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A Brief Introduction

Abstract This chapter sets the scene for the rest of the book. Across time and across cultures, functional somatic symptoms have presented under many different guises, been given many different names, and been conceptualized in many different ways. Theories and speculation have therefore abounded, but without any firm scientific foundation. It is only very recently that scientists have come to learn enough about the body—and about the stress system, in particular—that a scientifically grounded understanding of functional somatic symptoms and their treatment is beginning to take shape. After a few brief paragraphs about such background matters, this chapter turns to the three authors themselves and how each of them came to be involved in the issues addressed in this book. The hope is that readers will see parts of themselves in these stories and also, in the process, come to consider how they each came to be involved in this intriguing and challenging field.

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Every day in hospitals, doctors' surgeries, and school sick bays around the world, children (including adolescents) present with what have come to be known as *functional somatic symptoms*. These symptoms are ones that cannot be explained by an identifiable disease process—even after an extensive medical assessment has been done. They reflect, instead, disturbances of neurophysiological regulation that cause the child to suffer physical discomfort (e.g., pain, dizziness, or nausea) or disruptions of various kinds (e.g., irregular bowel or bladder function), to experience disturbances of motor or sensory processes or capacities (e.g., paralysis, loss of vision, or seizure events), or to lose the sense of health and well-being (e.g., exhaustion, general malaise, or fatigue).

In contemporary medicine, doctors use the term *functional* to distinguish such disorders or symptoms from those that are caused by an objectively identifiable disease process (Roenneberg et al. 2019). In hospital corridors one might therefore hear doctors saying that the neurological symptoms or abdominal pain or hearing loss is functional rather than organic. What they're communicating is that standard medicines will not work; some other approach is required. The term *functional somatic symptoms* thus parallels how *functional* is used in medical contexts: to borrow from Mayou and Farmer (2002, p. 265), it assumes 'only a disturbance in bodily functioning', with no further implication regarding causation. It is important to note, too, that the word *functional* as used in this book has *no connection* to how the word is used within the fields of clinical psychology or family therapy, where the clinician may, for example, conceptualize a symptom or dynamic as having a function for the child within the family system.

In this book our use of the term *functional* moves beyond the functional/organic distinction to take into account recent advances in neuroscience. As the reader will see in the following chapters, the 'disturbance[s] in bodily function' underlying functional somatic symptoms involve disturbances in neurophysiological regulation. These disturbances (resulting in too much activation, too little activation, or aberrant patterns of activation) are the result of cumulative or, in some cases, acute stress, either physical or psychological. And these changes in neurophysiological regulation are themselves often accompanied by discernible changes in structure on a cellular or tissue level (not just function; see Chapters 4 and 8, and Online Supplements 4.2, 4.3, and 8.2).

Throughout history—and in today’s contemporary medicine—functional somatic symptoms have been given many different names and been classified, by different medical specialties, in many different ways (for more about terminology, see Online Supplement 1.1). Throughout this book we use the term *functional somatic symptoms* as an umbrella term that includes all the different types of functional symptoms that occur across all body systems and that present to doctors who work across the full range of medical specialties.

Because functional somatic symptoms occur more frequently in girls than in boys, we generally use the pronoun *she* to reflect this clinical reality.

The Goal of This Book

The goal of this book is to communicate our current understanding of functional somatic symptoms and how best to treat them. The audience includes any clinician—whether in medicine, nursing, social work, psychology, psychiatry, or other fields of health care—who works with children experiencing functional somatic symptoms. These clinicians know that until very recently, research on functional symptoms has been sparse and that the knowledge base about functional illnesses has lagged behind developments seen in the rest of medicine. These clinicians have also experienced the challenges of trying to explain functional symptoms to children and their distressed families. They have witnessed the efforts of parents struggling to understand why their previously well child has become so sick. They have seen families who have gone from doctor to doctor, in search of help and an explanation that makes sense to them—just to be told that there is nothing wrong and that the physical exam and test results are normal. In an effort to explain what’s wrong, these clinicians have found themselves with little choice but to use language derived from models of dissociation and conversion (from more than a century ago) or somatization and psychogenesis (from the early 1990s). But when patients and their families ask what these words mean, and what exactly the underlying mechanisms are, clinicians have typically been at a loss.

