MILD FACTICIOUS DISORDER BY PROXY

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Sample Case: Jason is a 14 y.o. with multiple diagnoses, dating to age 7. These include: chronic Lyme disease, chronic migraine, fibromyalgia, chronic fatigue syndrome, and irritable bowel syndrome. Jason missed most of 8th grade this past year, but has done well on homebound education. Oddly, Jason’s records do not corroborate his stated diagnoses.

Mom (Ellen) and dad accompany Jason, and Ellen does almost all of the talking. Dad is very quiet and defers to mom. Jason has one older sibling, still living at home and commuting to college.

Ellen is very excited when telling us about Jason’s various medications, doctors, and tests. Jason is on two antidepressants “for pain”, an anticonvulsant, NSAIDs, plus muscle relaxants. He has physicians in three states, and averages two doctor visits a week. On the surface, Ellen is very friendly and courteous. She tells us about an upcoming sleep study, as she is convinced Jason has a sleep disorder, “...but the doctors missed it on the first sleep study.” Overall, she is very dissatisfied with his medical care. When we inquire as to Jason seeing a psychotherapist, or having psychological testing, mom agrees to this, stating he will go, “as soon as he is finished with all his other tests.”

There are a number of warning signs in this case that point to a factitious disorder: multiple diagnoses without solid medical evidence, the patient seeing a number of physicians in various locations, multiple doctor visits and repeated tests, and a caretaker requesting more tests, doctors and diagnoses. The mother’s demeanor and affect are typical for parents in the mild factitious disorder by proxy (FDP) situation: very friendly, overly interested, excited and involved, and dissatisfied with the medical care.

The caretakers, usually the mothers, are often personality disorders themselves, with narcissistic tendencies. If they are confronted, anger and splitting can ensue. Confrontation and honesty would work with normal parents, but we are dealing with very psychiatrically ill parents.

Our goals are to gently nudge Jason and his family toward psychotherapy, and to minimize medications and tests. We want to take him from freshman year of high school through senior year, and eventually try and separate Jason from mom by his going away to college. It takes a unified effort to help a child and family in this situation, and we must recruit others, particularly mental health professionals.

DIAGNOSES: this case represents mild factitious disorder by proxy (FDP), as well as pediatric condition falsification(PCF).

APPROACH A: We establish a therapeutic relationship, determine that Jason is not being poisoned or seriously harmed, other than psychologically, by mom. Then, at some later date, we confront mom and dad with our true thoughts.

APPROACH B: We pursue a lower key, non-confrontational approach to parent and child. Dialectical therapy, utilizing acceptance, mindfulness, validation, and cognitive behavioral techniques among other tools, is currently a favored approach. After years of failure after my confrontations with parents, I have
utilized this laid-back “dialectical by proxy” approach with two young patients and their moms, with reasonable success. One young woman currently is doing well in college, having physically separated from her parents. If our goal is to continue a therapeutic relationship, and ease the young person away from home, I believe that this approach may be best.

LONG-TERM FOLLOW-UP: I have had ten mild FDP/PCF patients in 25 years of practice. Five were lost to follow-up (usually after we confronted the parent). Two patients did well into their 20’s, and are not considered to be personality disorders. One young woman was diagnosed with a borderline personality disorder, and has done poorly. Another young woman is doing well in college, and one other 15 y.o. is improved, and attending high school part time, at least. My impression is that, after the vitally important separation from parents, many victims may do well as adults, as long as they themselves do not have a personality disorder.

DISCUSSION

The sample case represents a mild form of factitious disorder by proxy (FDP), mild pediatric condition falsification (PCF), and possibly mild medical child abuse (MCA). FDP is primarily a psychiatric diagnosis that relates to the caregiver who exaggerates or completely fabricates the child’s symptomatology. PCF relates more to the child/victim, who has had symptoms falsified. MCA relates to the healthcare providers, who may prescribe unnecessary and possibly harmful treatments, including drugs. The MCA diagnosis recognizes the role of healthcare providers in the abuse of the child.

The incidence of FDP is not entirely known, but is relatively rare. The incidence has been quoted as ranging from 0.4 to 2 cases per 100,000 (among parents of children less than 16 years of age). Boys and girls appear to be equally affected, and typically younger children are involved. However, with mild FDP presenting as headaches, we have witnessed most cases occurring in early adolescence. The incidence of the milder forms of these conditions is unknown.

The three participants are the child/victim, the parent/perpetrator, and the healthcare team. The child (or adolescent) is often passive, giving way to the caretaker, who, despite the age of the patient, does almost all of the talking. Older children may collude with the parent. The adolescent often is dependent and immature, with separation anxiety.

The perpetrator parent, 90% of whom are the mothers, is often very attentive, knowledgeable, overly friendly, and comfortable in the medical setting. The vast majority of these parents have moderate to severe psychopathology, often some form of personality disorder. Some of the mothers display hypochondriacal traits, and occasionally have been involved in factitious disorders themselves. The caretakers that we have encountered with mild FDP are essentially “doctor addicts”, and are not actively inducing physical symptoms in the children. They seek various types of secondary gain, including sympathy, attention and social interaction with the medical staff, being relieved of their usual chores or work, etc.

The healthcare team is the third participant. Often the primary provider is a subspecialist eager to help with an unusual diagnosis. Healthcare providers have widely different levels of psychiatric acumen, and
often ignore or miss obvious signs of FDP. In moderate or severe cases, it is more obvious as to the correct course, with psychiatric intervention, as well as legal notification of the child protective services. However, with mild cases, the correct means of intervention are not as clear.

The role of the internet has grown over the years. Parents can obtain a great deal of medical knowledge without being part of a healthcare environment. Many of the perpetrators display a wealth of knowledge about the various conditions, though it tends to be superficial. Also, angry parents may use the internet to post negative statements about healthcare providers.

Management of these conditions varies from case to case. It “takes a village” to help these families, and we need other “villagers”. These often include psychotherapists, psychiatrists, social workers, the pediatrician, etc. With moderate or severe cases, legal intervention is important. However, with the milder cases that I have seen over the years, the correct course is unclear. In the majority of the first seven cases I encountered, confrontation usually led to an angry scene, with the parent stalking out of the office, never to return. In the three most recent situations, I have taken a more subtle “dialectical” approach, which has been much more successful. One case was of a 15 y.o. young woman with severe daily headaches and multiple diagnoses who was not in school for two years. We gently guided her into individual and family therapy, with little confrontation, and she is now off to college and doing well. However, most of the time the parents will resist or refuse psychotherapy. I believe that the correct approach to mild FDP/PCF is not known, and we need research and studies on this milder form.

For further reading: