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Connecting body and mind: The first interview with somatising patients and their families

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Abstract

In this article we outline the framework our consultation-liaison team has developed for interviewing families whose children present with medically unexplained symptoms. The framework was developed over many years in the context of our work with a large number of families, who collectively taught us to be more sensitive with regard to the experience of such families in the medical system, and who reacted strongly when we moved prematurely to the use of psychological language or to questions about family relationships or emotional functioning. Throughout the interview we maintain a focus on the body: the family history of illness and, in particular, the story of the child's symptoms. We take a detailed, temporally ordered history of the symptom and ask for collateral information – family illness, family life events, events at school, family emotional responses – all in relation to the story of the symptoms. In the assessment interview and in our work in general, we focus on the body. We move very carefully and very slowly from the physical to the psychological, from talking about the body to talking about relationships and about the mind.

Keywords

medically unexplained symptoms, family assessment, conversion disorder, somatoform pain disorder, DMM

Introduction

Some ten years ago, our consultation-liaison team assumed responsibility for providing a consultation-liaison service to the neurology ward and the Pain Clinic (Kozlowska et al., 2008) at The Children's Hospital at Westmead. In this context we found ourselves working with a large number of families whose children had presented to hospital with conversion symptoms, medically unexplained pain or symptoms that had been construed as 'factitious' by the treating physician (see Text Box 1). We found this group of families to be wary of psychological services in general and difficult to engage. In addition to being upset that the medical doctors had failed to find an explanation for the children's symptoms, it was common for families to deny any psychological or relationship

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issues, to respond with distress or irritation to routine questions and to report feeling misunderstood by our team and the medical system as a whole. Against this background we began what proved to be a steep, ongoing learning curve to develop a more effective framework for assessing, engaging and treating this group of families. In recent years we have received numerous requests from clinicians and hospital teams asking us to share our clinical experience and to help them in their struggle to understand and work with similar families. This article describes our current framework for conducting initial interviews with families whose children present with medically unexplained physical symptoms. We hope that the article will help answer commonly asked questions and that the framework presented can be adapted by therapists for use in their own clinical contexts. Other aspects of our work—our conceptual framework, rehabilitation program, and approach to working with individual children, research program, as well as specific cases—are described elsewhere (Kozlowska, Rose et al. 2008; Kozlowska, Foley et al. (in press); Kozlowska et al., in press A; Kozlowska et al., in press B; Kozlowska, Scher & Williams, 2011; Kozlowska & Williams, 2009; Kozlowska & Williams, 2010; Kozlowska, 2009).

TEXT BOX 1: NOMENCLATURE

Medically unexplained symptoms is an overarching term that refers to any clinical presentation – conversion disorder, somatoform pain disorder, factitious disorder or factitious disorder by proxy – where the patient's symptoms and impairment cannot be explained by any known organic pathology.

Conversion disorder refers to a disturbance of body function characterised by neurological sensory or motor symptoms where known medical explanations do not explain, or fail to account for, the severity of the patient's impairment (APA, 2000). Conversion *symptoms* include medically unexplained motor weakness, loss of other sensory function such as touch, sight or hearing and non-epileptic seizures (also knows as pseudoseizures). Symptoms are experienced by patients as involuntary and vary in severity from mild, transitory somatic concerns to chronic functional impairment. The diagnosis of a *disorder* requires that symptoms be associated significant distress or disability (APA, 2000). Conversion disorder does not include the broader array of non-specific unexplained medical symptoms such as fatigue or nausea, although these may be seen as comorbid features. Patients who present with medically unexplained pain alone may meet criteria for the diagnosis of **somatoform pain disorder**.

Psychogenic non-epileptic seizures – also referred to as psychogenic seizures, pseudoseizures or stress seizures – are a subtype of conversion disorder. Non-epileptic seizures involve a loss of motor-control or changes in consciousness that look like epileptic seizures, but are not caused by abnormal electrical discharges. They are induced by stress or intense negative emotions.

Factitious disorder by proxy refers to clinical situations where children are put at risk of harm when parents persistently focus on, exaggerate, fabricate or induce medical symptoms for which they then seek intrusive medical treatment (Royal College of Paediatrics and Child Health, 2009).

The referral process

In our clinical setting, children and their families are referred to our team by paediatricians and subspecialists (neurologists, rheumatologists, adolescent physicians) who work at our hospital.

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Most of the children referred to our team are very ill and represent the severe end of the 'somatising' spectrum (Kozlowska, 2009; Kozlowska et al., 2008; Kozlowska, Scher & Williams, 2011; Kozlowska & Williams, 2009). They suffer from significant physical disability (weakness or paralysis in a limb, disabling pain or recurrent falls due to non-epileptic seizures) and are often unable to manage activities of daily living (eating, toilet or dressing) or to attend school. We accept the referral for family assessment once the referring team has completed an adequate medical examination, along with appropriate medical investigations, and has clarified that the child's symptoms cannot be understood by a disease process.

At the threshold, it is fundamental to exclude organic illness. Medical teams are busy and do not usually feel comfortable treating medically unexplained symptoms. Thus, once they ascertain that the patient's symptoms are unlikely to reflect a disease process, they are keen to refer to psychological services, with the consequence that medical investigations are sometimes prematurely discontinued. If medical investigations are inadequate, organic disease may well be missed,[1] leaving the child at risk from an untreated medical condition and the psychological medicine team in the position of searching for a phantom psychological cause for a condition whose origin is organic rather than functional. This will ultimately undercut the patient's and family's trust in the health care system in general, and in their treatment teams (both medical and psychological) in particular. Even if the medical team has conducted a full, exhaustive investigation to eliminate organic causes, they may not have taken the time to explain their conclusions effectively to the family. As a consequence, the family may continue to feel that the medical team has not properly investigated their child and that their concerns have been prematurely dismissed and not properly answered. For similar reasons, any failure to clarify the organic/functional distinction leaves the child and family in a state of high anxiety: Is the child suffering from some terrible illness? Will he (or she) die or be left permanently disabled?

Left with this diagnostic uncertainty, families do not – and in our opinion, cannot – make the transition to reconceptualising the child's situation in terms of a psychological formulation.[2] By the same token, this uncertainty can impel families to seek clarification of their concerns, leading to 'doctor shopping' and to an ongoing situation in which the child remains untreated and continues to suffer from somatic symptoms, with the risk of long-term physical, psychological and educational complications (Kozlowska, Foley & Crittenden, 2006; Kozlowska et al., 2007; Kozlowska et al., 2008; Kozlowska et al., in press C). More generally, families that feel worried, upset and angry – the likely upshot of continuing uncertainty about a child's illness and the medical system's capacity to help – will have difficulty engaging with psychological medicine even when they finally decide to begin such a process.[3] And since many 'psychological' interventions (including biological treatments such as antidepressants) work in part due to the effects of hope, expectation and placebo (Benedetti, 2011), the patient's or family's continuing anxiety or continuing distrust or ambivalence concerning psychological treatment can seriously reduce, or even eliminate, the likelihood that any treatment for somatoform illness will prove successful.