The good news is that advances in research methodologies have emboldened researchers to become interested in functional somatic symptoms yet again; the neuroscience of functional somatic symptoms is beginning to take shape. In this context, the present book sets forth the *stress-system model for functional somatic symptoms*. This model has been developed over the past decade through the research and clinical experience of the first author (KK). Building upon her own work and the work of other neuroscientists, the model brings together what is known about such symptoms and defines an approach to understanding and treating them in children and adolescents.

About the Authors

In this section (in the voice of the first author), we discuss how each of us came to be engaged in the problems addressed in this book. What has been apparent to all three of us is that the paths of engagement with functional somatic symptoms, like the symptoms themselves, are diverse and idiosyncratic. The many different dimensions of the problems engage clinicians in different ways. Our hope is that, in the descriptions of our three stories, readers will find that their own paths of engagement mirror and, in various ways, interweave with ours.

For interested readers, Online Supplement 1.3 contains a reference list for the work of individuals who are mentioned in this chapter.

The First Author: Kasia Kozłowska

The three co-authors of this book each came to this field through different routes. Speaking for myself as first author and as a child and adolescent psychiatrist, I had my initial encounters just over 25 years ago with patients experiencing functional somatic symptoms. It was during a six-month placement as a child psychiatry fellow at The Royal Alexandra Hospital for Children in Sydney, Australia. In 1994, Dr. Kenneth Nunn (my then supervisor) had established an inpatient treatment program for children with functional symptoms—now known as the Mind-Body

Program—in response to the presentation of children with functional paralysis of the legs. As a member of a multidisciplinary team that treated these patients—and in the role of the children’s individual therapist—I was in much the same position as health professionals are even now. How should one conceptualize such problems, which occupy what seems to be a middle ground between the mind (as in psychiatry/psychology) and the body of standard, biological medicine? And how does one treat such problems effectively? These questions demanded answers, but what they tended to generate were more and more puzzles.

During the two-year training period to become a child and adolescent psychiatrist, I also became acquainted with different psychological theories, including the work of psychoanalysts Sigmund Freud and Melanie Klein, both of whom put particular emphasis on the role that infantile fantasies—generated from unconscious internal conflicts—played in child development and the emergence of psychopathology. I saw these theories as no better than weakly founded speculation. My aversion was particularly strong regarding Freud’s construction of sexual abuse as an internal psychic conflict (rather than as involving real events in the lives of children and young women) and Klein’s emphasis on the central role of parental figures in children’s fantasy lives (rather than parents’ actual impact on their real lives). From my contact with Dr. Carolyn Quadrio—a child and adolescent psychiatrist and my supervisor in family therapy—I was well aware that sexual abuse and ongoing family conflict were not only common but could seriously compromise children’s health and well-being.

Disillusioned by psychoanalytic models, I also questioned Freud’s theory of conversion—namely, that unacceptable mental contents (usually unconscious sexual conflicts) were transformed, or converted, into somatic symptoms. This conception of functional somatic symptoms, which influenced the third and fourth editions of the US-based *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III and -IV), was the one that I was obliged to learn and to use for documenting diagnoses. But if the conversion hypothesis was correct, then what were the biological mechanisms by which it happened? The psychoanalytic models couldn’t even hint at an answer. And why focus exclusively on imagined events or internally created conflicts as generating

conversion symptoms? Real-life, external events can generate psychological responses that are just as strong as, or even stronger than, internally generated events or conflicts. If internally generated phenomena are enough to trigger conversion symptoms, why couldn't mental phenomena tied in with external events do the same?

My child psychiatry training—unlike that of the third author (HH; see below)—had an Anglo-American bias. I have no memory of having been taught anything about Pierre Janet's dissociation model, developed in France in the late nineteenth and early twentieth centuries, which better acknowledged that functional somatic symptoms and dissociative symptoms arose when patients had experienced terror or severe stress, illness, or fatigue.

