Identification and Management of Factitious Disorder by Proxy

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ABSTRACT
This paper presents a literature review of current research on factitious disorder by proxy (FDP). It identifies common symptoms and management techniques of both the child and caregiver in hopes of aiding primary care practitioners to better recognize the diagnosis and implement treatment. FDP is a subtle and dangerous form of child abuse that can cause significant morbidity and mortality. Knowledge of common symptoms displayed by the child and caregiver can assist in immediate legal and medical intercession, as well as initiation of treatment for all parties involved.

Keywords: factitious disorder by proxy, identification, management

Factitious disorder by proxy (FDP), formerly known as Munchausen Syndrome by Proxy, is 1 of the most elusive and dangerous forms of child abuse. FDP is thought to be rare (although this may be from significant underdiagnosis), with an estimated annual occurrence of 0.4 to 2 cases per 100,000 people or approximately 600 new cases each year in the United States.\(^1\) Despite its assumed rarity, FDP can result in dire consequences—approximately 6%-10% of cases are thought to be fatal. The diagnosis is often poorly understood or identified, even by those in the psychiatric field.\(^2\)

Most cases present in primary care settings because physical symptoms predominate the diagnosis, and therefore the following information is specifically significant for nurse practitioners (NPs). This article presents a literature review of current research on FDP and identifies common symptoms and management techniques of both the child and caregiver, with the goal of aiding NPs to better recognize the diagnosis and implement treatment.

OVERVIEW OF FACTITIOUS DISORDER BY PROXY
Asher originally created the term Munchausen Syndrome in 1951 with historical reference to Hieronymus Karl Friedrich von Munchausen, a German baron who was known for telling improbable stories describing his experiences in the Russian-Turkish war.\(^3\) In 1977, Munchausen Syndrome by Proxy was defined by Meadow as a form of child abuse in which the perpetrator intentionally fabricated or induced illness in a child in order to acquire attention through association.\(^3\)

The Diagnostic and Statistical Manual (DSM) III formally recognized Munchausen Syndrome by Proxy under the term Factitious Disorder Not Otherwise Specified (NOS) in 1980.\(^4\) The term changed little from the DSM-III to DSM-IV-TR (only to be recognized in Appendix B of the DSM-IV-TR as Factitious Disorder by Proxy in addition to Factitious Disorder NOS). Much discussion has taken place concerning categorizing in the upcoming DSM-V and whether a new term, Pediatric Condition Falsification, should be used to refer to the child and FDP should be used to refer to the caregiver.\(^2\)

Appendix B (Criteria Sets and Axes Provided for Further Study) of the DSM-IV-TR (2000) currently presents FDP diagnosis criteria as the following:

A. Intentional production or feigning of physical or psychological signs or symptoms in another person who is under the individual’s care.
B. The motivation for the perpetrator’s behavior is to assume the sick role by proxy.
C. External incentives for the behavior (such as economic gain) are absent.
D. The behavior is not better accounted for by another mental disorder.5

The abusive behavior of FDP is manifested in the following ways: “pretense of illness, fabrication of illness or medical history, inducement of illness, exaggeration of genuine illness, enforced invalidism, and false allegations of abuse.”6 It can be episodic or continuous in nature and ranges greatly in severity. Affected children are generally younger than 2 years old but cases have been identified in children as old as 16.2

Although an estimated 90%-98% of caregivers in these cases are women, there appears to be no clear gender distinction among children.2 On average, the diagnosis of FDP is often delayed for more than a year because of clinician unawareness, hesitation, and ambiguous diagnosis criteria.7 Complicating matters further, up to 55% of children may have a genuine comorbid disorder.1 The pathological nature of FDP is believed to cause disruption in the attachment relationship between a parent and a child and is thought to have severe short- and long-term effects on the child, both physically and psychologically.8 In addition, feigned illness is estimated to cost the health care industry approximately $40 million a year.9 Due to its perilous and expensive consequences, early recognition is essential.