For the reasons outlined above, the referral to psychological medicine is much more likely to be successful if the medical team have completed their investigations properly and have carefully explained the outcome of these investigations to the family in ways that the family can understand. In some cases, in order to achieve these goals, the medical team may need to organise a second opinion so that the family have the opportunity to voice their questions and concerns to more than one person. For each referral received by our team – and before our first interview with the patient and family – we check with the referring medical team to ensure that the above processes have already taken place. In addition, we further clarify (for ourselves) the child's medical status, either by reviewing the medical notes or by initiating a discussion with the treating

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physician. We understand, however, that our resources for clarifying the medical situation exceed those that that may be available in other settings; it may not be possible to conduct the required investigations or to determine exactly what other clinicians, whether medical or psychological, have communicated to the family.

Setting up the first family session

We insist that the entire family – that is, all the people residing in the household – attend the assessment session. We take this position for several reasons. First, it is much easier for our team to reach a formulation if we are provided with sufficient information about the family: attendance of all family members ensures that diverse points of view are heard and that alliances within the family become clear. Second, the multimodal mind–body rehabilitation that we provide requires the participation of the entire family, preferably from the outset press (Kozlowska et al., in press A; Kozlowska et al., in press B). In particular, running a rehabilitation programme from within the hospital is a collaborative effort between the treating team and the family, and it cannot be run without the consent and involvement of both parents, at the minimum. Third, many of the issues that need to be addressed to reduce the stress suffered by the child, or to enhance wellness, require changes to be implemented by individual family members (e.g. having their own depression treated) or by the family as a whole (e.g. addressing grief issues, addressing conflict or modifying unhelpful caregiving behaviours). We like to be clear and upfront with all family members in explaining that implementing such changes is a key part of the multimodal mind–body treatment. Fourth, since the patient's siblings may be anxious about the patient's well-being, their attendance at the first session serves to inform them about what might be happening – which, in turn, helps to settle their concerns. Fifth, the costs, both human and financial, of inpatient beds demand that treatment interventions be designed to maximise the likelihood of a good outcome and minimise the risk of relapse. Because the family are an integral part of the treatment team and will continue to deliver the treatment when the child is discharged home, engagement with the family as a unit is fundamental.

For simple cases, where the child is functioning reasonably well and it is likely that the family will be delivering the treatment intervention from home, the assessment may be done by a single clinician. For more complex cases, where the child's physical functioning is severely impaired and a hospital admission or multidisciplinary intervention may be needed, the assessment is done by a mini-team that typically comprises a consultant psychiatrist, registrar, psychologist and nurse. This more extensive process allows the family to meet and engage with the whole team, and allows each clinician to engage with the family and be part of the process of unravelling the family story from the very beginning. Including a diverse group of medical staff from the outset also helps to prevent the family from becoming engaged or aligned with one clinician.

If, for some reason, some family members are unable to attend the initial session – and we assess that we will be unable to deliver treatment without those particular family members' consent or involvement – we inform the referring doctor that we are unable to provide the family assessment as requested. The paediatrician is then left with the job of communicating our team's expertise and requirements for treatment, and of renegotiating the family's treatment options – that is, family assessment with our team, a trial of managing the child at home, or referral to a private practitioner who is willing to work with the child alone or with only part of the family system.

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The first session

Introduction

We begin the family assessment by introducing ourselves and informing the family of what will happen in the session. After noting that one of the key goals of the assessment is to clarify whether our team can be of any help to the family, or conversely whether the family assess that we may be able to help them, we complete a family tree, explore the onset and 'story' of the child's symptoms, probe for concurrent family life events, co-construct a formulation, and discuss the family's options with regard to treatment choices.

The genogram: Maintaining a focus on medical history

We begin the assessment itself by drawing up a three-generation family tree to acquaint us with the names of the family members, the family context and the family's medical and psychiatric history. We often seek assistance from the youngest child (in terms of chronological age) because we find it more difficult to involve that child in the latter parts of the session, where the symptoms are being discussed in detail (typically with the presenting child and the parents). While drawing up the genogram, we focus first on the family's medical history – the common illnesses that run in families, such as heart disease, diabetes and asthma. Next we enquire about any history of depression, anxiety or drug and alcohol issues. Our initial emphasis on physical illness is strategic and serves to communicate to the family that we are interested in physical illness, including the physical symptoms manifest by their child, and that we will not focus exclusively on psychological issues. For many families this focus on physical illness helps decrease the anxiety they feel at the prospect of being interviewed by mental health clinicians. This focus also assists families to begin the transition from a focus on physical illness/symptoms to a focus on psychological symptoms. At this point in the interview, we rarely ask specific questions about family relationships or emotional functioning; the emphasis is on information about physical illness and the family structure. In our experience many families find it easier to explore emotional themes once they perceive that we have a good understanding of their child's problem, that we have listened carefully to their concerns, and that any unanswered medical concerns have been clarified. A premature focus on emotional issues – before respect, trust, and safety have been established – can trigger anger or anxiety and can undercut or prevent engagement.

History of the presenting symptoms: Linking the symptoms to context

After completing the family tree, we move on to the history of the presenting symptom – for example pain, motor weakness, paralysis, sensory loss, or non-epileptic seizures – and probe also for other non-specific somatic symptoms such as tingling, dizziness, fatigue, racing heart, abdominal queasiness and yawning (Kozlowska et al., 2007). Many non-specific somatic symptoms are markers of anxiety and depression, and concurrently provide information about the child's mental state without our having asked any mental-state questions directly.

Our key aim in this part of the interview is to obtain a detailed family story. We want to:

1. clarify what was happening in the family prior to the onset of the child's illness;
2. obtain a detailed, temporally ordered history of the medical symptoms, the family's attempts to obtain medical help, the explanations offered by health professionals and the quality of interactions between the family and the medical system;

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3. identify any concomitant life events that took place at any point in this history;
4. explore any connections between the symptom's onset, frequency, or intensity and family life events, which may include: physical or emotional illness suffered by the child, parents or grandparents; loss or traumatic events such as death, family separation or moving home or school; family conflict; bullying or other difficulties at school; and adverse interactions with the medical system.

The above interview structure – including the use of a timeline (Deal, 2007; Hanney & Kozlowska, 2002) – is informed by our clinical experience and by the recurring theme in the literature that recent life events, cumulative life events and unresolved loss or traumatic events can be important in understanding the onset or maintenance of medically unexplained symptoms (Bowman & Markand, 1999; Kozlowska et al., 2011; Seltzer, 1985). We begin this section of the interview by asking the symptomatic child when she was last completely well. Having established the timing of the onset of symptoms, we explore what was happening in the family and at school in the 12 months before the symptoms began, unless the family identifies an earlier starting point as being more appropriate. We then ask the symptomatic child to tell us about the onset of the symptoms, the history of what happened at doctors' visits, what medical investigations were done, what explanations the doctors gave for the symptoms and what was happening in the family (or at school), all in a temporally ordered sequence. If the child is unable to provide this story on her own, we ask the parents and the other siblings to fill in details as the story is being told.