My deep reservations about models of thinking that were available in the early 1990s continued during my first job as a child psychiatrist, working as team leader of the preschool program at a child psychiatry unit (Arndell Children's Unit, Royal North Shore Hospital). A key strength of the unit was its family orientation and its family admissions program; a multidisciplinary team worked with the family to help the parents manage their own emotional states, thereby enabling the family to help the distressed child to regulate more effectively. When this family-based intervention was successful, the child's behavioural, emotional, or somatic symptoms would actually just melt away. What was also evident was that most of the children referred to the program had developed emotional, behavioural, or functional somatic symptoms in the context of family conflict, loss events, mental illness in the family, or maltreatment. Many were quite distressed—even traumatized—by these experiences, and in the supportive environment that we provided in the unit, the children were able to communicate their experiences both verbally and in imaged form (Kozłowska and Hanney 2001; Hanney and Kozłowska 2002). After a thorough family assessment, it was usually clear to the treatment team that the children's experiences were real and tangible, and that their symptoms needed to be understood and treated against that background.

In this context, it was not surprising that I was drawn to the work of John Bowlby, who believed that psychoanalysis needed to open itself to scientific debate and inquiry and who contended that psychoanalysis neglected the role of loss and trauma events. Bowlby's scientific enquiry

took the form of empirical observation of what happened to young children when they were separated from their mothers and put in the care of strangers. The research findings and the ideas emanating from these findings were articulated in *Attachment and Loss*, whose three volumes were published from 1969 to 1980. In Bowlby's view, children's development and their emotional, behavioural, and somatic problems are shaped by the quality of their emotional bonds with attachment figures and by adverse life events such as separation, loss, trauma, and maltreatment.

Bowlby's work, along with that of Mary Ainsworth (who had worked in Bowlby's research unit at the Tavistock Clinic in the early 1950s and later collaborated with him as an equal colleague), set the stage for a further development of attachment theory, the Dynamic-Maturational Model of attachment and adaptation (DMM). This model was being elaborated in the 1990s and 2000s by Patricia (Pat) McKinsey Crittenden, a developmental psychologist and attachment researcher who was herself a student of Ainsworth's. In 1996, soon after finishing my child psychiatry training, I had the good fortune to attend a daylong lecture by Pat. From that time and continuing through 2015, I worked together with a wonderful group of clinicians from around the world, helping Pat to gather the clinical materials that enabled her to fill in the model's details (Crittenden 2006). Pat's 1999 monograph, *Danger and Development: The Organization of Self-Protective Strategies*, influenced me profoundly. Against this background—which included many hours spent under Pat's astute clinical eye watching children interact with attachment figures—I came to realize that the child's close relationships shape biological regulation processes (Francis and Meaney 1999) and that the chronic disruption of what are normally comfortable and nurturing attachments could disrupt those processes. Most importantly for the purposes of this book, I also came to realize that chronic or severe stress, including but not limited to the stress and danger associated with disrupted attachment relationships, contributes to the emergence of functional somatic symptoms.

Also in the mid-1990s, when I was still a young child/adolescent psychiatrist, I came across the work of Bruce Perry and Frank Putnam, two American child psychiatrists who were engaged both in clinical work with traumatized children and in neuroscience research. Their published

works engraved in my mind the idea that developmental experiences—including those with attachment figures—help shape the organization and function of the developing body and brain.

And in 1998, when I started working at The Children's Hospital at Westmead, I read *The Web of Life: A New Synthesis of Mind and Matter*, by Fritjof Capra, a physicist and a systems theorist. In contrast to family therapists, who applied systems thinking to relationships and to the family, Capra applied it to all living systems—beginning with the level of the cell. This extended way of applying systems thinking enabled me to conceptualize the problems of my patients as involving different system levels—governed by different laws and representing different levels of complexity—while being at the same time interrelated and interdependent. By using systems thinking I was able to shift my attention back and forth between system levels to identify and address different issues: the brain and body, the mind, the child's attachment relationships, the family, and the school. What this meant in practice was that I could apply all the skills that I had learnt in my training—my skills as a doctor, as a psychiatrist, as an attachment clinician, and as a psychotherapist and family therapist—without prioritizing one system level as being more important than another.

