



17

Conclusion

Abstract In this brief conclusion we take a step back and reflect on the continuing need for health professionals and health care systems to develop a more holistic (systemic), mind-body approach to diagnosing and managing functional somatic symptoms in children and adolescents. And as we have seen, specialized multidisciplinary, multimodal programs are necessary when these symptoms are severe, causing significant impairment. We also need to recognize that our current knowledge in this field remains approximate, though the evidence base continues to grow. In the interim, especially given the diversity of functional symptoms and presentations, we need to be creative and to move beyond established silos and settled approaches to research and treatment. And because these symptoms are so common in children and adolescents, we encourage readers to take an educational and leadership role in their own professional communities.

When the final chapters of this book were being completed, the first author (KK) was engaged in an ongoing, trans-Pacific email conversation with a parent who happened to be a well-known professor at a major

US university. His 13-year-old daughter had been hurt in an outdoors accident, and she remained unwell despite the family's proximity and access to a world-renowned medical centre. After recovering from her concussion, she continued to experience a barrage of progressive trauma-related symptoms: non-epileptic seizures (NES) (see Chapter 11), vocal cord adduction (see Chapter 7), disturbed sleep (see Chapter 5), anxiety and panic attacks, and post-traumatic re-experiencing. The NES, which were occurring so frequently as to disrupt all family routines, were triggered by exercise or environmental cues reminiscent of the accident. Cognitive-behavioural therapy—the therapy with the best evidence base for NES—had not been particularly successful. At the time of the correspondence, the hospital-based clinical care involved neurology, the ear, nose, and throat team, psychiatry and clinical psychology, and the ambulance service.

Robert, the father, described the experience as being one

trapped in a void between medical specialties. Once the neurologists determined the events were NES, they didn't have anything neurological to add, either in terms of diagnosis or treatment. Our daughter's psychiatrist didn't have any expertise with NES, nor did, apparently, the psychiatrist's pediatric colleagues. And none of the specialists had ever encountered NES complicated by vocal fold closure. Fourteen months of CBT with a skilled provider had little impact, with the NES actually developing out of what were initially only panic attacks during this treatment. Clinicians in private practice—who offer alternative ways of working—have declined to see my daughter because of her NES and the fear that a seizure might occur in their offices. As far as I can tell, this void between specialities is simply a function of historical divisions of labor and discipline, with little defensible intellectual basis given how we now (since the early 90s) think about mind, brain, and body. But particularly in our country, 'mind-body' medicine is still considered alternative, and no one seems to tackle problems like my daughter's with a multidisciplinary approach. A lot of researchers are looking at brain networks (and using very cool machines), but the clinical impact, especially with children, is slight to non-existent. And though data bases such as UpToDate, DynaMed, and Clinical Evidence have some useful information and frameworks regarding adults, none of it relates to children, and in any event, the clinical usefulness is no better than thin. On my reading, it

seems that what is missing is work that is more neuroscientifically engaged, and clinically concrete. It's a huge gap that needs to be filled.

This book is about that gap, that void. This book is our attempt to share with mental health clinicians, paediatricians, and other health professionals our clinical journey and what we have learnt in helping hundreds of children (including adolescents), along with their families, who presented to our hospital settings with functional somatic symptoms. Like the clinicians in Robert's story, we began our journey in the void, with little information to guide us and with no sure idea of how to fill the gap between existing medical specialties or between mind and body. Slowly, in a journey of many years, drawing on our clinical observations and the research literature—and in particular, George Chrousos's concept of the stress system (Chrousos et al. 1988) (see Chapter 1)—we began to gain insight into the functional presentations that we encountered. Like Robert, his daughter, and family, we had to search for alternative treatment options and pathways whenever accepted therapeutic techniques fell short of what we—and the patient—needed.

Throughout this book, using the lens of contemporary neuroscience and applying a systems approach, we have considered the complex, reciprocal influences of the brain, body, and mind—as well as the role of the relational and social contexts that define each person's immediate environment—in the biology of stress and in the emergence of functional somatic symptoms. The key point emerging in this book is that brain, body, and mind are deeply integrated in the person and do not follow Cartesian dualism; for our purposes, there is no distinction between physical and psychological stress. Mind and body are inseparable, as are, in effect, the phrases *embodied mind* and *minded body*. No matter how stress is generated, when it becomes cumulative, chronic, uncontrollable, or associated with extreme distress, it can dysregulate the stress system and affect the well-being and health of the individual child.

Using this systems approach, we have presented what we refer to as the *stress-system model for functional somatic symptoms*. Under this model, functional somatic symptoms are conceptualized as emerging when

the person's stress system is activated in response to stress that exceeds the person's capacity to cope. Accordingly, from the perspective of the stress-system framework, the treatment of functional somatic symptoms involves interventions that help the child shift her stress system back to a more regulated state, one that supports health and well-being and is incompatible with functional somatic symptoms.

In many ways, writing this book is an act of courage. When our *science* colleagues read this book, they may cringe at the simplicity of our metaphors for what is very complicated science. When our *evidence-based* colleagues read the book, they may see the material as (for the present) lacking the evidence base that they require for inclusion in evidence-based reviews and publications. When our *medical* colleagues read the book, they may find the material confronting because it steps outside of and between medical specialties and because we utilize systems thinking, shifting from system level to system level, in a way that ignores the neat silos of contemporary medicine. When our *psychology* and *mental health* colleagues read the book, they may see the book as too medical, too biological, and too focused on processes that take place in the human body, with only two chapters about the mind as such. And when *philosophers* read the book, they might find it too concrete, too rooted in biology rather than the mind.

