, or neurologist who has excluded organic illness, provided a positive diagnosis of conversion disorder – also known as functional neurological symptom disorder (American Psychiatric Association, 2013) – explained the findings to the patient and family from the medical examination and medical tests, normalised conversion symptoms as normal and common, and provided an optimistic and clear way forward with regards to the patient’s path towards health (Carson et al., 2015; Stone, 2014). My experience is that families cannot engage unless this first step has been done properly. At times a second opinion may be necessary so the family can have this conversation with a paediatrician, physician, or neurologist who understands the issues, who understands the therapeutic elements of history taking and medical assessment, and who is comfortable with answering and explaining a lot of questions about the body’s responses to stress, illness, pain, and injury.

When the treatment plan involves referral to a mental health clinician, it is important that the paediatrician, physician, or neurologist has a clear understanding of what the mental health professional may be able to provide and is able to explain this in a
clear and practical way – that helps the patient understand why cognitive, family, and mind–body interventions may be helpful to the patient in terms of ameliorating his or her somatic symptoms.

Personally I have found the concept of the stress system and activation of the patient’s stress system as a useful framework for having these conversations (Kozlowska, 2013b; Kozlowska et al., 2008). When tracking the history of the symptoms, it usually becomes apparent that the symptoms emerged in the context of adverse life events – loss, family conflict, discord within close friendships, physical injury, pain, or illness of some sort. In addition, patients with conversion symptoms usually also experience a range of non-specific somatic symptoms – pain, fatigue, dizziness, breathlessness, muscle tension, sleep disturbance – which reflect up-regulation of the stress system. After taking a detailed history, the clinician can point out that it appears that X and Y and Z functioned to activate the patients stress system, as evidenced by their non-specific somatic symptoms, and that this activation then provided the conditions under which conversion symptoms could be triggered. Using this framework it can then make sense to patients and families why interventions that decrease stress or the body’s stress system – be it family work, emotion regulation strategies, de-arousal strategies, cognitive-behavioural interventions, regulation of disturbed sleep, regular exercise/physiotherapy – may be helpful for their health and recovery.

It must now be apparent that therapists who work with patients with conversion symptoms must be body-minded (Kozlowska, 2013b) and must feel comfortable with the broad range of psychological interventions that help with emotional regulation, interventions that help process adverse or traumatic life-events, and mind-body interventions that target the body. This requires a constant up-grading of skills as new interventions become available. Alternatively, clinicians can work collaboratively with other colleagues who may have skills that may help patients and families in the recovery to health. In addition, working with patients with conversion disorders also requires solid interdisciplinary relationships with the medical professional and physiotherapists, who are key in the process of assessment and recovery. In essence, whether the treatment occurs within an institution or is cobbled together in the community, a multidisciplinary approach – where interventions that target different identified problems concurrently – is most likely to work.

Finally, it must be said that therapeutic work with this patient group is interesting, challenging, and potentially very rewarding for children, families, and clinicians. Likewise the research advances in the field keep the work interesting and ensure that there is never a moment of dullness.

**Conclusion**

So the question is, where to next? Whose research has relevance to our children and adolescents with conversion disorders? What system level do we need to look at next? What intervention could we add that might hasten the recovery process? Is there some other way that we could act on brain connectivity to enhance the effect of the interventions we currently use.

I do not know the answer to any of these questions. What I do know is that I need to keep my mind open and remain interested in what other clinicians and researchers are doing. Sometimes the answer comes from an unexpected source – a system level that I may know nothing about. For me, inherent in my position as a
systems-oriented clinician is respect for the work of others – whose work may lie on a system level whose laws I do not fully understand. Respect needs to be coupled with flexibility, the flexibility to move between system levels, integrating different ways of healing into my work with children and their families.

References


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Commentary: Similarities and Differences between Conversion Disorder in Adults and Children

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As a psychiatrist working with conversion disorder in adults, I have always had a degree of envy of those treating children. It has seemed that all parties to paediatric cases treat them with a relative seriousness, that consequently all parties remain relatively engaged, that consequently it’s relatively possible to engineer a therapeutic change in the patient’s environment, and that outcomes are consequently relatively good. But perhaps the grass merely seems greener. Dr Kozlowska describes a situation with childhood conversion disorder that is familiar, if not identical, in many respects to that with adults. Though in adults we rarely see the whole family in consultation, they usually loom large, and rarely benignly, in the patient’s history; the disordered attachments she describes in her child patients often seem to be present in my patients in disordered adult attachments to partners or health providers; the initial resistance to a psychiatric interpretation from families she describes is in adult cases presented by the patient, with the partner sometimes even less, sometimes markedly more, open to such a view.

