

Munchausen's Syndrome by Proxy, Factitious Disorders in Children and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Chronic fatigue syndrome / myalgic encephalomyelitis is a condition of unknown cause that has recently been exhaustively reviewed by the Institute of Medicine¹ (IOM). A summary for clinicians has been provided:

<http://www.iom.edu/~media/Files/Report%20Files/2015/MECFs/MECFscliniciansguide.pdf>.

Their recommendations include renaming the illness 'Systemic Exertion Intolerance Disease', or SEID. Given that fatigue is generally defined physiologically as a recovery state from well defined exertion, the ongoing inability of patients with this condition to exercise or exert themselves at all for a period of six months (one of the diagnostic criteria) does not fall within that definition.

Controversies surrounding ME/CFS have been present since at least the Los Angeles outbreak of 1938 and are fueled by the relatively 'normal' physical examination and routine laboratory evaluation in persons who can be extremely limited in their activities. Furthermore the unavailability of a specific etiologic agent or diagnostic marker has raised doubt as to the physical nature of the disease. The IOM report, however, is clear about the impact: "ME/CFS can cause significant impairment and disability that have negative economic consequences at both the individual and societal levels. At least one-quarter of ME/CFS patients are house- or bedbound at some point in their lives."¹

Opinion that this disease was psychosomatic in nature was galvanized by an outbreak of ME involving over 200 persons among hospital workers at the Royal Free Hospital in London in 1955². Several years later, two psychiatrists, McEvedy and Beard, retrospectively concluded that the outbreak represented 'mass hysteria' and was not due to a medical illness³.

Today we have a much more clear vision of the illness thanks to current research conducted by the Centers for Disease Control and the Australian government⁴. Persons in the county of Dubbo, Australia, who became ill with Epstein-Barr virus (EBV), Ross River virus (RRV) or Q fever (QF) were prospectively studied to see how many of these persons would develop ME/CFS, as defined by the CDC criteria⁵. Each of the three agents led to ME/CFS in 6% of those infected when evaluated one year after infection. This is particularly interesting in that the three agents were different: EBV is a DNA virus, RRV is an RNA virus, and QF is caused by a rickettsial organism. Detailed studies noted that there was no psychiatric involvement resulting in disease. Rather, the severity of the initial infection was predictive of subsequent ME/CFS. The Dubbo study demonstrates that ME/CFS is not an ongoing chronic infection with persistence of

an infectious agent, but a post-infectious phenomenon and may follow many different types of infections.

However, the underlying message that ME/CFS is an organic disease has been slow to take root. In particular, children and adolescents, along with their parents are frequently accused of illness falsification in order to escape school attendance or to elicit sympathy from family members. Commonly, they are diagnosed with Munchausen's Syndrome by Proxy, a subset of patients with 'factitious disorder' (FD).

Munchausen's Syndrome by Proxy (MSBP) is a form of abuse in which a caregiver deliberately produces or feigns illness in a person under his or her care⁶. A rare disorder, it most frequently consists of poisoning of an infant by an adult caregiver. A related condition is 'factitious disorder by proxy'⁷, also referred to as 'pediatric condition falsification'. The Diagnostic and Statistical Manual of Mental Disorders⁸, requires the intentional production or feigning of physical or psychological signs or symptoms for the diagnosis of factitious disorder. It also suggests that the motivation for the behavior is to assume the sick role, and that there be no external incentives for the behavior such as economic gain. "The diagnosis of FD can only be confirmed if observation of symptom-producing behavior occurs or is admitted."⁹

Thus the essential feature of both MSBP and factitious disorder is the intentional and conscious imitation or production of illness. While there have been legitimate controversies concerning ME/CFS, the intentional or conscious attempt to feign the illness is close to impossible because of the complexity of the symptoms. Very few medical providers are even aware of the ME/CFS symptoms involving sleep, orthostatic intolerance, post-exertional malaise and sensory sensitivities. If pediatricians were better aware of ME/CFS, MSBP or factitious disorder would not enter the conversation.

It can be argued that the impossibility of mimicking the symptoms is put aside when a parent has disabling ME/CFS. Conceivably, a pre-teen or young adolescent could copy the symptoms of an adult with the illness if abnormal family dynamics are in play. But, as with all chronic illnesses, family dynamics should be assessed early in the course of pediatric ME/CFS, with particular attention to scape-goating, abnormal inter-family communication and enmeshment. Furthermore, as the majority of pediatric ME/CFS cases are adolescents, it is possible to interview them apart from the parent to assess symptoms.

When a child does not attend school, the school is obligated to begin an investigation. As the treating pediatrician is not likely to understand ME/CFS, no diagnosis is forthcoming, and a report to social services is initiated. Less than 20% of ME/CFS patients are diagnosed¹⁰, and this figure is probably less in the pediatric population. Without a medical explanation, a social service initiated diagnosis of "educational neglect" can be made, resulting in the possible forced

removal of the child from the home, on the assumption that a 'parent-ectomy' will bring about the cure of the ill child. The term 'Munchausen's Syndrome by Proxy' is invoked inaccurately.

Treating medical clinicians are responsible for a correct diagnosis in these circumstances. It could be considered malpractice in a court of law for a clinician to fail to diagnose malignancy, known autoimmune diseases, and other illnesses that limit school attendance, particularly when such a 'failure to diagnose' could result in foster care placement for the child. Failure to fail to diagnose ME/CFS could also be considered malpractice given that the Centers for Disease Control has maintained an active website of ME/CFS, and diagnostic criteria have been published since 1988¹¹. The opening statement of the CDC website states, "Chronic fatigue syndrome, or CFS, is a debilitating and complex disorder characterized by profound fatigue that is not improved by bed rest and that may be worsened by physical or mental activity." Furthermore, the World Health Organization has stressed the reality of the illness as classified in the ICD-10 as G93.3 under "Postviral fatigue and myalgic encephalomyelitis. (<http://apps.who.int/classifications/icd10/browse/2014/en#/G93.3>)

ME/CFS in children is not rare, and estimates range from 0.5% to 2.3% of children may have the condition, not all of which are severe cases. As early as 1997 research in the UK found that school absence due to ME/CFS was the most common cause of prolonged school absence¹².