During this process the family usually corroborates the 'story' and adds more detail as the 'story' unfolds. If the family appears engaged, we may ask some more direct questions about the child's mental state, the emotional impact of the illness on other members of the family, the different ways in which family members manage worry, anger and stress, and so on. If, however, the family are uncomfortable with the interview, we do not raise these more direct questions about emotional states and family relationships, leaving them for later sessions when the family have come to know us better and feel more at ease. In either case, we do not allow any of these 'psychological' questions to distract the family from the key focus: the timeline of the child's physical symptoms.

Co-constructing a formulation

The process of constructing a timeline with the family allows us – both the family and the treatment team – to co-construct a formulation. In many instances we find that the process of constructing the timeline allows the child and family to make their own connections between particular stresses and the child's somatic symptoms (see vignettes one and four) (Kozlowska, 2007b). In such cases family members experience an 'a-ha' moment and become suddenly aware of the illness pattern. By contrast, when families struggle to make these connections themselves, the team will comment on the timeline that the family has given, and will try to highlight the connections between life events and the child's symptoms more explicitly. In the latter scenario, the process of commenting on the family story allows us to offer a formulation (explanation) that builds directly on the information that the family have just provided (see vignettes two and three). We have found that the formulation is usually more acceptable to the family if it is consistent with the child's subjective experience as reported by the child, consistent with the family story as a whole as reported by the family, and framed using the family's

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own language or the shared language that has emerged as part of the conversation between the team and the family.

When the presenting history is very complex, we may need more than one session to complete the timeline. Alternatively, we may find that the information gained at the first interview (and used to construct the timeline) does not provide us or the family with a clear understanding of the problem. In such cases we may try to collect additional data, either by scheduling an individual session with the child or adolescent or by ringing the school, family doctor or other health professionals involved in the child's care (Kozlowska et al., in press C). In yet other cases, unanswered medical questions may arise during the interview, and we may either suggest a joint session with the referring paediatrician to clarify these questions or organise a case conference so that the unresolved issues can be discussed with other professionals (Kozlowska et al in press C). Finally, the medical or nursing members of our team may sometimes decide that that the existing medical understanding of the child is incomplete or unsatisfactory, in which case we may seek further clarification from the referring physician or request that further medical investigations be undertaken. For example, in one case of a 13-year-old child presenting with abdominal pain, our history elicited no family life events or issues, and the history of the pain appeared concordant with a biliary problem. We declined to see the family again until the medical team had conducted an endoscopic retrograde cholangiopancreatography (ERCP).[4]

Explaining the treatment

After co-constructing a formulation, we complete the first session by outlining what the multimodal mind–body rehabilitation programme involves (Hechler et al., 2011; Kozlowska et al., 2008; Kozlowska et al., in press A; Flor & Turk, 2011). In our particular context, rehabilitation typically involves an outpatient or inpatient treatment programme that includes physical, medical, psychological and educational/social modules. These modules may be run by our team in collaboration with the family or may be coordinated by a local case manager and the family using services in the family's local area (Calvert & Jureidini, 2003; Hechler et al., 2011; Kozlowska et al., 2008; Kozlowska et al., in press C). Key components of the multimodal programme – whether outpatient or inpatient (Kozlowska et al., in press A; Kozlowska et al., in press B) – involve:

The physical therapy module

- Physical rehabilitation – physiotherapy or occupational therapy – to address physical impairment, to prevent physical complications related to immobility and to maximise the child's general physical functioning and well-being.
- A daily self-care programme that aims to help the child move away from the sick role, helps increase the child's physical independence and functions to minimise the development of unhelpful caregiving behaviours from family members. If the child is in hospital, nursing staff take on the role of helping the child complete her own self-care (insofar as possible). If at home, family members are coached not to perform tasks that the child can do herself.

The medical module

- Pharmacotherapy for pain or for comorbid anxiety and depression.
- Organising for individual family members, especially parents, to have their own conditions adequately treated.

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The psychological module

- Individual work with the child, both to enhance her capacity to articulate emotional states and to teach her mind–body strategies for managing the pain or other symptoms (Hechler et al., 2011; Kozlowska & Khan, 2011; Kuyk, Siffels, Bakvis & Swinkels, 2008, Flor & Turk, 2011).
- Family work that coaches the family, enabling them to support the child in implementing the programme, and that addresses any health issues, relationship issues and illness-reinforcing behaviours that may be contributing to or perpetuating the child's symptoms.

The educational/social module

- Attendance at school and, if relevant, a school intervention to address educational issues or bullying.

Our team offers treatment to families who agree to participate in all components of our intervention. For families who have come from a distance to secure our services, these expectations are modified for workability, including the parents' need to take care of other children back at home (Kozlowska et al., in press C).

After we have outlined the multimodal rehabilitation programme, the family typically ask about the child's prognosis. In view of the good outcomes in childhood conversion disorders and somatoform pain disorder, we are often able to reassure the family that in paediatric practice most children recover[5] (Hechler et al., 2011; Kozlowska, 2008; Kozlowska et al., in press B; Pehlivanturk & Unal, 2002). We emphasise to the family that the treatment programme is designed to facilitate a good outcome and that their commitment to the programme is essential if their child is to recover. We also inform the family that in our experience the time taken for the child to get well is usually as long as he or she has been sick and that symptoms of pain, fatigue, and nausea are always the last to disappear – which is often long after the child has recovered full functioning. We suggest to the family that, before coming to a decision, they may want to discuss the session and our recommendations privately, and that they also might want to discuss the treatment options with their referring physician. We ask them to contact us to inform us of the choice that they have made. Concomitantly, we ring their physician and provide a summary or our findings and recommendations. Depending upon where the family are located and also upon the child's degree of impairment, the actual treatment programme may be undertaken at our hospital or be implemented using local services. In the latter case, we provide both a referral letter and a detailed treatment plan to help guide local caregivers.

In the section below, we provide detailed examples of assessment interviews with four different families. For readers who are interested in treatment, we have published a number of case studies that address treatment more directly (Kozlowska, 2007b, 2010; Kozlowska et al., 2006; Kozlowska et al., 2008; Kozlowska et al., in press C; Kozlowska et al., in press A; Kozlowska et al., in press B). We should mention that we have seen many children with medically unexplained symptoms and have had many opportunities to practice the skills described in this article. What we can now accomplish in one session may have taken us two or even three sessions when we were less familiar with this type of work. Finally, although we have very high rates of success – we expect to engage most families – we still experience failures. Some families may walk angrily out of our interviews because they resent the suggestion that psychological issues may play a role in their child's illness. In some families the underlying issues may remain hidden: chronic misattunement between the child and the caregivers, abuse or neglect within the family system, undeclared marital

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problems or unresolved parental loss or trauma that affects current parental behaviour. In these cases it may take us weeks, months, or sometimes even years to begin to understand the nature of the child's predicament. In a handful of cases, understanding has eluded us altogether.