However, though I entirely agree that a skilful neurological assessment is vital to further engagement and prognosis, I am not sure how to interpret the moral outrage presented by families regarding their preceding neurological encounters. When I came into the field I had heard enough legends of appalling behaviour by neurologists to think this might hold the key to the whole therapeutic problem of conversion disorder: that their accusations of malingering might force patients to remain ill to validate their distress and prove the neurologist wrong, and to shun psychiatry as representing an acceptance of that neurological dismissal. Though my initial investigations certainly uncovered more legends (Kanaan, Armstrong, & Wessely, 2009), the story of current practice seemed much more nuanced. Few neurologists today openly endorse such views (Kanaan, Armstrong, & Wessely, 2011), though I think deception remains an issue for them – after all, their investigative approach hinges on ‘tricking’ patients into doing what they say they can’t, or otherwise unmasking a simulation of a neurological disorder (Kanaan, 2010).

Furthermore, when I have explored these previous distressing medical encounters with patients, I am often surprised by how similar the offending neurologist’s explanation seems to have been to my own. Of course much nuance may be lost in translation: if neurologists really do harbour significant concerns over feigning, these may be revealed in subtleties of emphasis and intonation. It may also be that the neurologist is conveying the same message in a less sensitive way: though I have never met a
neurologist I didn’t like (well, maybe one), neurologists, at least by caricature, are not selected for their empathy. But finally, it may be that the patient seeing me is just further along on their journey of acceptance, and that whoever gave that first assessment would have been met with anger: by the time I see them in outpatients, after all, they have already accepted the message to the extent that they are willing to come along and speak to a psychiatrist. I think the stage and the setting make a big difference.

I also find it interesting that the outrage comes from the family in Dr Kozlowska’s cases. This may be unimportant of course — the child’s shyness or deference to their parents, or their limited grasp of neuropsychiatric subtleties, may be all that’s needed to explain their reticence. But I wonder what is the moral responsibility accorded to a child with conversion disorder? I assume it is less than an adult patient’s, perhaps matched with their age. With adults there is a moral seriousness about their behaviour, with a child there is often rather less — at least in the non-clinical world, and in the very young. Both of my young children developed hemipareses this morning, for example: the first, because they didn’t get enough sympathy for a trivial injury; the second because the little sympathy the first got was not equally given to them.

I have no wish to trivialise the issue, or detract from the devastating impact the disorder may have, but seriousness is precisely the point: in children we are able to involve a range of explanations — play-acting, pretending, copying — that would be unconscionable in an adult, in large part because we don’t think the child’s actions are morally serious. To stretch a point, the illness deception widely recognised in non-human species such as monkeys is routinely described as malingering (Byrne & Stokes, 2003), never as conversion disorder. Why? Not because we think they better understand their own behaviour, are more insightful, surely — if anything, we think they are less — but because it doesn’t matter, morally. To that end, the family’s outrage may represent something rather different than the child’s, or indeed my patients’.

It’s interesting too, given the similarities, that I don’t see more adult patients in whom it’s possible to clearly identify an episode of childhood conversion disorder. To be clear, my patients often have a background of related conditions or symptoms that raise doubts as to their origin, but a clear-cut conversion disorder in their childhood definitely seems rarer than it should — accepting that our epidemiological knowledge of conversion disorder is too limited for me to offer any attempt at a quantification of this. If I’m right, why might this be? It could be, of course, that the treatment offered to children is more successful, as described, but also more comprehensive, addressing the roots of the disorder as well as its symptoms, so that child patients get something closer to a real cure. It could also be that the disorder in adults, though perhaps related, is importantly different — that, for example, the disordered attachment or family dynamics are simply not risk factors or causes of the same significance in adults, or that the different psychological or neurobiological development of an adult translates into a fundamentally different mechanism.

But finally, it could be that these symptoms are not inevitable consequences of a certain kind of development and environment but also depend on an event — a trigger — as Dr Kozlowska describes — and that such events, though perhaps not uncommon, only produce their effects when the conditions are right, be that in childhood or adulthood. The aetiological relevance of such events is a matter of some debate in the world of adult conversion disorder at present (Jankovic, 2014; Stone & Edwards, 2011) but I have no doubt that their significance will only be properly understood.
when, as Dr Kozlowska attempts, they are taken in their full bio psycho-social context.