A literature review was performed using the search engines PSYCINFO, OVID, CINAHL, and PubMed. The PSYCINFO search terms used were Factitious Disorder by Proxy OR Munchausen Syndrome by Proxy and Factitious Disorder by Proxy AND treatment. The OVID search terms were Factitious Disorder by Proxy AND treatment and Munchausen Syndrome by Proxy AND treatment. The CINAHL terms were Factitious Disorder by Proxy OR Munchausen Syndrome by Proxy AND treatment. Finally, the terms used in PubMed were Factitious Disorder by Proxy OR Munchausen Syndrome by Proxy AND treatment, and results were limited to free full texts. All search engines were accessed between August 29 and September 4, 2012. The DSM-IV-TR, Washington State Department of Health Web site (http://www.doh.wa.gov), and Mitchell and Black’s book Freud and Beyond were used as additional resources.

IDENTIFICATION OF FDP
Characteristics of and Symptoms Presented by the Child
This article focuses specifically on FDP cases involving children and their adult caregivers. Other FDP relationships have been identified (eg, clinician and patient, adult caregiver and adult recipient), but the child and adult caregiver relationship is by far the most prevalent.

The diagnosis of FDP has long been 1 of exclusion and must become 1 of conscious consideration.10 Although undeniably difficult to acknowledge, children display warning symptoms that can indicate a diagnostic consideration. This article suggests 2 mnemonics created by the author that may act as adjuncts to formal diagnostic guides in order to assist NPs in identifying children and caregivers (Tables 1 and 2). Key identifiers in a child include an unexplained, recurrent, or prolonged illness that is inconsistent with reported medical history, clinical assessment, or laboratory/test results and is resistant to standard treatment. Symptoms are often vague, difficult to validate, happen only in the caregiver’s presence, and resolve in the caregiver’s absence.11 The child frequently endures multiple hospitalizations and treatments and repeatedly shows a “passive tolerance of painful procedures.”6,11 The child’s illness is often prone to unexplained deteriorations and relapses.12

Table 1. Mnemonic for Early Identification of FDP
Children: IRREGULAR

| I | Inconsistent medical history, clinical assessment, and laboratory findings |
| R | Recurrent/prolonged illness |
| R | Resistance to treatment |
| E | Emotional abnormalities |
| G | Growth and developmental delays |
| U | Unexplained symptoms |
| L | Lack of outside relationships |
| A | Asymptomatic in absence of perpetrator |
| R | Relapses frequent |
Physical symptoms can vary greatly and be complicated by genuine comorbid disorders. However, certain symptoms often repeat in cases of FDP, with the most common being related to poisoning or suffocation. Frequent symptoms include bleeding, seizures, apnea, unconsciousness, diarrhea, vomiting, fever, rashes, allergies, asthma, anorexia/feeding problems, and pain. Children often meet a diagnosis of failure to thrive and appear pale, small, and thin for their age. They may present as lethargic or drugged on examination.

Developmentally, children can appear to fall behind their peers. As a result of frequent isolation, hospitalizations, incapacitation, and being withheld from social contacts, children may present as developmentally and socially delayed. Frequent absences or schooling from home can incorrectly be identified as learning disabilities. Children may regress in the presence of the caregivers and thrive in their absence.

NPs often find the children to be more developmentally and socially appropriate than the caregiver reports. The children are often restricted by caregivers in physical ways (eg, forcing victims to remain wheelchair bound, constraining them from performing activities of daily living) and emotional ways (isolating them from all or most social contacts, discouraging verbal interaction, confining them to bed), which may perpetuate delays. The children may experience anger and resistance from the caregiver when they demonstrate progress in independent functioning or development.

Multiple emotional abnormalities are often present in children of FDP cases, including hyperactivity, oppositional defiance, social withdrawal, passivity, immaturity, lack of independence, separation anxiety, and submissiveness concerning medical procedures and decisions. Children frequently present as overly protective of the caregivers and clear relationship boundaries may be absent. It is common for older children of abuse to contribute to their disorder by reporting false symptoms as a way of receiving acceptance from their caregivers.

### CHARACTERISTICS AND SYMPTOMS PRESENTED BY THE CAREGIVER

Approximately 90%-98% of perpetrators of FDP are women, 85% of whom are the children’s biological mothers. The remaining percentage consists of fathers, guardians, foster parents, adoptive parents, caretakers, or extended family members. In psychoanalytic analysis of FDP caregivers, Adshead and Blueglass state that a “parent’s own experience of parenting and attachment is relevant, especially if that experience is itself abusive.” Childhood abuse, rape, familial mental illness, and witnessing domestic violence are common among caregivers.