Vignette one: Susan

Susan,[6] a 15-year-old girl, presented with recurring left foot pain, recurring whole body pain, headaches, sensory loss in both legs, gastric discomfort, and a sensation of having a 'floating body'. Susan lived in a country town with her parents, Mr. and Mrs. Stephens (47 and 45 years old, respectively) and her brother Christopher (10 years old). Mr. Stephens was a full-time salesman, and Mrs. Stephens worked as a secretary. Susan had stopped attending her local school some three months before and was being home schooled. After finishing her schooling, Susan planned to study hotel management.

Completing the genogram

The process of drawing up the genogram (see Figure 1) revealed that Mr. Stephens's parents were divorced and that both suffered from heart complaints. Mr. Stephens himself had a complicated medical history, which included: (a) a malignant tumour requiring surgery seven years ago (the family reported that Mr. Stephens had a good prognosis); (b) an autoimmune disease and an associated

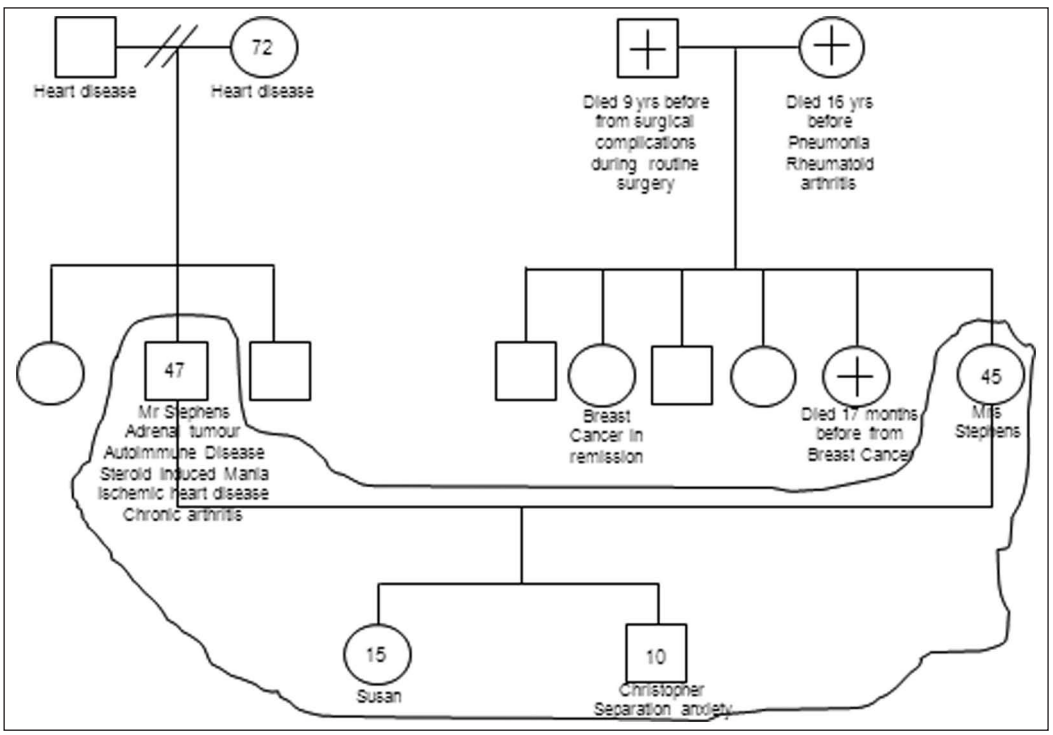

Figure 1. Susan's family genogram.

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period of steroid-precipitated mania diagnosed four years ago, (c) ischemic heart disease also diagnosed four years ago, and (d) chronic arthritis. Mrs. Stephens's parents were both deceased. Her mother had died of pneumonia just prior to Susan's birth, and her father had died from complications following routine hernia surgery when Susan was seven years old. There was a strong history of breast cancer. Mrs. Stephens's oldest sister had been diagnosed with breast cancer seven years previously and was in remission, and another sister had died 17 months previously from breast cancer that had metastasised to the lung. Mrs. Stephens had no significant medical history and undertook yearly breast-screening examinations. Christopher, Susan's younger brother, had a history of separation anxiety. The process of drawing up the genogram – with little room being left on the page –demonstrated that Susan and her family had been exposed to a large number of cumulative life events.

The timeline: Linking the symptoms to context

The onset of symptoms at eight years of age. Susan reported that the last time that she felt well had been seven years before, when she had been eight years old. She recalled how prior to her illness she had attended basketball training each Thursday night and Saturday morning. One day, a month of so before her ninth birthday, she had awoken with a painful left foot, which her mother attributed to a 'twisted ankle'. In spite of her painful leg, Susan continued to compete in basketball. Over some weeks the pain became progressively worse and spread to involve the right leg and both arms. Susan then developed localised changes – a cold, blue left foot – and required crutches to mobilise. She was admitted to hospital, where she was treated with physiotherapy and various combinations of pain medications. On discharge there was significant disagreement between the medical professionals regarding Susan's diagnosis: did her symptoms reflect chronic regional pain syndrome (CRPS), or were they medically unexplained?

Clarification of the temporal order of events revealed that the onset of Susan's symptoms had occurred in the context of three important family stressors: Susan's maternal aunt had been diagnosed with breast cancer; her father had been diagnosed with cancer and had suffered from significant complications post-surgery; and due to financial stress the family had had to move from a house into an apartment. Susan had disliked the new family home and had been forced to repeat second grade in a new school, where she failed to be accepted into a peer group and became socially isolated.

As this history unfolded we expressed our dismay that the family had endured so many life events in such a short period of time. We asked all family members how they had coped emotionally with these events. When it was her turn to reply to this question, Susan revealed that her father's diagnosis and the aftermath of the operation had been 'pretty stressful', that she had dealt with it poorly, and that she was 'the biggest worry wart in the family'. She recounted how she had hidden her emotional pain and anxiety from the family, in part to prevent her mother from worrying about her. Mr. and Mrs. Stephens agreed that Susan was a sensitive child who would do her best to look after the well-being of other family members and who attempted to deal with painful feelings on her own.

We asked probing questions to clarify whether there was a link between Susan's intense anxiety about her father's well-being and her previous experience of death: that of her maternal grandfather, who had died secondary to surgical complications when she was seven years old. Susan used powerful connotative language to describe the emotional impact of the grandfather's death: for example, 'he was everything to me', and 'I hit the roof after he passed away'. She related how her mother had reassured her prior to the surgery that the grandfather would not die. In view of this misfired effort to reassure Susan, we suggested that when her father became ill, it would have been

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difficult for Susan to accept any reassurances about her father's safety. Susan confirmed that throughout her father's illness, she had worried that her father would die.

Ten to twelve years of age. Between ages 10 and 12, Susan continued to have minor episodes of pain in her foot or hands secondary to minor falls or sprains. These episodes were treated at home and in out-patient physiotherapy. During this time the family anxiety levels fluctuated in response to health issues, multiple moves and Susan being bullied at her new school.