From my family therapy training I had retained an interest in the work of Milton Erickson, an American psychiatrist who specialized in medical hypnosis and family therapy. In my mind I held an image of Erickson sitting in front of a crackling fire talking with patients and bringing about positive change in their lives by his use of metaphor and suggestion (see also Chapter 15). In 2002, I enrolled in a two-year course in clinical hypnosis so that I could use hypnosis in my own work and also better understand the writings of Janet and other clinicians who had used hypnosis with patients with functional somatic symptoms.

Around that same time, I also became acquainted with the work of Antonio Damasio, a neurologist and neuroscientist whose clinical work led him to be interested in the neurobiology of consciousness, emotions, and feelings. Damasio wrote, 'Emotions play out in the theater of the body. Feelings play out in the theater of the mind. As we shall see, emotions and the host of related reactions that underlie them are part of the basic mechanisms of life regulation; feelings also contribute

to life regulation, but at a higher level’ (Damasio 2003, p. 28). For me, Damasio’s work solidified the idea that psychological, emotional, and behavioural phenomena were all embedded in a biological substrate. So, when I began to see a lot of children with functional somatic symptoms—referred by paediatricians describing the problems as *psychogenic*—my basic assumption was that the functional symptoms were embedded in a biological substrate, a substrate that we did not, as yet, understand (Kozłowska 2005).

It was from this neuroscience perspective that, in 2006, I began my PhD on functional neurological disorder (FND), with the neuroscientist Dr. Leanne Williams as my primary supervisor. The PhD research program was a series of studies that looked at various biological markers in children and adolescents presenting with FND.

As I was working on the PhD, I came across the work of Hans Selye (1907–1982), an endocrinologist who introduced the idea of the *stress response* and, with it, the word *stress*—including *le stress*, *der stress*, *lo stress*, *el stress*, and *o stress*—into our vocabulary across cultures and languages (Selye 1956). According to Selye’s broad definition, stress (or a stressor) is any event, whether physical, chemical, or psychological, that causes the body to activate an adaptive (or in some cases, maladaptive) response. The stress response includes the many different ways in which the body responds or adapts to the myriad challenges, ranging from the negligible to the catastrophic, that we encounter as part of our daily lives—what Selye called *the stress of life*. Selye highlighted that mild, brief, and controllable states of stress could be perceived as pleasant or exciting, and could function in a positive way to facilitate the individual’s emotional, physical, or cognitive health and subjective well-being. By contrast, more severe, protracted, or uncontrollable stress—exceeding a tolerable threshold and associated with distress rather than pleasure, excitement, or goal-associated determination—could have a different outcome. In particular, it could lead to a stress response that had a negative effect on the individual’s well-being and that, over time, could result in what Selye called *diseases of adaptation*. For a fuller account of Selye’s work and that of other scientists who laid the foundations for the stress-system model presented in this book, see Online Supplement 1.2.

During this same period of working on my PhD, I also came across the work of George Chrousos, an endocrinologist and neuroscientist. Together with colleagues, Chrousos had introduced the idea of the *stress system* as a systemic framework for looking at the diverse, interrelated biological systems that underpin stress-related illnesses (Chrousos et al. 1988). According to Chrousos, the stress system comprises a set of overlapping and interrelated hormonal, neural (autonomic nervous system), immune-inflammatory, and brain systems involved in mediating the brain-body stress response and underpinning the body's ability to regulate itself in response to the stress of life. Chrousos defined stress as 'a state of disharmony, or threatened homeostasis' and introduced the term *stress-system disorders* (for Selye's *diseases of adaptation*), which he conceptualized as arising from hyper- or hypo-activation of the stress system (Chrousos and Gold 1992, p. 1245).

I realized that Chrousos's overarching stress-system framework provided a systemic way of thinking about a broad range of functional somatic symptoms. This realization was confirmed by the data that emerged from the studies that made up my PhD: the children with FND showed activation of all components of their stress systems. My clinical team and I incorporated this way of thinking into our daily clinical practice; some examples of our clinical work were published in the *Harvard Review of Psychiatry* as 'Stress, Distress, and Bodytalk: Co-constructing Formulations with Patients Who Present with Somatic Symptoms' (Kozłowska 2013). Building upon my PhD research, these clinical results, and the work of other neuroscientists, I presented a more fully elaborated *stress-symptom model for functional neurological symptoms* in a 2017 contribution to the *Journal of the Neurological Sciences* (Kozłowska 2017).

