

Fits, faints, or fatal fantasy? Fabricated seizures and child abuse

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Children thrive on a holistic approach to health care

Munchausen syndrome by proxy (MSbP) is now an established form of child abuse.¹ It carries the risk of significant harm to the dependent child and siblings, with long term physical and emotional consequences for many.²⁻⁴ It is known from retrospective studies that many cases go unrecognised for long periods and that the long term outcomes may be poor.⁵⁻⁷ In many cases there have been previous sibling deaths, likely to be due to abuse.^{2,3} The high degree of certainty that paediatricians often require before intervening has been highlighted.²

Seizures have been reported to be the most common presentation of fabricated illness. The authors' experience, mirrored by many case reports in the literature, suggests that the current threshold for the diagnosis of fabricated seizures remains too high and that abuse may continue for years before the diagnosis is made. There is a need to move towards earlier diagnosis of child abuse in these cases.

DEFINITION

Four modified criteria for MSbP have been proposed⁴:

- (1) A parent or someone in loco parentis fabricates illness in a child.
- (2) The child is presented for medical care (usually persistently).
- (3) The perpetrator denies the aetiology of the child's illness.
- (4) Symptoms and signs of illness cease when the child is separated from the perpetrator.

The essential feature is that the child's illness has been deliberately fabricated or induced by the carer and the child has suffered harm as a result.

TERMINOLOGY: FACTITIOUS, FICTITIOUS, OR FABRICATED SEIZURES?

Various terms have been employed in the literature in an attempt to be more descriptive—illness induction syndrome, factitious illness syndrome, and fabricated illness spectrum. These terms are often used loosely without a clear distinction between them. Dictionary definitions may be illuminating:

Factitious: "specially contrived, not genuine, artificial" (could apply to some cases).

Fictitious: "imaginary, unreal, counterfeit" (applies to illness where the parent deliberately provides a false history).

Fabricated: "construction or manufacture, invention or concoction. To put together by art and labour" (perhaps the most useful and encompassing description of the harmful behaviour of the carer).^{8,9}

THE VALUE OF LABELS

The appeal of using an observational or descriptive label for the abuse is clear. Ambiguity and misconceptions are avoided, the medical duty is apparent, and implicit assumptions about specific perpetrator illness are avoided.¹⁰ The word "syndrome" is misleading, implying a grouping of specific symptoms or signs. A recognisable terminology has the advantage of gaining rapid attention and understanding of the abuse under consideration and may help to mobilise resources. The authors prefer the use of the descriptive terminology "fabricated and induced illness in children", while acknowledging that MSbP is the most recognisable "journalistic" term and has its place if used properly. The term "Meadow's syndrome" has been used synonymously with MSbP abuse; however, as with eponymous labels generally, it has fallen out of use in favour of more descriptive terms.

THE ROLE OF THE PAEDIATRICIAN IN THE ABUSE

Almost all of these cases present in a medical setting, and it is rarely the case that there is a single dynamic of the carer making unsolicited presentations to a doctor who does nothing to contribute to the abuse. More common is the scenario of a "folie a deux" between the physician and a fabricating carer in which the former inadvertently but avoidably harms the child by investigating, treating, or providing the carer with the means to continue the deception. Carers

may adopt a perverse mode of relating with healthcare professionals, a conscious violation of social norms in the relationship, which leads the physician into colluding with the abuse.^{11,12} Some argue that MSbP could not exist but for the healthcare professionals.^{13,14} It is clear however that the abuse is a symptom of disordered parenting and it is inappropriate to blame the doctor. It is however our imperative to recognise it early on and respond appropriately.

BACKGROUND

Previous authors have highlighted the relation between MSbP abuse, poisoning, and suffocation.² There is also considerable overlap with other forms of abuse. Diagnostic confusion may arise between MSbP and various other conditions that may result in abuse of a child, including severe anxiety, "hypochondriasis by proxy", delusional disorders, "masquerade syndrome", "vulnerable child syndrome", and "mothering to death".^{1,6} There has been extensive debate about diagnostic criteria in the literature and some authors have expressed practical concerns about the diagnosis.¹⁵

Child abuse involving fabrication or induction of illness is clearly on a spectrum. There is an inherent discrepancy between the doctor's and carer's perception of the need to consult.¹³ A child at one extreme of this spectrum may present with illness that was consciously induced, for example by smothering or poisoning. Alternatively, a child may be presented with exaggerated normal symptoms or lesser degrees of fabrication when the harm that arises is through the excessive medical contact itself. In all cases the parent is to some extent unable to distinguish the child's needs from their own. At the mild end of the spectrum, the carer may lack insight into their damaging behaviour, believing that they are acting in the child's interests. These cases are probably not appropriately labelled MSbP, which implies deliberate fabrication.

The child may present initially with "episodes" which are exaggerated normal phenomena, where the medical response precipitates a train of events that culminate in deliberate induction of illness. Inherent in this model are firstly a misdiagnosis on the part of the clinician, then the "folie a deux" with the susceptible parent and a resulting escalation from the more benign to more serious scenario.^{16,17} What we do not know is which children may be at risk in this way, whether they may present on different parts of the spectrum at different times, and how we can ensure that harm does not occur.