References
Commentary: Explaining the Diagnosis of Functional Disorders: Trust, Transparency, and Avoiding Assumptions

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Kasia Kozlowska has outlined a useful approach to the clinical assessment and treatment of children and adolescents with functional disorders. Unusually for articles about treatment of functional disorder in this age group it does not insist on an exclusively psychological model either for understanding or explaining the symptoms.

Avoiding Assumptions

We have for over a century been used to a model in which functional neurological symptoms, in particular, have been viewed as occurring purely as a result of psychological processes – whether as part of a conversion model, ‘somatising’ or as ‘psychogenic.’ Although the biopsychosocial model has been with us for decades, it is only recently that it has finally reached these symptoms, especially those neurological symptoms like paralysis and seizures which are so entwined with the historical development of psychoanalysis.

Why has the hydraulic notion of ‘conversion’ in which symptoms arise as some kind of by-product of intrapsychic conflict, or its successor ‘somatisation’ of distress, retained intellectual appeal? This is partly because all clinicians, including myself, meet patients in whom those models appear to work. More worryingly though I think they have survived because they help clinicians simplify something which is actually much more complex. As Dr Kozlowska points out, in some children and adolescents you can’t find an obvious stressor, and even if you do, that may not necessarily be relevant to the symptoms. Consider how often you could, if you tried hard enough, formulate a spurious psychosocial explanation for your patients who have a brain tumour or epilepsy? I was forced to do this during a case control study as part of my PhD (Stone, Warlow, & Sharpe, 2010). It helped me understand how easy it is to make assumptions about stress and life events in functional and conversion disorder and how much harder it is to put them aside and adopt a model that is truly biopsychosocial.

Neuroscience in conversion disorder has produced some fascinating insights but still has a long way to catch up with our knowledge of biological factors and neural pathways in depression and anxiety, or indeed other physical symptoms such as chronic pain and fatigue which we now understand in more complex ways than purely ‘psychogenic,’ even if it is important to retain a psychological dimension to those illnesses.

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Kasia Kozlowska’s article describes several helpful perspectives to formulate family issues: attachment theory, physiology of stress/autonomic nervous system and cognitive neuroscience of emotion and motor control. Children and adolescents are perhaps more likely to have identifiable stressors than adults but still parents look for an answer to the question – yes but why is their leg weak, why do they have seizures? Answers to these questions are emerging from the fields discussed, but also from phenomenological studies (Hendrickson et al., 2014; Stone, Warlow, & Sharpe, 2012) and understanding how a predictive organ like the brain can respond to abnormally focused attention (Edwards et al., 2012).

A change of aetiological thinking is just one of several changes in the approach and management of conversion disorder that has been proposed over the last decade. The conventional model of conversion disorder started with a patient who had a symptom such as paralysis. The neurologist declared, without explanation of how they really knew, that there was no disease, and the patient was told that the problem must be psychological. The psychiatrist would then find the ‘trauma,’ or if they couldn’t find it declare ‘no psychiatric disorder,’ or that the stress must be present in some repressed form. The treatment was almost exclusively psychological without any further input from the doctor who made the diagnosis. Although some patients did well, a typical experience was one of an angry and confused patient, frustrated doctors, and seeking a second opinion.

We, and others, have proposed a different way of approaching the problem based on a standard model of consultation used for most conditions in medical practice (Stone & Carson, 2015). Importantly it relies on an understanding that functional disorders, especially in neurology, should not be diagnoses of exclusion. The diagnosis depends critically on demonstrating the presence of positive physical signs such as Hoover’s sign of limb weakness (weakness of hip extension that returns to normal with contralateral hip extension), tremor entrainment (cessation or synchronisation of a symptomatic tremor when copying movements with the contralateral hand), or clinical features of attacks (such as resistance to eye opening during a seizure). These are specific for functional disorders and in the correct context allow a positive diagnosis to be made even if there is an additional disease diagnosis. This principle is now much more explicit in DSM-5 (Functional Neurological Symptom Disorder (Conversion Disorder)) (Stone & Carson, 2015).