Many caregivers experienced their own mothers as rejecting or neglectful and formed insecure attachments at an early age that lead to “transgenerational” repetition of pathological parent-child relationships. In some cases, caregivers replaced maternal attention with medical attention and therefore began “pathological attitudes toward illness that has resulted in a dependent relationship with the medical profession” and formation of “maladaptive coping strategies linking love and illness.”

Robins and Sesan address the unmistakable relationship between women and FDP and hypothesized that these mothers are dissatisfied with the traditional “mothering role” and therefore form pathologic expressions of caring because of their ambiguous views on caring for yet feeling afraid of or burdened by their children. Psychoanalytically speaking, caregivers seek attention from an outside source (ie, medical professionals) as a result of early object loss in their own childhood relationships and use their children as “objects of control” to get that
This assessment is rooted in the Object Relations theory, which proposes that if a child’s dependency needs are unmet by a parent, the child compensates by substituting real relationships with fantastical ones that are not based on genuine exchanges. Emotionally, the most devastating effect of such behavior is the violation of trust within the parent-child relationship.

Caregivers with experience working in health care are strongly overrepresented in cases of FDP, with approximately 14%-30% working as healthcare providers (often nurses or nursing assistants). Many caregivers have a criminal record (shoplifting, theft, and arson are common) and history of violence (domestic violence, assault charges, and Child Protective Services [CPS] involvement). Serious marital problems are reported in approximately 40% of cases, and the parents often only “come together around a sick child.”

Comorbid psychiatric diagnoses are common among people who have FDP. Approximately 21% of caregivers have been admitted to inpatient psychiatric facilities and 71% have received outpatient psychiatric care. Sixty-five percent of caregivers are believed to have diagnosable personality disorders, the most common being antisocial, borderline, avoidant, narcissistic, schizotypal, dependent, paranoid, and histrionic. Caregivers are often viewed as dominant, passive-aggressive, rigid, inflexible, self-centered, dependent, hostile, deceptive, helpless, exploitative, sadomasochistic, devoid of empathy, and desirous of attention. Dramatic shifts in affect and inappropriate interpersonal boundaries are frequent. In addition, somatoform disorders, eating disorders, anxiety, depression, factitious disorders, malingering, repeated episodes of self-harm, and pseudologia fantastica (pathological lying) are widespread.

Caregivers often initially present to NPs as caring and medically experienced. However, as time progresses, parental presentations transform into overbearing involvement, enjoyment of the “spotlight,” inappropriate familiarity with medical staff, gratification and comfort in the hospital setting, uncertainty in relating to the child, and refusal to leave the child’s side. They may appear inappropriately excited and advocate for drastic interventions. The caregivers’ life appears to revolve around their children’s illness. They frequently show no relief with normal test findings, promote invasive examinations and procedures, predict relapses, describe symptoms that only they have observed, and provide false reports of etiology. “Doctor shopping” is customary, as well as erratic use of health care services, frequent emergency department (ED) visits, multiple changes in clinicians, lack of continuity of care, and premature cessation of hospital care. Caregivers and their families are frequently isolated and have little involvement with their extended families or outside organizations.

CHARACTERISTICS OF AND SYMPTOM PRESENTATION BY A THIRD PARTY

For the purposes of this article, the term third party refers to siblings of the FDP child or the parental coprovider. Coproviders, usually the married father of the child, often deny or minimize the caregiver’s behavior, hindering proper protection and treatment. They are generally distant, uninvolved, and “emotionally and physically detached from the family system.” Unlike the caregivers, fathers frequently take a passive role in health care decisions, don’t interact with hospital staff, and seldom visit because of claims of schedule conflicts. They are often reported to be less intelligent than their partners and submissive to the caregivers’ dominant personality. Fathers commonly abuse alcohol or other substances, have histories of aggression toward their families, and may be sexually assaultive in their marriages.

Frequently, siblings of FDP children also have complicated medical histories, unexplained deaths, or have died of sudden infant death syndrome. A study by Sheridan reported that 25% of siblings were deceased and 61.3% had medical symptoms of “suspicious origin.”

MANAGEMENT OF FDP

Legal Obligations

Like any case of suspected child abuse, FDP requires mandatory reporting to CPS and early legal intervention is essential. NPs who make a report will be asked the name and age of the child, the name and address of the child’s current parent/guardian, the nature and extent of the abuse, any evidence of
previous incidences, and any further information that may establish cause and help to identify the perpetrator. CPS and investigating detectives typically order records from outside hospitals, schools, insurance companies, employment and disability claims, police reports, and court documents. The responsibility of validating charges lies with law enforcement, while the NP’s responsibility is thorough documentation, expert court testimony, and the request for court-ordered ongoing supervision of the child’s medical treatment.