Since that time, other prominent clinicians and scientists have influenced my work and thinking. Of special note on the clinical side are Peter Levine, Kathy Kain, Pat Ogden, and Richard Gevirtz, who have developed bottom-up interventions for working with patients in psychotherapy. In this context, and in order to hone my own clinical skills in bottom-up somatic interventions, I completed Levine's three-year Somatic Experiencing psychotherapy training and Kain's 16-day Touch Skills for Therapists course (training in somatic awareness and tactile skills for trauma resolution). Of special note on the research side are Bruce

McEwen, who looked at the biological cost, over time, of an overactivated stress system, and Michael Meaney, whose research established the foundation for understanding how a child's early-life experiences become biologically embedded in the brain and body. For interested readers, Online Supplement 1.2 summarizes, within a historical framework, key aspects of their work and that of other scientists whose work has contributed to my understanding of the stress system.

The Second Author: Stephen Scher

The second author, Stephen Scher, joined this journey just over a decade ago, when my article 'Healing the Disembodied Mind: Models of Conversion Disorder' was being finalized for publication in the *Harvard Review of Psychiatry*. His close, acute attention to the article (as Senior Editor) helped me to sort out various conceptual and linguistic problems, and it also began an ongoing conversation about mind and body. But his own interest in these problems far antedates our work together on that article. Beginning with his undergraduate work in philosophy and continuing through his PhD work in the same field, one of his primary interests was philosophy of mind, at the centre of which—going back to the seventeenth-century writings of Descartes—was the mind-body problem. His PhD dissertation, 'Freedom and Determinism in Kant's *Critique of Practical Reason*' (Scher 1977), was itself a historical study of this problem, and his clinical work on medical ethics in hospitals affiliated with Harvard Medical School was a response to what he perceived as an all-too-narrow focus on the intellect in trying to understand how health professionals learnt to think and act ethically. That line of thinking, years later, ultimately led to the publication—with me as co-author—of *Rethinking Health Care Ethics*, our Open Access book in which we follow the logic of his initial insights to develop an approach in which clinical ethics is literally embodied in each clinician's own history and his or her own thoughts, emotions, and actions (Scher and Kozłowska 2018). In a wonderful way, that book might be understood as coming full circle to our original encounter—that is, to an embodied mind, as it were, that enables clinicians to better understand and advance their own ethical thinking, feeling, and acting.

The Third Author: Helene Helgeland

The story of Helene Helgeland's involvement in this book is more complex. My initial contact with Helene, a child/adolescent psychiatrist in Norway, dates from 2015, when she invited me, via email, to give a series of talks at Oslo University Hospital in 2017. Those led to additional series of talks in 2018 and 2019—at the Cato Center in Son, at Tromsø University Hospital in Tromsø, and again in Oslo—and also to some further collaboration, including this book. Her own interest in the problems addressed in this book dates from around 2000, when she was working as a psychiatrist in a child and adolescent outpatient clinic.

Early on, it was Helene's impression that patients with functional somatic symptoms were almost absent from the clinic's patient population and also that very few were referred to their clinic because of such problems. But then—inspired by her husband, Per Olav Vandvik, a physician who was conducting research on functional abdominal pain in adults—she started asking her patients about the presence of abdominal pain. To her surprise, she discovered that not only abdominal pain but also other nonspecific somatic symptoms such as headache, nausea, and musculoskeletal pain were common among her young patients. In some, the symptoms had a huge impact on their daily functioning.

