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Functional Somatic Symptoms in Children and Adolescents: The Stress-System Approach to Assessment and Treatment

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Online Supplement 2.1

Positive Diagnosis of Functional Disorders and Outcomes from Specialist Programs

This online supplement to Chapter 2 provides the reader with additional information about positive diagnosis and treatment outcomes. In contemporary paediatric practice – across medical specialties – providing the child and family with a positive diagnosis of a functional disorder is current best practice. Furthermore, long-term outcomes are better when the positive diagnosis is provided early on, before symptoms become chronic, and when appropriate treatment is provided. In this scenario, the majority of children – more than two-thirds – return to health and well-being.

Providing Children and Families with Positive Diagnoses

Traditionally, functional disorders were diagnoses of exclusion, made only after extensive medical investigation. The patient would be told that the medical investigation was normal and that a disease process had been excluded. Over the decades, it became increasingly clear that this approach often led to unnecessary and potentially harmful investigations and that it

increased uncertainty and worries among patients with functional somatic symptoms. In response to these concerns, the medical profession began to pursue a different strategy. Given the absence of diagnostic markers for functional somatic disorders, the profession has endeavoured to develop consensus guidelines for specialty-specific functional somatic disorders. Since the guidelines are based on clinical history and physical examination – recognition of typical signs and symptoms – and on limited diagnostic testing, the diagnostic process does not depend on the exclusion of other disorders. Symptom/sign-based criteria have been developed for functional gut disorders, chronic fatigue syndrome, functional neurological disorders, and postural orthostatic tachycardia syndrome (POTS) (Hyams et al. 2016; Drossman and Hasler 2016; Fukuda et al. 1994; Espay et al. 2018; Freeman et al. 2011; Singer et al. 2012). Likewise, diagnostic criteria statements are available for assessing and treating patients with complex/chronic pain (Nicholas et al. 2019; Treede et al. 2019).

In addition to avoiding unnecessary and harmful investigations, consensus guidelines for specialty-specific functional somatic disorders have helped to communicate acceptance of the patient's symptoms, to reduce fear of serious illness, and to facilitate a good therapeutic physician-child/parent relationship (Spiller et al. 2010; Kellow 2007). With time, it is hoped that diagnostic tests, which are currently being used in research on a group level of analysis, may become available in clinical practice to facilitate diagnosis by identifying patterns of change in neurophysiological measures.

The effort to develop guidelines for positive diagnoses of functional somatic symptoms has surely been a move in the right direction, but there is also a problem. What these specialty-specific diagnoses fail to communicate is that all diagnoses pertaining to functional somatic symptoms are interrelated and overlap – not only within the domain of functional disorders but also with other stress-related disorders, such as anxiety, depression, and posttraumatic stress disorder (see vignette of Paula in Chapter 2; see Online Supplement 1.1 for changes in terminology over time). To overcome this shortcoming, which can itself undercut the process of achieving a clear and accurate diagnosis, as well as the process of treatment and recovery, some researchers and clinicians have suggested the use of a unifying diagnosis, such as bodily distress syndrome (BDS) or

bodily distress disorder (BDD; see ICD 11) (Gureje and Reed 2016; Fink et al. 2007; World Health Organization 2018). At present, functional neurological symptoms are not included in BDS or BDD.

Treatment for Patients with Functional Somatic Symptoms: A Stepped-Care Approach

Because functional somatic symptoms range from symptoms that are transient to symptoms that result in significant functional impairment, both the paediatric and adult literatures propose a stepped-care approach to treatment. Depending on the level of functional impairment experienced by the patient, treatment may involve the following steps: initial basic care, extended basic care, and multimodal treatment/psychotherapy/rehabilitation (Roenneberg et al. 2019; Garralda and Rask 2015). In paediatrics the choice of treatment interventions – independent of the level of care – is informed by the outcome of the comprehensive family assessment. Interventions are chosen to target the identified areas of dysfunction at the body, brain, mind, family, and school system levels (see Chapter 13).

Outcomes in Children with Functional Somatic Symptoms

The literature suggests that outcomes in children with functional somatic symptoms are generally good. The literature also suggests that early diagnosis and treatment are associated with better health outcomes. Unfortunately, a recent Danish study showed that among children whose functional somatic symptoms were severe enough to be admitted to hospital – and who needed follow-up care after discharge – only a quarter were actually referred to community psychological services (Tot-Strate et al. 2016; Garralda 2016).

In our own work, we (the first author [KK] and her clinical team) have now documented outcomes in five cohorts of children referred to our Mind-Body Program for treatment of functional somatic symptoms: children with chronic pain (Kozłowska et al. 2008); children with functional neurological symptoms comorbid with other functional somatic symptoms

(Kozłowska et al. 2013, 2015, 2017); and children with non-epileptic seizures (Kozłowska et al. 2018). The outcome data across the samples are as follows:

- Two-thirds get well and are able to return to school and normal life.
- One-sixth relapse with stress, but they get better at managing stress with time, and they are well between episodes.
- One-sixth either continue to have chronic functional somatic symptoms or, more commonly, develop a chronic mental health disorder such as chronic anxiety or chronic depression.

As part of these studies we have also found that outcomes were less good in children who presented with chronic functional somatic symptoms that had been left untreated (Kozłowska et al. 2018) and in children who reported higher levels of maltreatment, including physical abuse, sexual abuse, and domestic violence (Kozłowska et al. 2017). These clinical findings are consistent with a recent imaging study in which ‘connectivity strength analyses showed that physical abuse severity positively correlated with amygdala and insula coupling to motor cortices’ in adult patients with functional neurological disorders (Diez et al. 2020). In other words, the study showed that adverse childhood events – in this case, physical abuse – contributed to changes in brain function and structure (brain plasticity changes) that increased patients’ risk for developing functional neurological symptoms and that may also effect the brain’s capacity for healing. Other studies have found that premorbid adjustment and coping mechanisms are important factors that are associated with improved outcomes (Walker et al. 2012; Pehlivanurk and Unal 2002). See also Garralda and Rask (2015) for discussion of outcomes across disorders.

Similar good outcomes in child and adolescent patients are reported by other clinical teams who run specialized programs for functional somatic symptoms (Rangel et al. 2000; Hechler et al. 2011; Sherry 2000). Together, these studies highlight that with prompt (positive) diagnosis, followed by prompt multidisciplinary assessment, engagement, and treatment by teams who specialize in treating functional symptoms, even children and adolescents who are very disabled by their symptoms are able to achieve good outcomes.

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