

Pediatric Chronic Fatigue Syndrome and Munchausen-By-Proxy: A Case Study

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SUMMARY. Pediatric chronic fatigue syndrome (CFS) posits even more challenges for professional caregivers in comparison with adult CFS samples. Most children with CFS display a decrease in school attendance and a decrease in social activities. As several conditions such as school phobia, primary psychiatric disorders or family disturbance present the same characteristics, the diagnostic process appears more complex. Family disturbance, moreover, is often specified as child abuse, neglect or even Munchausen-by-proxy. As skepticism is fre-

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quently associated with a diagnosis of CFS, patients and parents must fend for themselves, fighting allegations of child abuse and neglect. This case study illustrates what happens when such allegations are put forward. doi:10.1300/J092v13n02_02 [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2005 by The Haworth Press, Inc. All rights reserved.]

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INTRODUCTION

Chronic fatigue syndrome (CFS) is still a controversial diagnosis in adolescents. In studies of prolonged and chronic fatigue, the symptom pattern observed in child and adolescents samples has been found to be similar to that observed in adult presentation with a few exceptions (Smith & Carter, 2003). Most children with CFS also display an impaired school performance and a decrease in social activities (Van Hoof & Maertens, 2002). The impact of this illness is profound as one survey suggested that CFS is responsible for 50% of long term absences from school (Colby, 1994).

Widespread skepticism among the medical professionals increases when confronted with child CFS. As a result, after routine examination, the child is frequently dismissed, as also mentioned by Bell in this volume.

The core problem of this skepticism is that it spreads to educators and possibly members of the family. Consequently, patients and parents must fend for themselves, arranging school accommodations and fighting allegations of child abuse and neglect for truancy from school. The lifelong potential for harm in this scenario is enormous as it occurs during an important period of identity formation.

This case study reports the experiences of an adolescent with CFS. The subject is a 17 year old boy who reported significant complaints since January 2004. In this period, he frequently fell ill and reported not to recuperate from these seemingly benign infections. After examinations, his general practitioner (GP) found several infections in his blood for which he received treatment. In July 2004, he suffered from appendicitis and had an emergency surgery. After this procedure, the subject reported an improvement of his symptoms.

In September 2004, however, his condition began to deteriorate. He was referred to a specialist in order to receive nutritional supplements and to another specialist who performed intestinal lavages. Although he gradually reported improvement and began to function at a higher level, he suffered a relapse in March 2005. From this moment, his compliance to the medical protocol decreased significantly.

SCHOOL ATTENDANCE

From the anamnestic information, the subject seemed to suffer from recurrent infections during childhood. Nevertheless, he achieved 80-85% in primary school. During primary school, he was viewed as an intelligent and cooperative boy with lots of interests and good social interactions with his peers. In seventh grade, more independence and effort was required from students. The subjects' family reported that as he never had to study hard in first grade up to sixth grade, he only achieved 60% which was still an average result. In 8th grade, the infections became more frequent and started to interfere with his school attendance. For every absenteeism, the subject had a legal sickness certificate. Due to his frequent absenteeism, he had to follow his 8th grade twice. Ninth grade was even more problematic as he did not have the energy to keep up with his 'healthy' peers. He became an irregular pupil. In total, the subject attended 90 school days (accepted < 21 days). This academic year, his peers gave him class notes so he could study for his exams. No other special arrangements were made.

At the moment, he is in 10th grade and still frequently absent. No special arrangements or class notes are provided. Furthermore, he experiences no support from his teachers. In general, the subject senses increasing hostility from the school environment.

RELEVANT ANAMNESTIC INFORMATION

During his early childhood (< 5 years of age), he experienced physical abuse from his father. His parents eventually got divorced. After the divorce, he did not want to keep in touch with his father. His father, however, had legal visitation and forced his son to visit every Saturday during the next two years. Consequently, the subject suffered from psychosomatic complaints. Four years later, his father died. He followed psychological counseling in 7th and 8th grade to deal with his past. The

therapy was successfully terminated in 8th grade. After his father died, his siblings and mother all became legal guardians over him.

CHRONIC FATIGUE SYNDROME

The subject was referred to our department because he suffered from a severe relapse in March 2005. The subject attributed this relapse to emotional stress he experienced due to increasing hostility at school. His GP wanted to introduce some special arrangement so he could recuperate. At the time the intake took place, no leisure activities were present. He gradually gave them up in order to keep up at school.

During the intake, the mother handed over a note from the child protective services (CPS) that stated that they had to attend an inquiry in their center.

The physician from this center revealed to our department that the school made a formal complaint against the mother and the school moreover suggested the mother suffered from Munchausen-by-proxy.