Eleven to twelve years of age. When Susan was 11 years old, Mr. Stephens became medically unwell and suffered significant psychiatric symptoms in response to his medications. His fluctuating mental state and precarious physical condition put considerable strain on family relationships and the health of all family members. Susan's brother experienced separation anxiety, for which Mrs. Stephens sought assistance from a psychologist. Susan recounted that her fears that her father would die were rekindled, but that she had successfully hidden her distress and anger from her family until the family dog died, when this strategy failed her. It appeared that in the context of the dog's death, Susan was no longer able to inhibit physical signals of her distress, and she began to suffer from overt panic/anxiety symptoms and a major grief reaction requiring formal intervention. From our point of view, it seemed that the death of the dog allowed Susan both to express her fears – the anticipated loss of her father – and to feel her emotional pain in a more open way. Interestingly, during this decompensation, when Susan was more overtly expressive of her distress, she did not suffer from any concomitant physical symptoms. When her anxiety symptoms settled, her foot pain recurred for a period of five months.

Thirteen to fourteen years of age. When she was 13 and in the first year of high school, Susan once again experienced increased foot pain with localised changes. This relapse correlated with the illness of her other maternal aunt, who was diagnosed with metastatic breast cancer. At this point in Susan's medical history, the possible role of stress began to be considered by her treating doctors. Susan received education about CRPS and psycho-education regarding the role of stress factors in this condition, and continued with regular physiotherapy and a variety of pain medications. Unfortunately, the doctors did not ask Susan or the family what was happening in the family. Thus the role of stress remained theoretical and was not seen as connected to actual family events.

In February of the following year, when Susan was 14, her aunt died. Susan reported that her aunt's death had sent her 'a bit loopy'. She recalled how she worked hard to hide her distress from her parents and described a powerful imaged memory detailing how she had attempted to elicit comfort from one of her plastic dolls. She remembered that she cried a lot at the funeral and that, soon thereafter, she developed other somatic symptoms (stomach aches and headaches) in addition to her fluctuating foot pain.

Susan's physical condition further deteriorated around the time of her 15th birthday. She began to experience generalised whole-body pains in addition to her other symptoms. A referral to a psychiatrist was unhelpful because Susan masked her inner distress – a depressed mood and anger at having to see a psychiatrist – and gave the impression that she had everything under control. Her functioning slowly deteriorated. She developed a new array of somatic symptoms: sensory loss in her lower limbs, the sensation of having a 'floating body', chronic headaches, and gastro-oesophageal reflux discomfort. She also became wheelchair-bound. Her parents arranged for her to be home schooled, with the consequence that she lost contact with her remaining friends. It was at this point in the story that she was referred to our team for a second opinion.

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Co-constructing a formulation

At the completion of our assessment, it was unnecessary for the team to highlight that most of Susan's episodes of physical symptoms in the previous seven years had been associated (precipitated or maintained) with physical or emotional injuries or threats. The structure and process of our assessment and the questions that we had asked the family – questions that probed for concomitant stressors and life events – had enabled the family to make this link as they told their story. The family was incredulous that neither they nor their treating physicians had previously made this link.

The family wanted to know what diagnosis best described Susan's difficulties: conversion disorder or CRPS? We suggested that conversion disorder – neurological symptoms that are medically unexplained – in conjunction with an anxiety disorder and some symptoms of depression seemed appropriate. We explained that CRPS was a controversial diagnosis, with many 'experts' propounding their own perspectives. We said that in terms of our experience, which came from the treatment children with resistant CRPS, we saw it simply as a subtype of conversion disorder that could be precipitated and subsequently maintained by either physical or emotional injuries (immobility of a limb over time associated with the threatened loss of an attachment figure, bullying, the death of a family member, and so on). The family was comfortable with this explanation because it made sense of the family story.

We used an attachment lens to help Susan and her family make further sense of Susan's symptoms. We suggested to the family that Susan was prone to experiencing medically unexplained symptoms, as well as anxiety and depression, because of the self-protective strategies that she had developed to cope with emotional injuries (Crittenden, 1999, 2006). For us, the family story had highlighted that Susan was a sensitive young woman who tried to care for other family members when they were sick or distressed and who concomitantly inhibited expressions of her own distress so as not to further add to the family's anxieties.[7] We mentioned to the family that we had observed Susan's use of this caregiving strategy (Type A3, i.e. compulsive caregiving) during the interview (Crittenden, 1999; Kozlowska & Williams, 2009). We had noticed, for example, that Susan's affect (facial expression and body posture) was frequently discrepant with her internal emotional state as probed by our questioning. Thus, when telling us her story, she would smile when she ought to have been crying, or she would sit with a still body when she should have been wringing her hands or rocking in emotional pain. We suggested that this inhibition of body expression, now habitual, had functioned to hide the intensity of Susan's pain from her family, but that it came at a cost. The strategy was associated with a higher rate of medically unexplained symptoms because an individual's distress had to be expressed in some form, and if that was not done overtly in terms of emotional expression, it was done by the body in the form of physical pain or other physical symptoms. We suggested humorously that Susan was so masterful at hiding her emotional state that she had even managed to disguise the magnitude of her distress from the treating psychiatrist who had trained for many years to learn the skills to assess patients' emotional states!

Explaining the treatment

We suggested to the family that Susan required multimodal mind–body treatment that addressed the various aspects of her difficulties. We said that any one component of the treatment on its own was unlikely to work and that a combination of strategies was usually more successful. The following multimodal programme was recommended:

- continuation of Susan's physiotherapy programme to maintain mobility in her leg (thus preventing CRPS-type symptoms) and to strengthen and maintain her physical health;

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- simple analgesia for pain if it was helpful;
- treatment using a selective serotonin reuptake inhibitor (SSRI) antidepressant to treat Susan's major depression and comorbid anxiety (SSRIs often concomitantly decrease subjective pain);
- individual psychological work to enhance Susan's capacity to articulate emotional states and to teach mind–body strategies that could help her manage both her psychological and physical symptoms (Susan said she would prefer to be seen by a female therapist);
- family therapy that supported Susan in the therapy she needed and that addressed any residual issues – such as unresolved grief or adjustment to chronic illness – from the family story
- attendance at school as soon as possible so that Susan could reengage in peer relationships

Outcome

After the assessment interview, Susan followed the treatment recommendations. She continued her physical rehabilitation, started an SSRI, and went to see an individual therapist with whom she addressed issues of unresolved grief. Susan reported that from an emotional perspective, the individual therapy was extremely painful and that her physical symptoms began to resolve only after she worked through her grief. Altogether, the process of getting well took approximately two years. Half a year later (at her two-and-a-half-year follow-up), Susan was still taking her antidepressant and was physically active, following through on her plan to study hotel management and running a small business in which she sold homemade cakes.

Vignette two: Mark

Mark was a very academic 13-year-old boy who was referred to the hospital by his local paediatrician for assessment and treatment of worsening headache of eight months' duration and stabbing whole-body pains. Mark was the third of four children and lived with two of his siblings and his mother in a country town. Following the workup by our pain physician, Mark was referred to our psychological medicine team. He attended the assessment with his sister and mother. We present this vignette because both Mark and his mother were irritated by the referral to psychological medicine, and because our efforts to engage with Mark and treat his pain failed.