So, in the end, we just have to focus on who we are and what we do, and to communicate our work to other clinicians in the clearest way possible. We—the first and third (HH) authors—are clinicians who work on multidisciplinary teams using a systems (biopsychosocial) framework in collaboration with our medical and mental health colleagues. We treat children with functional somatic symptoms and give particular attention to the circumstances (familial, social, educational) in which the symptoms arose. When we initially meet with the children and families, we provide a careful assessment and reach a formulation that guides our choice of treatment interventions on multiple system levels: body, brain, mind, family, and school. Working systemically, we expect that our interventions will have a synergistic effect—that the overall effect of working on multiple system levels at once will be greater than the effects of the separate treatments. Likewise, we expect that the interventions will shift the child's stress system from an activated and

dysregulated state to a more regulated state not compatible with functional somatic symptoms. And we have documented our outcomes—in three research cohorts—with studies published in mainstream medical journals (see Online Supplement 2.1). From this data we know that the majority of children whom we treat return to health and well-being.

The writing of this book has been an exercise of stepping outside the box or of stepping out on a limb of a tree. Here we are comforted by Fritjof Capra's words that all knowledge is approximate (Capra 1997); the knowledge in this book is, inescapably, approximate. It describes what we know today, in full recognition that we shall know more, and with better evidence, tomorrow. We are also comforted by Desmond Sheridan's analysis of evidence-based medicine, as both best practice and restrictive dogma (Sheridan 2016). We are conscious that the evidence base in the field of functional somatic symptoms is still taking shape, though we should note that the published research of the first author, in particular, constitutes an important part of the existing evidence base. We (the first and third authors, in particular) should also note that this work, here and elsewhere, has been markedly improved by the contributions of the second author (SS), who, in a role approximating that of participant-observer, has brought his background in philosophy, psychiatry, consulting, and publications to bear on this project. He has, among other things, facilitated the process of reaching what we all see as an effective accommodation between theory and practice, and to communicate our knowledge in a way that is actually accessible to, and useful for, readers.

In the time that we have been working with children with functional somatic symptoms, the era of talking therapies, with an emphasis on psychoanalytic paradigm, has been largely displaced by a cognitive-behavioural paradigm. But that newer paradigm has been oversold as the fix-all therapy, and we have found it to be of only limited use in ameliorating the functional somatic symptoms of our child patients. Clinicians working more directly with the body—many of whom are quoted in the pages of this book—have been pioneering other ways of understanding and working with somatic symptoms, including those of our patients. More broadly in the therapy world, clinicians have come to recognize that working on the mind system level (see Chapter 15) is one therapeutic option among others and that working with the body harnesses healing

properties of the body/mind/person that might not otherwise be available (see Chapter 14). Clinicians have also recognized that, in actual clinical practice, targeted interventions from multiple system levels can be combined to address stress-system dysfunction, functional impairment, psychological distress, relational difficulties/issues, and issues within the family and school systems. Even more broadly, this shift in our understanding of the interconnections between mind and body has been moving into the mainstream, as is apparent in David Brooks's 2019 *New York Times* column entitled 'The Wisdom of Your Body' (Brooks 2019).

The need to move beyond established silos and settled approaches to research and treatment is not unique to the field of functional somatic symptoms. We note, for example, that in response to frustrating failures to develop new curative treatments in mental health, the *Harvard Review of Psychiatry* has started a new feature, 'Disruptive Innovations'. The aims are to catalyse clinical translation of cutting-edge science and expert perspectives, 'to challenge orthodoxy in thoughtful and well-reasoned ways, and [to] propose new ideas, approaches, and methods to tackle intractable problems in psychiatry' (Roffman 2019, p. 275). The need to step outside the box is also known to our medical colleagues interested in the long-term effects of early-life stress on health and well-being across the lifespan—or as some researchers put it, 'searching outside the streetlight' (Bush and Aschbacher 2020, p. 17).

A recurring theme from all these clinicians, researchers, and writers is that the pathway beyond the void—the space where healing can be found—requires one to step outside the box, out on a limb, past what's visible under the streetlight. We need to be comfortable with approximate knowledge, to avail ourselves of information from multiple system levels, and to use that information in a fluid and flexible way, all in an effort to work collaboratively and productively with our patients and their families. And because what we know now is only approximate, we need to remain forever curious about body and mind, about the way that the body regulates itself, and about how the stress system (and for our purposes, each child) responds to the challenges of daily living—the *stress of life* (see Online Supplement 1.2).

We hope that mental health clinicians, paediatricians, and other health professionals will enjoy the book and use it as a helpful resource

for their day-to-day clinical practice. We hope that, in our clinical vignettes, they will recognize the children and families that they work with in their own practices. And we hope that in describing our clinical work, we have provided sufficient detail for readers to implement our approach in their own work with the children—and their families—who come asking them for treatment of functional somatic symptoms.

Finally, we hope that readers will come to see themselves not only as having a role in treating their own patients but as having the capacity to educate their own colleagues about functional somatic symptoms. Mental health professionals, as a group, have only recently come to have the tools available—as presented here—for working productively with children with functional somatic symptoms. Readers can, themselves, play an important role in increasing professional awareness of these problems, of spreading knowledge of the available treatment interventions, and of helping to ensure that children with functional somatic symptoms are identified early and obtain effective treatment.

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