Helene soon realized—no doubt, like many readers of this book—how very little she knew about functional somatic symptoms and how very little she had learnt about this patient group as a medical student. She also realized that the majority of her colleagues both in general and mental health care had little knowledge—and often little interest—in these patients. Once a disease process was excluded, many paediatricians felt that they had finished up with such patients and felt no further responsibility for treatment. And many mental health clinicians, in turn, dismissed these patients because they did not show any obvious psychological symptoms such as anxiety and depression. Even when clinicians moved past these threshold obstacles, the baseline problem was still the same: what is happening to these patients? The clinicians themselves typically felt helpless, and their relations with patients and families often deteriorated, triggering anxiety, worries, anger, and misunderstandings.

Helene then embarked on the path that ultimately led to our acquaintance and to her work as a co-author. The first step was the research on her

PhD—on functional abdominal pain in children. In reading the international research literature she became increasingly interested in clinical hypnosis as an effective treatment for children with functional abdominal pain. Another source of inspiration at that time was her mother-in-law—Dr. Inger Helene Vandvik—a child and adolescent psychiatrist who has been one of the pioneers promoting the implementation of clinical hypnosis in paediatric patients in Norway (Helgeland 2018); in 2008, Dr. Vandvik established a one-year professional education program for using hypnosis clinically with children and adolescents. The program continues today under the leadership of Helene and her colleague Maren Lindheim (Lindheim and Helgeland 2017).

Although Helene's own knowledge and clinical experience continued to grow, she remained acutely aware that few health professionals had the understanding and capacity to help patients with functional somatic symptoms. To change the situation, it was necessary, she realized, to disseminate knowledge not only to health professionals but also to health authorities, decision makers, and the general population. In 2014, when Norway established its National Advisory Unit on Psychosomatic Disorders in Children and Adolescents, Helene joined the effort and recognized it as her opportunity to make a difference. Her searches of the literature led her to me. What was especially valuable for her (and other professionals in Norway) was that my articles presented both a well-developed clinical approach to treating functional somatic symptoms and a comprehensive model that integrated emerging research evidence on the underlying neurophysiological mechanisms.

What Connects Us Together as Authors

Finally, what also ties the three authors together is our interest in the well-being of the person as a whole, whether this be the well-being of our patients and their families, our teams, or our students. We try to support, and to promote the growth of, the whole person in our practice of medicine as a healing art (Cassell 2013), in working collaboratively with colleagues and respecting their moral voices (Scher and Kozłowska 2018), and in our mentoring of students and trainees when they spend time in our programs.

What the three of us hope is that, with our different but overlapping perspectives, knowledge, and skill sets, we have been able to put together a book that communicates what we know in a way that makes it accessible and usable by health professionals. With good luck, the presentation will engage the reader, and the trip through the pages will be both rewarding and a source of pleasure. We hope that after reading this book, all clinicians will hold in mind the many ways that physical and psychological stress can affect the child's body and compromise her health and well-being.

In an effort to make this material on functional somatic symptoms most accessible to the reader, we have divided the book into three parts representing the three overarching intellectual and clinical challenges that the clinician needs to address: (Part I) Children with Functional Somatic Symptoms: The Clinical Encounter; (Part II) Mind, Body, and the Science of Functional Somatic Symptoms; and (Part III) The Treatment of Functional Somatic Symptoms. For interested readers we also provide additional references—and references to basic science articles—in Online Supplement 1.3 for each of the chapters of the book.

* * *

In this closing paragraph we would like to address the limitations of the book. First, because the book's primary audience is mental health clinicians—and because we often try to articulate ideas in a way that can also be used to talk to children and families—we have tried to simplify the neurobiology as much as possible. But in simplifying the neurobiology we lose some of the detail and some of the complexity, and our neuroscientist colleagues may find the simplification a bit frustrating. Second, we have had to put a boundary around what we cover and what we do not cover in this book. The child's pattern of presentation may involve other comorbid, stress-related disorders such as anxiety, depression, and post-traumatic symptoms. Early-childhood stress also increases the risk for medical disorders such as diabetes, cardiovascular disease, inflammatory diseases, and obesity. Limitations on length do not allow us to discuss the interplay of functional somatic symptoms with these comorbidities. Third, knowledge about functional somatic symptoms and the processes underlying them is rapidly evolving. Much is becoming known and much is unknown. In this context, this book should be understood as just one step in the larger story.

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