Completing the genogram

The genogram revealed that the four children had three different fathers and that the family had moved frequently (seven moves during Mark's lifetime). Mrs. Carter, Mark's mother, was a retired dietician who had given up work nine years ago after developing a relapsing autoimmune condition. Mark had no contact with his biological father, and he called his stepfather, Mr. Carter, 'Dad'. Mark's mother and stepfather had recently separated after a 10-year relationship that had begun when Mark was about three years of age. Mark had a history of recurrent tonsillitis and had undergone a tonsillectomy twelve months prior to presentation to psychological medicine. His two older sisters suffered from depression, and both had made suicide attempts via overdose. His younger brother, Andrew, had been diagnosed with a behavioural disorder. The genogram suggested that Mark's history of presenting illness was punctuated by many adverse life events and stressors.

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The timeline: Linking the symptoms to context

When we asked what had been occurring in the family in the 12 months prior to the onset of illness (eight months prior to presentation), the family was unsure where to begin. We suggested that they give us a summary of the preceding years since it appeared that the family history was complicated. The following story emerged.

There was a long history of verbal and physical abuse by Mark's stepfather toward the children and, to a lesser extent, toward Mrs. Carter. Mark and his mother said that until Mark was 11 years of age (sixth grade at school), Mr. Carter had focused his anger on the older children. During that year, as the older children began to leave home, Mark had become the focus of the stepfather's anger and denigration. Mark had also taken on some of the role of caring for Mrs. Carter and protecting her from Mr. Carter's anger. In the context of this chronic abuse, Mark's older siblings had developed a variety of mental health concerns. The eldest sister had tried to commit suicide by overdose when Mark was nine years old (fourth grade). His 16-year-old sister had twice attempted suicide by overdose when Mark was 12 years old (seventh grade). In that same year Mark's health had begun to deteriorate. He suffered from various infections and finally had a tonsillectomy. Also in that same year, Mark was vaccinated with typhoid and yellow fever vaccines because the family intended to visit relatives in South America, although the visit was later aborted. Mark and his mother were convinced that the vaccinations caused his illness. A local herbalist reinforced this 'vaccine hypothesis'.

Early in the following year (when aged 13, in eighth grade), Mark was shamed by his teacher in front of peers. From this time on, Mark experienced recurring conflict with teachers and began to suffer from a variety of stress-related symptoms: insomnia, followed by headaches, stabbing pains over the body, nausea, fatigue, dizziness, pins and needles, light-headedness, unsteadiness on his feet and daily episodes of loss of consciousness. He was investigated by multiple local paediatricians and emergency department physicians, with no one being able to find a medical explanation for his symptoms. Mark reported that various diagnoses had been suggested, including rebound headache due to analgesic withdrawal, chronic migraine, tonsillitis and factitious symptoms. Though lacking a clear diagnosis, Mark was not well enough to go to school and missed approximately half of the academic year. Mark expressed anger at the apparent incompetence of doctors and their inability to find what was wrong with him. He was convinced that the vaccines were the cause of his illness.

In the middle of the eighth grade school year, while Mark was ill, Mrs. Carter finally asked Mr. Carter to leave the family home. Although the separation put an end to Mr. Carter's denigration of the children and Mrs. Carter, it also had some unpleasant consequences. Mr. Carter put significant pressure on the family to take him back into the family fold, and at times this insistence verged on stalking. Another consequence was that in Mr. Carter's absence, Mrs. Carter was unable to manage Mark's nine-year-old brother. This inability led to a variety of dangerous incidents, such as the brother throwing rocks at Mark when he was angry.

Co-constructing a formulation

Mark summarily dismissed the suggestion that any of the events at home or at school had had any significant impact on him. We tried to explore what Mark and his family knew about the impact of chronic stress on the body. We highlighted that according to the family's timeline, Mark's body had begun to show the effects of chronic stress in seventh grade, when he had suffered from a series of chronic infections – at least twelve months before the onset of his headaches in eighth grade. We hypothesised that this sudden propensity to chronic infections may have been mediated by suppression of his immune system secondary to

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chronic stress, a phenomenon that is well documented in the literature (O'Leary, 1990; Chrousos, 2009). We then emphasised the multiple cumulative life events that Mark and his family had reported, and suggested that Mark's body was manifesting a range of commonly seen stress-related symptoms.

Outcome: Unsuccessful engagement

Although Mark's mother was willing to consider the links between stress and Mark's symptoms, Mark remained unconvinced. Likewise, our team psychologist was unable to engage Mark in co-constructing a formulation in subsequent individual sessions. Thus, although we were clear that Mark's pain was unlikely to remit unless the family was able to make the home environment more safe, and unless Mark was able to recognise the links between his recurring symptoms and his distress – whether past, present, or remembered – Mark declined the psychological formulation, and no coordinated treatment was ever implemented. Some years later we heard that the family were still looking for answers and had presented to yet another hospital in a different city.

Vignette three: Hannah

Hannah was a 12-year-old girl who presented to the emergency department with unusual motor movements. She had developed tic-like movements of her head and left shoulder and arm – which occasionally involved the entire body. She had also, on a number of recent occasions, become so angry that she smashed household objects (and reported, during her subsequent assessment, that she was unable to control herself during these episodes). Hannah was admitted to hospital and underwent a series of investigations. Neurological assessment suggested that her shoulder–arm movements were best conceptualised as stress-related movements (conversion disorder presenting in a tic-like way). The episodes of breaking objects could not be explained in terms of any neurological syndrome. Her past history included recurrent asthma and episodic obsessive-compulsive disorder.

Completing the genogram

All current members of the household were invited to the assessment session, which occurred two weeks after the initial presentation. The session included Hannah; her mother, Mrs. Andrews; her stepfather, Mr. Andrews; and her biological sister. Hannah's biological father and grandmother were subsequently invited to a separate interview. Mrs. Andrews was a teacher, Mr. Andrews was an accountant and Hannah's biological father worked as a salesman.

The timeline: Linking the symptoms to context

Hannah reported that her symptoms had begun a week earlier. When the interviewing team enquired about what life events may have happened in the family or at Hannah's school in the previous year or so, the family provided the following story.

Hannah was described by her family as a compliant girl who was always writing stories and plays. Two years earlier she had been offered a place at a performing arts school for unusually talented children. Hannah told us the new school had not gone well: the teachers had been very critical and would shout at the class rather than addressing difficulties with individual pupils. Unable to manage this situation – the perception that she was being blamed and criticised for difficulties over which she had no control – Hannah became very unhappy, suffered from anxiety symptoms, and developed a depressive illness. These symptoms had resolved after removal from the school.

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In the following year (ten months prior to presentation), Hannah's mother had suffered life-threatening injuries in an automobile accident. This initial event was followed by numerous medical complications and hospital admissions. During the interview Hannah and her sister acknowledged that they had experienced pervasive anxiety about their mother's health, with ongoing fears that she could die. The children's anxieties about illness and death were exacerbated by the subsequent death of a friend's mother, by their stepfather experiencing abdominal pains that had required medical investigations and by Hannah fracturing her leg and also having an appendectomy for an inflamed appendix.