Parents of children with ME/CFS speak for their minor children in hearings to determine whether placement out of the home environment is necessary. In the IOM report, specific mention is made of the serious nature of the disease, and it is only natural for a parent to emphasize the seriousness of the child's condition in the face of a medical environment that may dismiss the illness as hypochondriasis. In this context, enmeshment, or overly sympathetic parenting is not MSBP because it is not a deliberate attempt to cause illness. It is an attempt to portray to which a child is compromised by an illness over which they have no control. Furthermore, it is possible that a parent who is quietly accepting inappropriate removal of the child from the home could be accused of neglect.

One important question remains however: can an overly sympathetic parent cause activity limitation in an adolescent? While this has never been answered scientifically, it is highly unlikely. Behavioral problems caused by family dysfunction usually result in hyperactivity not hypersomnolence. An overindulged and undisciplined child is clearly not characterized by activity limitation. And in the era of rheumatic fever, where strict bed rest was prescribed as a treatment, it was invariably unsuccessful.

A further factor to consider is the increased incidence of ME/CFS within families¹³. Among clinicians there is a consensus that there is an increased incidence of ME/CFS within

families, although differences in criteria have created difficulty in coming to exact percentages. However, the genetics of ME/CFS are currently being investigated^{14, 15}.

This results in the unfortunate circumstance that a parent (usually the mother) is ill with ME/CFS and adolescents within the family may have the illness as well. When this occurs, it is common for social services to assume that the children are mimicking the parent, resulting in school absences. Without attempting to seek an accurate clinical diagnosis, foster care becomes an option in the social worker's mind, particularly when the outcomes can lead to removal from the home.

Conclusion: The lack of training and awareness of pediatricians in the subject of ME/CFS has led to the inappropriate diagnosis of MSBP and factitious disorder, both of which can result in placement of the child or adolescent in either psychiatric hospitalization or foster care. There is ample evidence that ME/CFS is not a psychiatric condition, and the recent IOM publication has clearly stated "Seeking and receiving a diagnosis can be a frustrating process for several reasons, including skepticism of health care providers about the serious nature of ME/CFS and the misconception that it is a psychogenic illness or even a figment of the patient's imagination... Physicians should diagnose myalgic encephalomyelitis /chronic fatigue syndrome if diagnostic criteria are met following an appropriate history, physical examination, and medical work-up."¹

David S. Bell MD, FAAP
1 Dunbridge Heights,
Fairport, NY 14450
drdsbmd@gmail.com
585-727-1691

1. Institute of Medicine. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington DC: Institute of Medicine of the National Academies; National Academies Press; 2015.
2. Ramsay A. Encephalomyelitis in north west London. An endemic infection simulating poliomyelitis and hysteria. *Lancet*. 1957; **2**: 1196-200.
3. McEvedy C, Beard A. Royal Free epidemic of 1955: a reconsideration. *1*, 7-11. *British Medical Journal*. 1970; **1**: 7-11.
4. Hickie I, Davenport T, Wakefield D, Vollmer-Conna U, Cameron B, Vernon S, et al. Post-infective and chronic fatigue syndromes precipitated by viral and non-viral pathogens: prospective cohort study. *BMJ*. 2006; **333**.
5. Fukuda K, Straus S, Hickie I, Sharpe M, Dobbins J, Komaroff A, et al. The chronic fatigue syndrome: a comprehensive approach to its definition and study. *Ann Intern Med*. 1994; **121**: 953-9.
6. Burton M, Warren M, Lapid M, Bostwick J. Munchausen syndrome by adult proxy: a review of the literature. *J Hosp Med*. 2015; **10**(1): 32-5.

7. Shaw R. Factitious disorder by Proxy: Pediatric Condition falsification. *Harv Rev Psychiatry*. 2008; **16**: 215-24.
8. DSM-IV-TR. Diagnostic and Statistican Manuel of Mental Disorders, 4th Edition, text revision. 2008.
9. Eastwood S, Bisson J. Management of factitious disorders. *Psychotherapy and Psychosomatics*. 2008; **77**: 209-18.
10. Jason L, Richman J, Rademaker A, al e. A community-based study of chronic fatigue syndrome. *Arch Intern Med*. 1999; **159**: 2129-37.
11. Holmes G, Kaplan J, Gantz N, al e. Chronic fatigue syndrome: a working case definition. *Ann Intern Med*. 1988; **108**: 387-9.
12. Dowsett E, Colby J. Long-term sickness absence due to ME/CFS in UK schools: an epidemiological study with medical and educational implications. *JCFS*. 1997; **3**(2): 29-42.
13. Bell K, Cookfair D, Bell D, Reese P, Cooper L. Risk factors associated with chronic fatigue syndrome in a cluster of pediatric cases. *Rev Inf Dis*. 1991; **13**(Suppl 1): S32-8.
14. Furberg H, Olarte M, Afari N, Goldberg J, Buchwald D, Sullivan P. The prevalence of self-reported chronic fatigue in a U.S. twin registry. *J Psychosom Res*. 2005; **59**(5): 283-90.
15. Farmer A, Scourfield J, Martin N, Cardno A, McGuffin P. Is disabling fatigue in childhood influenced by genes? *Psychol Med*. 1999; **29**: 297-82.