Munchausen-by-proxy (MSBP) is described as the intentional production or feigning of physical or psychological signs and/or symptoms in another person who is under the individual's care for the purpose of assuming the sick role by proxy. The child is presented for medical assessment and care, usually persistently, often resulting in multiple medical procedures. The perpetrator has to deny knowledge of the etiology of the child's illness. Furthermore, in MSBP, acute symptoms and signs of the illness(es) decrease when the child is separated from the perpetrator. There are about 2-4 cases per million in the general population (Alexander et al., 1990). In general, as the diagnosis is complex, a high index of suspicion is needed to make the diagnosis of MSBP. The symptoms and signs also have to disappear when the child is away from the perpetrator.

MUNCHAUSEN-BY-PROXY

A meeting was organized involving the CPS, our department, all legal guardians of the subject, the school and the medical staff of the school. The medical staff of the school who filed the complaint did not attend. In this meeting, it became clear that the confidence in the school and its personnel was affected. There had been no contact with the family (mother or legal guardians) regarding possible concerns the teaching

staff and the medical staff might have. Rightfully, the physician of the CPS requested a medical as well as a psychological report.

MEDICAL AND PSYCHOLOGICAL SCREENING

The subject reports fatigue that increases due to physical activity, recurrent flu-like illness, early awakenings during sleep, headaches, dizziness, non-restorative sleep, muscle and joint pains, fever, recurrent herpes infections, attention problems, sore throat, recurrent sinusitis, dyspnoea when exercising, and concentration disorders.

He reported a significant level of psychological and physical dysfunctioning indicating anxiety, physical symptoms, interpersonal sensitivity, hostility and sleep problems. Avoidant behavior was present including minimizing the threat of the stressor using emotion-focused as well as avoiding the actual situation (for example distracting himself by thinking of pleasant thoughts). His physical functioning appeared significantly lower in comparison with healthy age-matched controls. Especially, physical and social functioning are problematic as well as bodily pain. He reported significant fatigue and motivational problems that significantly influenced his daily activities. No depressive or anxiety disorder was apparent. Reduced motivation could be related to the situation that presented itself at school. The subject attributed a part of his complaints directly to the complaint and subsequent anxiety and worries.

A neurocognitive screening revealed memory problems, especially with short-term memory. No attention problems could be objectified. The subject seemed an intelligent person with otherwise average neurocognitive capacities in comparison with his peers.

The medical investigation indicated he complied to the CDC criteria for CFS of 1994 (Fukuda et al., 1994). Physical findings included monocytosis, bowel dysbiosis, low natural killer cells percentage as well as activity, and a RNase L ratio of 0.8 (normal < 0.5). The maximal exercise capacity was $39.4 \text{ ml}\cdot\text{min}^{-1}\text{kg}^{-1}$ which falls in the normal range. The medical treatment focused on the bowel dysbiosis that is hypothesized to be a sustaining factor.

INVESTIGATION

Due to the investigation into the possible presence of MSBP, the communication between the school staff, the legal guardians and the

subject became problematic. No arrangements were put forward in order to ensure the education of the subject. Meanwhile, the academic year was half way.

Unfortunately, during the inquiries, the assigned physician went on maternity leave. As a consequence, the whole procedure needed to start from the beginning because the new physician wanted to conduct her own interviews.

At this point, the legal guardians were fed up. The subject refused to conduct any more interviews as he already lost several months at school. The physician, on the other hand, became restless and confused as she was never confronted with a patient with CFS nor a MSBP case before. Finally, the physician turned to our specialized center for information. She received recommendations on how to establish an individualized educational program in CFS. Furthermore, contacts were offered of other schools that had already implemented such a program. Finally, scientific information was handed over to this physician.

A couple of weeks later, the physician was ready to take a final decision and again invited all parties involved. However, some of the parties were reluctant to participate. Fortunately, some arrangements could be made at the end.

The subject was able to do his exams at the same school. The school was going to prepare the notes on which he had to study. Furthermore, an exam roster was prepared. Two days before his first exam, the subject and its family received all study information. The family was responsible to tutor and prepare the subject. This procedure again led to mistrust and a lot of anxiety.

During this exam period, the family got an invitation of the committee for special youth care for again, another interview. This invitation had a very stressful connotation as this committee can hand over children to foster care and deny parental rights.

Although some guidelines were put forward, the CPS thus forwarded the complaint to a higher level without consulting the family. Once again, all medical records were forwarded to a new physician. After reviewing all records, the complaint was dismissed and sent back to the CPS. Surprisingly, this department now closed the file and dismissed the complaint after a short phone call with the subject. Finally, in August 2005, no MSBP seems present according to the CPS.

As a result, the school that the student was attending requested a replacement to another school.