In the wake of these distressing life events, and just prior to Hannah's presentation, her biological father, who had not seen the children for a year, contacted the family and expressed a wish to spend some time with his children. According to Hannah, this phone call had triggered intense anxiety, and she developed her movement disorder shortly afterward. The family explained that Hannah was anxious about contact with her father because she felt responsible for the maintenance of this relationship. Hannah's sister had less of an attachment with their father because she had been very young when the parents had separated and because she had made allegations (which child protection services had never been able to confirm, one way or the other) of sexual abuse by a paternal cousin. The family reported that the relationship with the biological father had always been difficult and stressful because he would regularly promise to keep in contact but then remain out of touch for months or years at a time.

Co-constructing a formulation

Hannah's family had been suspicious that her movement disorder could have been precipitated by stress, and they expected the assessment to confirm these suspicions. We noted that Hannah appeared to be a very good, compliant girl[8] who tried to please others (Crittenden, 1999, 2006) and who had coped with a series of significant stressors. Every individual has a breaking point, and when this breaking point is reached, the individual manifests either emotional or physical symptoms of distress; it seemed that Hannah had reached a breaking point on a number of occasions. Eighteen months previously, her distress had manifested in the form of anxiety and depression when she was unable to manage the punitive environment of the new classroom. More recently, the ten-month period of intense stress and worry about her mother's well-being, coupled with the most recent stressor – the renewed contact by her biological father – again pushed Hannah past her breaking point. Her body had communicated its distress by displaying uncontrolled movements and by exploding into episodes of anger.

Explaining the treatment

We suggested the following multimodal plan to Hannah's family:

- an initial step of containing Hannah's symptoms through a pharmacological intervention: the use of an atypical antipsychotic to decrease anxiety and arousal in the short term, along with the use of an SSRI to achieve the same goal in the long term;
- an individual assessment of Hannah and subsequent individual work to teach Hannah strategies for controlling her symptoms, including skills for recognising emotional distress and for expressing the distress in more adaptive ways than physical symptoms;
- organising joint therapy for Hannah and her biological father to facilitate communication, help the father understand Hannah's feelings and concerns and clarify any unresolved issues;

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- continuation of family work (the family was already seeing a therapist in the context of the mother's car accident, which had had a profound effect on all family members).

Outcome

Hannah's father did not avail himself of the opportunity to repair his relationship with Hannah and his other daughter. He broke off contact, thus repeating the pattern of approach and rejection. The family implemented all the other interventions using services in their local community. Some seven months after presentation, Hannah was free of any unwanted movements on most days, although they would recur intermittently, usually in the context of a stressor. Since she continued to struggle with outbursts of anger, the focus of the psychological intervention shifted in the short term – from exploring that anger to helping her manage it in more appropriate ways.

Vignette four: Amber

Amber, a 16-year-old girl, presented to our hospital via the accident and emergency department during an episode of painful dystonia in the right arm. She was admitted to the adolescent ward, fully investigated by a paediatric team and referred for psychological assessment once all organic aetiologies had been eliminated. Amber – wrapped in a sheet so to contain the painful writhing movements in her right arm – was brought to the assessment appointment by her parents, Mr. and Mrs. Leary, along with her ten-year-old sister Mary. Mr. Leary worked as a truck driver, and Mrs. Leary assisted in a shop owned by a friend. Amber wanted to be a doctor.

Completing the genogram

The process of drawing up the genogram revealed that Mrs. Leary had suffered idiopathic cardiomyopathy and a range of anxiety symptoms since her early twenties. Mrs. Leary's sister had a diagnosis of lupus erythematosus. Mr. Leary had chronic back pain secondary to a workplace accident, and both of his parents had had back operations for back pain. Amber's younger sister had a history of fainting at the sight of blood. Although there was no formal psychiatric history in the family, Mrs. Leary described a long history of anxiety symptoms.

The timeline: Linking the symptoms to context

Amber and the family told us that Amber had had difficulties with her right arm for approximately six years. At 11 years of age, following a fall at basketball, Amber had suffered from unremitting, fluctuating right arm pain. At times Amber's arm symptoms – pain, swelling, allodynia, changes in skin temperature and colour – met criteria for chronic regional pain syndrome, and at times chronic pain was her only complaint. Amber had been treated at two different hospitals by three different medical teams. Treatment had included pain medications (paracetamol, neurophen, gabapentin, pregabalin, and, for short periods of time, oxycodone); physical therapies (physiotherapy and acupuncture); and psychological interventions (breathing techniques and positive thinking). A month prior to presentation at our accident and emergency department, Amber had begun to suffer from episodes of uncontrollable tremor. At times the tremor progressed to a painful dystonia; at other times the arm became temporarily paralysed. Although Amber's treating team had diagnosed a conversion dystonia, no particular treatment had been recommended. Amber and her family believed that Amber's symptoms must have an organic basis, had not accepted the diagnosis and

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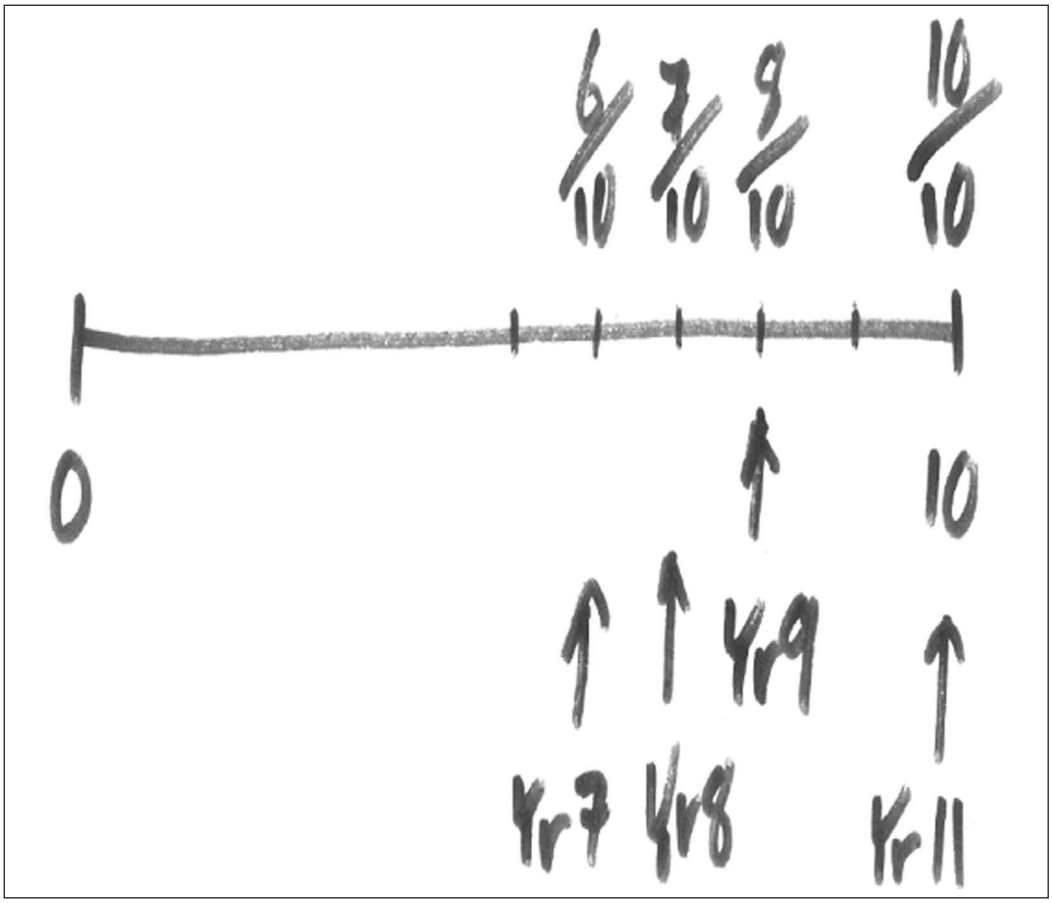