NPs should document all interactions between the caregiver/child and caregiver/NP, symptom presentation by the child when the caregiver is present and absent, and medical reasoning behind all ordered tests and procedures. Specific interventions include critical testing of samples for authenticity, ensuring chart accuracy, and using covert video surveillance in a secure setting (ie, a hospital) if enforced by legal request. A forensic evaluation by law enforcement is crucial and prosecution may be necessary.

Treatment of the Child
The child’s safety is of utmost importance, and therefore accurate identification and immediate reporting by an NP is essential. Once a diagnosis is suspected and referral to CPS is made, a multidisciplinary team approach should be taken that includes an NP, social worker, nurse, psychiatric expert, legal consultant, hospital administrator, bioethicist, statistician, CPS personnel, and law enforcement. NPs should avoid ordering expensive, unnecessary, or invasive tests, and the safety of the child becomes the immediate focus of treatment while further investigation occurs. One-to-one observation with exclusion of the caregiver should commence. CPS professionals take the responsibility of deciding whether temporary or permanent separation (foster care, planned hospitalization) may be necessary.

The role of the NP involves a thorough developmental, physical, and psychosocial examination and should be performed with meticulous documentation. A comprehensive review of the child’s past medical history, laboratory results, symptom presentation, treatment responses, parents’ and siblings’ medical and psychological histories, and provider/caregiver/child relationships should take place. Interviews with extended family, teachers, and babysitters can be beneficial. Monitoring by the same NP is important for continuity and evaluation.

Long-term psychiatric therapy for the child should be customary. Young children may benefit from art or play therapy, whereas older children can gain from direct and honest discussion of personal denial, guilt, and misperceptions. Consistent providers and a stable, safe residential placement should be prioritized. A comprehensive management plan must be included in the child’s medical record. If separation is required, parental visits that are closely monitored in a neutral location with strict guidelines (no discussion of health, no gifts or giving of food/drinks/medicine, constant observation) may be appropriate at some point in treatment. The risk of sibling abuse is high, and continued CPS monitoring of the family is desirable. Regular school attendance and a semblance of normal routine should be prioritized.

Treatment of the Caregiver
Immediate confrontation without significant evidence may be harmful to the child, caregiver, and the NP as part of a future legal case; therefore, initial interactions by the NP should be carefully planned. Caregivers should be addressed without family members or the victim present. The purpose of bringing forth the observations is not to prove the caregiver “wrong” but to empower her to seek autonomy and fulfillment of her needs outside of the health care system. Goals should be for the caregiver to take responsibility for her actions, act out distress in a healthier manner, and learn to satisfy her needs internally rather than through external attention. Firm limits need to be set but caregivers should be addressed with respect and professionalism.

Caregivers should be referred to a psychiatric provider for their own specific treatment of FDP. The psychiatric provider could then request an extensive psychiatric evaluation of the caregiver and perform a thorough review of her medical history.
These goals do not excuse caregivers from the legal consequences of child abuse, and formal legal action must still be taken.

Caregivers who admit responsibility are more likely to benefit from psychotherapy and treatment. Treatment options include supportive therapy, group therapy, family therapy, individual therapy, couples therapy, women’s/feminist therapy, parenting classes, psychopharmacologic treatment, vocational rehabilitation, role modeling, and anger management.

CASE STUDY

Baby J is a 21-month-old boy who spent the first 8 months of his life in the neonatal intensive care unit (NICU) because of multiple complications related to a bowel obstruction and perforation that resulted in the placement of an ostomy. Baby J’s mother, Anna (name changed), was a former certified nursing assistant who chose to stop working to care for Baby J’s significant medical demands. During Baby J’s NICU stay, his mother became very involved in his medical care and was praised by staff for her eagerness to participate. As discharge approached, Anna began telling multiple staff members how they had become her family and expressed worry about caring for Baby J by herself. She asked nurses for personal phone numbers so that she could call if she had questions. The day Baby J was discharged, Anna prepared a feast of baked goods for the staff and was very emotional.