The subject began to look for another school where he could integrate and start education. The new school was immediately informed and all

possible information was handed over. At first, they appeared reluctant to accept the patient as no legal document could validate the closure of the file and the dismissal of the complaint at that time.

Finally, the official documents arrived and by the end of September 2005, an individualized educational program was implemented. The subject is going to divide his next year into halves and will be tutored by a home-tutoring service.

DISCUSSION

This case study clearly indicates the mistrust and dismissal some CFS patients experience. Pediatric CFS is still an unknown condition. This case study shows that CPS should be informed about chronic conditions as here it was mistaken for MSBP.

MSBP is a serious and potentially lethal form of child abuse in which a person who assumes the role of a caretaker induces or reports factitious symptoms in a child. The child-victim suffers from the caregiver's actions and health care providers unknowingly become 'accomplices' when they provide unnecessary testing and therapies. The perpetrators are nearly always the mother and psychiatric disorders are common in particular personality disorders and depression. Family history often reveals evidence of similar abuse affecting other siblings. An illness or condition that happens 'all the time,' or only when observed at home, but never in the hospital, is suspect. Furthermore, inconsistencies or contradictions among findings and presentation of child are suspect. In this case, no inconsistencies or contradictory medical findings were reported by the treating team. Both the medical and psychological evaluations did not indicate anything suspicious. The family history did not reveal similar problems in other siblings, except for physical abuse by an alcoholic father. After his death, all other siblings became legal guardians over the subjects. The siblings are all included in the decision-making process regarding the subject. The psychologist who the subject visited in 7th and 8th grade could not present anything other than the presence of psychosomatic complaints during the legal visitation right of the father. She successfully closed the counseling sessions and described the subject as an intelligent person with a lot of capacities. He had and has a good social network and a lot of support. The psychologist indicated that he had a good self-esteem and reported insight in the problems. However, due to the allegation, the subject lost half of a school year. He lost confidence in the institutions that were created to

protect and listen to children. Due to the unpredictability of the process in CPS and the committee for special youth care, he became worrisome and anxious.

His relapse in March 2005 was thus directly related to the increasing hostility he experienced from school. He sensed something was wrong but no one discussed these issues with him. As a result, the family was severely affected by the complaint and the subsequent process. The mother felt humiliated and reported feelings of failure. The whole family is currently trying to put things in perspective and works closely together to deal with this experience. The subject found support in his new school but is still physically recuperating from his last school year. Due to increased anxiety and stress, his condition deteriorated. At the moment, he is back at the functional level he had before his relapse.

It is thus important to keep in mind that an allegation of MSBP is serious and potentially life altering for the suspected perpetrator, regardless of the outcome of the case. Therefore, it is necessary for the primary caregiver, in this case the medical staff at school, to conduct competent, thorough, professional and well-documented investigative work before they levy any such allegation. Commonly, the diagnosis is made following the sharing of information, thus underlying the importance of good communication between those involved in the case.

Again, if the medical staff and the school personnel were informed on chronic conditions such as CFS, this situation could have been prevented. In adolescents with CFS, school attendance and leisure activities are most affected by the functional impairment. Functional impairment is a key aspect of the condition and it affects most areas in children's lives. Most striking, according to Rangel, Garralda, Lavin and Roberts (2000), two-thirds of the children with CFS had been totally unable to attend school, with a mean time out of school of at least one year. In a recent study, only 22% went to school full-time and 30% went through a standard exam schedule (Van Hoof et al., in press). Prolonged school absenteeism consequently is included in the definition as a proxy measure for functional impairment and severity (De Jong et al., 1997; Vereker, 1992; Garralda & Rangel, 2004). A lot of adolescents, furthermore, do not believe their grades match their capacities (Van Hoof et al., in press). In real life, the outcome of education is generally seen as the degree of success at national examinations and entry to further education. These are rarely reported in clinical literature. Furthermore, they experience a lot of conflicts at school and less help and support from the school environment. Summarizing, adolescents with CFS can not attend school full-time, do not get grades according to their intellectual capacities, and can

not participate in a social culture due to their complaints. If not supported in a correct fashion, their identity, their sense of self esteem, their value systems could be affected, and this creates insecurity.

To protect a healthy development of identity and sense of self, more support should be offered at school. Information about this condition should be presented to the school personnel. Moreover, information on development should be given. Subsequently, school personnel and family would be able to integrate education and social development. One could argue that an arbitrary division of 60% of the energy for school and education, and 40% of energy to social activities could improve and protect their identity development. Correlations revealed that a positive attitude of the teachers could create a positive attitude in fellow students and receiving appropriate guidance (Van Hoof et al., in press). This could diminish the chance of conflicts and would create an adapted school environment for the child with CFS.

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