Figure 2. Likert diagram depicting increasing stress at school.

had sought multiple other opinions. Three weeks after the onset of dystonia, Amber began to suffer from recurrent falls secondary to fainting episodes or sudden shifts in consciousness (non-epileptic seizures), where she would either fall to the floor or, when sitting, slump to the side. It was at this point that the family presented Amber to our accident and emergency department.

Whilst we were taking the above history, we asked the family about any concurrent stressors at school or work or in the family system. Recurrently, Amber and her family nodded, thought and smiled but denied any stressful events, apart from a brief mention of some conflict between Amber and the teachers at school. We told the family that we were baffled as to the chronicity of the symptoms. Not knowing what questions to ask next, we felt like we had reached a dead end. We were perplexed by a story that did not make sense, since conversion symptoms do not generally emerge without some emotional trigger. Following the only lead we had, we asked Amber to rate the stress at school on a 0–10 Likert scale, where 0 denoted no stress and 10 denoted intense stress (see Figure 2). On the Likert scale, Amber's ratings were unexpectedly high. In addition to being discrepant with the way that both Amber and her family had presented the issue, the ratings suggested constantly increasing levels of distress.

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With this clarification, we re-explored the story of presenting symptoms, being especially attentive to the various incidents between Amber and her teachers along the time line. Each time we enquired about the details of an episode of conflict, Amber's symptoms – arm dystonia and non-epileptic seizures – were triggered within the session. This gave us an opportunity to see how Amber and her parents managed the symptoms and to comment aloud about how difficult memories or painful feelings seemed to function like an on–off switch for Amber's symptoms. Despite the symptoms, we continued with the interview, but only after her arm dystonia settled or after she emerged from her non-epileptic seizure (during which she slumped to her side for a minute or so).

Co-constructing a formulation

After finishing the timeline, we asked Amber's parents whether they had previously realised the very significant emotional impact that the events at school had had on Amber. They had not. We also asked them whether they now better understood the meaning of conversion disorder: how strong emotions could trigger or perpetuate physical symptoms. Though shocked by what they had witnessed during the interview, they were able to acknowledge the importance of Amber's distress in relation to her symptoms. We also explained that Amber's non-epileptic seizures were analogous to her sister's fainting at the sight of blood – also known as neurocardiogenic syncope. We told the family that a propensity to fainting and loss of consciousness was a genetic variant within the population. We told them that doctors working from an evolutionary perspective believed that neurocardiogenic syncope had been protective in tribal contexts, where women who fainted – and were therefore not a threat to the intruder – were more likely not to be killed during an attack by an enemy tribe (Bracha, 2004). The family found this explanation amusing.

Outcome

Amber's non-epileptic seizures ceased after she no longer perceived them to be dangerous or a symptom of some incurable illness. During her two-week rehabilitation admission (which included individual therapy), she learned to identify the faint feeling that occurred before her non-epileptic seizures, and to manage the situation by sitting down and practicing controlled breathing. Her sleep was stabilised with a small dose of quetiapine, which was ceased some two months later when her SSRI dose – used in the treatment of anxiety, medically unexplained pain and non-epileptic seizures – was expected to begin having a therapeutic effect. During her therapy Amber identified a number of additional triggers for her symptoms (for example, nightmares about past conflict) and learned a variety of cognitive and body–mind techniques to manage the difficult feelings and memories. Although we had suggested that a change of school was likely to be the key intervention, it took many relapses, always caused by events at school, for the family to consider this suggestion more seriously. Amber finally changed schools four months after our initial interview and formulation. Her dystonia stopped immediately.

Conclusion

Families whose children present with medically unexplained symptoms often experience the medical system as stressful, difficult to negotiate and invalidating. When these families are referred to psychological services, they are often anxious about their child's illness and may not understand why psychological issues are being raised when their child presents with a physical problem. A key

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issue for mental health workers is their ability to engage the family. In this article we have presented the framework that our team has developed, over a period of ten years, for engaging families during our initial assessment interview. Throughout the interview we maintain a focus on the body: the family's history of illness and the story of the child's symptom. By co-constructing a timeline, we journey with the family and help them make links between the child's physical symptoms and the emotional events experienced by the child and family. This process allows many families to view the child's health problems as the body's response to stress or trauma, diffuses the mind–body schism and opens the door to treatment.

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Notes

1. With the event of imaging technologies, misdiagnosis has become an infrequent event (Crimlisk et al., 1998). Nevertheless, it can still occur.
2. If we put ourselves in the family's shoes, we as parents would likewise be unable to make this transition unless we were clear about the diagnosis. Of course, there are exceptions where the ambiguity remains.
3. Although somatising families are often perceived as 'difficult to engage' (Seltzer, 1985), our experience is that the family's anger and frustration are often a result of unhelpful interactions with the medical system.
4. ERCP is used primarily to diagnose and treat conditions of the bile ducts, including gallstones, inflammatory strictures (scars), leaks (from trauma and surgery) and cancer. ERCP combines the use of X-rays and an endoscope.
5. Outcome seems to depend on the level of risk associated with the presentation, along with the therapist's capacity to engage the family (Kozlowska, 2007b; Kozlowska, Foley & Crittenden, 2006; Kozlowska, Foley & Savage, in press). When engagement is not possible or the risk to the child is too high, a child-protection intervention is required.
6. All names used in this article are pseudonyms, and all identifying details have been changed. Some of the vignettes are amalgams of two or more similar cases. This manner of abstracting information has allowed the authors to condense common themes, presentations and patterns into single examples.
7. We did not assess Susan's attachment or self-protective strategy formally, but it was clear from the clinical interview that she used a compulsive caregiving (Type A3) self-protective strategy (Kozlowska, 2007a; Kozlowska & Williams, 2009).
8. The TAAI confirmed our clinical impression that Hannah used an inhibitory self-protective strategy similar to the patients in the first two vignettes (Type A3-4; i.e. compulsive caregiving and compulsive

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performance; Farnfield et al., 2010). In addition, her transcript had many markers of dismissed and preoccupied unresolved trauma in relation to her father's behaviour.

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