During the first month after discharge, Baby J’s follow-up visits showed him to be medically stable. However, as subsequent months passed, he began having complications related to dehydration and “dumping” from his ostomy, which is caused when the bowel does not correctly absorb formula and dumps needed nutrients out of the ostomy site in the form of diarrhea. Providers were confused as to the cause of the dehydration and dumping as the child vastly improved upon hospitalization.

Anna said multiple times that she believed Baby J required invasive abdominal surgery to explore the cause of the problem because each time she left the hospital, the diarrhea and dehydration would return. After a particularly worrisome ED visit in which Baby J was unresponsive as a result of extremely high sodium levels from dehydration, the provider agreed to exploratory surgery. Nothing of significance was discovered, and Baby J again improved after 5 days in the hospital.

As plans were being made to discharge the baby, Anna informed a nurse that he had just had such significant diarrhea that she was unable to make his ostomy bag stick. Anna relayed to multiple staff members that she thought the problem was beginning again and that Baby J’s discharge should be delayed. That evening, while Anna went to the cafeteria for dinner, a nurse discovered 3 empty saline enema packages in Baby J’s bathroom trashcan. Providers suspected Anna had been giving Baby J saline enemas through his ostomy site and causing the diarrhea and dehydration.

When initially approached, Anna vehemently denied the accusations, but she eventually admitted she had been giving Baby J enemas for months in order to “clear his system so that doctors could find out what was really wrong with his bowel.”

Baby J was released to medical foster care and legal action was taken against Anna. After months of investigation, supervised visits were approved between her and Baby J. Legal custody of Baby J remains with the state.

PROVIDER CONSIDERATIONS

Support for the NP and a forum for case debriefing are crucial in FDP cases. As mentioned, a multidisciplinary approach is preferable as it provides an outlet for collaborative decision-making, consultation, legal protection, and increased assurance of appropriate care for child and caregiver. Enhanced NP training, education about FDP, the creation of hospital policies, and the formation of committees to address FDP cases support both NPs and patients. In cases where treatment is deemed unnecessary, NPs...
can avoid being “unwitting collaborators” by using their professional judgment when ordering tests, procedures, and treatments.28

DISCUSSION
FDP is a subtle and dangerous form of child abuse that can cause significant morbidity and mortality and destroy the relationships and future well-being of both the child and caregiver. Early identification and intervention are crucial, and the responsibility of awareness lies with the NP. Knowledge of common symptoms displayed by the child and caregiver can aid in immediate legal and medical intercession, as well as treatment for all parties involved.

FDP remains a controversial diagnosis, both legally and medically. Many concerns, including those of malpractice litigation, hospital liability, and the destruction of family units by false allegations, cause hesitancy in diagnosis.11 Skeptics argue that an FDP criterion lacks “diagnostic precision” and coincides with genuine disorders.4,10 Questions arise as to whether the caregiver or the child receives the diagnosis of FDP and whether the diagnosis is even valid as it is listed in Appendix B of the DSM-IV–TR, which means it is determined to have insufficient information to warrant its inclusion as an official diagnosis.24,28 Many agree there is a significant lack of empirically validated screening tools, controlled research, resources for diagnosis, and agreement among providers.4,10

Mart28 argued that current research focuses almost entirely on mothers as caregivers and children as victims, even though criteria do not warrant such limitations. One of the most common criticisms of FDP is that the NP must determine a caregiver’s motivation and intent to diagnose FDP, which is arguably impossible.28 Rogers10 presented an interesting argument in that cultural differences in the definition of illness can greatly affect motivation for treatment and therefore their inclusion in the diagnosis. Legal and ethical considerations may become problematic when investigating cases of FDP (eg, covert video surveillance). Individual NP biases must be identified by continued education, training, and personal awareness.6

One suggestion for improvement is the creation of a diagnosis of pediatric condition falsification in addition to FDP so that future research can focus on specific interventions for each unique population.24 The request for further research, the creation of standardized screening tools, policies for management, and clarification of identifying symptoms and diagnostic criterion are necessary. While these suggestions are researched and new diagnoses or tools are developed, the mnemonics recommended in Tables 1 and 2 may support NPs in diagnosing both the child and caregiver. The mnemonics can assist NPs with their role, which includes thorough assessment, meticulous documentation, and referral to CPS. Early identification of FDP is crucial to protect children from significant harm and lifelong consequences.

References