If a child has Tourette syndrome, the consultation would generally start with ‘you have Tourette syndrome’ rather than describing all the conditions it is not, or explaining that the scans are normal. We should do the same for functional disorders. The choice of label may not be as important as making sure that one is provided in a supportive way. A diagnosis is important to a child and their family who are trying to make sense of frightening symptoms and is a signpost to information and understanding of the problem.

The diagnostic process can usefully be discussed with patients and their families, even children. Patients can be shown their Hoover’s sign so they can understand the potential for reversibility of the symptom or a video of their attack. In an article called ‘Trick or Treat,’ Mark Edwards and I described our positive experience sharing these neurological ‘secrets’ with patients (Stone & Edwards, 2012). We described how
it was possible to explain these features in a supportive way which emphasises positive diagnosis and could merge with physical and psychological rehabilitation. We encourage all health professionals we work with, and not just neurologists, to be familiar at eliciting and sharing these important signs with our patients not only to help them have confidence in the diagnosis but also to help the patient have confidence in the clinician who is trying to help them.

Most people want to know ‘why’ they have the problem. But in fact a more familiar question to answer is ‘how.’ After all, if someone asks why they have a stroke a discussion may follow about a problem with a blood clot causing damage to the brain. That helps patients understand how the symptoms arise but doesn’t explain ‘why’ the blood clot was there in the first place. The conversation may move to a variety of possible reasons, smoking, diabetes, or hypertension but the clinician would also recognise a ‘cryptogenic’ stroke in which no cause could be identified. If the patient used to smoke heavily, treatment would not necessarily revolve around long discussions about how that behaviour had led to this situation. If they still smoked you would encourage and give them help to stop but you would only see that as part of their overall treatment – not the sole entry and exit point of treatment – and you would not label the problem a ‘smokogenic stroke.’

One way of explaining a functional movement disorder is to describe it as a problem in the software of the nervous system as opposed to the hardware. This approach to describing the mechanism of the symptom does not need to involve a denial of psychological factors or family stress, but can be a way to integrate brain and mind. In our experience, an agreement on mechanism that everyone can sign up to can actually facilitate a more open discussion of risk factors later on. The ‘difficult’ patient or family may often become a lot less difficult when they feel they are believed and being taken seriously – not with the ‘tea and sympathy’ statement of ‘I understand that this weakness/pain is real for you’ – but with ‘This weakness/pain is real, and here’s something about how we think it is happening in your body.’

I agree with Dr Kozlowska that psychological questions can often wait until a therapeutic relationship is established. We also agree that discussions about the body should not be seen as a prelude to getting to the ‘psychological core of the problem’ – they should run right through treatment. Increasing evidence in adult patients with functional motor disorders points to the success of physical therapy when carried out by experienced therapists using cognitive behavioural principles (Jordbru, Smedstad, Klungsøy, & Martinsen, 2014; Nielsen et al., 2015a, 2015b). A multidisciplinary approach is a cliché, but also one that is often overlooked in these patients.

Transparency

We are used to providing written information or internet links for our patients. The same is now possible for functional disorders whereas previously it was invisible (e.g., www.neurosymptoms.org (I should declare my conflict of interest here in that I made this site – although it is free and has no advertising), www.fndhope.org, www.nonepilepticattacks.info). As with any disorder that people haven’t heard of information is especially important to help the patient and their family understand their condition and gain confidence that the diagnosis is correct. More is required to make suitable information for children and adolescents and their families. Patient organisations are a new development in the last few years and need to be encouraged.
Making patient information and wanting to send copies of my letters to patients has forced me to think about the issue of transparency beyond the consultation. Is it reasonable to expect our patients to trust us if we don’t share our correspondence to a third party with them? Similarly, if our patients trust us, shouldn’t they expect our statements and language in research articles and conferences to match what they hear in the clinic?

This final point is one that challenges us as professionals to think about the words we use and the structures we operate in. If we are really signed up to a biopsychosocial model then do words like ‘conversion,’ ‘somatisation,’ and ‘psychogenic’ allow enough freedom of thought or do they continue to constrain our view in a way that may hold back progress in developing both aetiology, mechanism, and treatment? (Edwards, Stone, & Lang, 2014; Fahn & Olanow, 2014). Is it any surprise that our patients have difficulty accepting a non-dualist explanation when they see a sign on one door saying ‘Neurology’ and another one saying ‘Psychiatry?’ This unnatural separation is a monolithic assumption that will not get overturned in a hurry but which we should be pushing hard at for the sake of our patients.

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