Abbreviations: EEG, electroencephalogram; MSbP, Munchausen syndrome by proxy

Training in paediatrics and child health does not encourage us to doubt the veracity of parents' histories. Clinical practice is based on an assumption of truthfulness and a shared interest in the welfare of the child. We also naturally enjoy the admiration and approval of our patients and are reluctant to offend them. We may therefore be poorly prepared to deal with those motivated to deceive in this way.

PREVALENCE OF FABRICATED SEIZURES

Meadow, in several of his papers, cited seizures as the most common false illness to be invented by mothers.¹⁶⁻¹⁸ In the British Paediatric Surveillance Unit study, seizures were the second commonest presentation behind apnoeas in MSbP abuse (authors' data). Rosenberg also concurs with this observation and found that seizures were a presenting feature in 42% of MSbP cases.¹⁹ However, there are no accurate data on the prevalence of fabricated seizures compared with the wider paediatric epilepsy population, and reported cases are likely to represent the "tip of the iceberg". Schreier and Libow, in their book *Hurting for love—Munchausen by proxy syndrome*, surveyed 880 paediatric neurologists in the United States.²⁰ There were only 190 respondees (21.8% return rate) but 107 reported contact with at least one case of Munchausen by proxy.

Seizures are especially vulnerable to fabrication for various reasons. They are fairly common (therefore evoke a high level of public awareness and sympathy), often discussed as part of the differential diagnosis of less serious conditions (high levels of suggestibility), perceived as medically serious and urgent (therefore "appropriate" for an acute presentation), frequently run a chronic, relapsing, and remitting course, and the physician is almost entirely dependent on history to make the diagnosis.^{4 16-18 21-23} There is no test which can absolutely refute the diagnosis. The epilepsy "sufferer" and the parent enjoy a certain morbid status in society and may be eligible for disability benefits.

MORBIDITY AND MORTALITY IN FABRICATED SEIZURES

There is little research focusing on outcomes in MSbP.^{2 3 7 19 24} Death rates are generally quoted as being around 10%.^{3 19} Surviving children are subject to unnecessary medical contact, investigation, and treatment which causes a degree of physical harm but more worryingly, an adoption of the sick role by the child and a self image as an ill or disabled person. This will seriously harm the child's emotional and social development and can lead to long term abnormalities in relating to health services.

Some children may go on to develop Munchausen syndrome or somatisation disorder themselves. Other abuse or emotional disturbance may coexist in the same family. This is reflected in the range of disorders seen in victims including emotional disorders, school related problems, poor concentration, and school attendance.⁷

Unfortunately, improving outcome by child protection intervention may be difficult if the abuse is not detected early. Statutory agencies, in the authors' experience, are more likely to intervene decisively if there is physical or sexual abuse, or neglect of a young infant. Fabricated illness abuse and emotional harm, particularly in older children, tend to be allowed to drift, despite the recognition that they may be damaging in the long term.

Some child victims of abuse with fabricated seizures die, often suddenly. Possible mechanisms include smothering, poisoning, and status epilepticus due to manipulation of medication by the perpetrator. If the fabrication is not recognised, children may be said to have died for no identifiable cause, a recognised phenomenon in epilepsy (sudden unexpected death in epilepsy or SUDEP). Survivors of smothering, poisoning, or induced status epilepticus may be brain damaged or suffer chronic invalidism. The most vulnerable victims are those under 5 years of age, where abuse has involved suffocation or poisoning,³ where there has previously been a sudden death in the family, where there are adverse social factors, and where there is persistent denial by the perpetrator after confrontation.¹⁴ A long delay in making the diagnosis also suggests a poor long term prognosis.³

PERPETRATORS

In common with other types of fabricated illness, mothers are implicated much more frequently than fathers. The perpetrator must necessarily be someone with responsibility for caring for the child and will need to be spending some time alone with the child in order to engineer a fabricated illness.²⁵ Archetypal MSbP personality types and risk factors for this abuse have been described and it is beyond the scope of this article to discuss these in detail, though it is clear that there is a wide range involved and that MSbP abuse cannot be diagnosed from "profiling" the suspected perpetrator.^{18 26-28}

Perpetrators of fabricated seizures may be less likely to be from a medical or nursing background than in other forms of fabricated illness, where more esoteric presentations may be the mode.¹⁸

In the authors' experience perpetrators are quite frequently complaining, hostile, and aggressive in their interactions with healthcare professionals. Taking hospital discharge against advice

may be a significant risk factor.²⁹ The threat of complaining behaviour by the perpetrator may be a significant deterrent for a paediatrician at the point of diagnosis or during subsequent management. The authors are aware of cases where child protection procedures have been stifled by a formal complaint by the perpetrator. There is a challenge here not only for professionals but also their employers and professional bodies, since failure to manage a complaint effectively can lead to a failure to protect the child.^{30 31}

IMPLICATIONS FOR PERSONAL PRACTICE

It is necessary to question whether carers are being truthful without becoming so sceptical that the usual confident partnership between most doctors and their patients is lost. There is a risk of becoming over defensive for fear of missing a child abuse case, just as there is a risk of over reacting to the increasing threat of litigation over clinical errors.

A clear understanding is necessary of the reasons why patients or carers consult, the different personal styles of communication, cultural variations, the dynamics of the physician/patient relationship, and how we as clinicians respond to them and reinforce healthcare seeking behaviours. This implies a level of self awareness of our personal vulnerabilities such as fear of missing a diagnosis, the need to feel approved of or thorough, and to concede to parents. With proper awareness of the dynamics of the consultation the paediatrician is better placed to help with real issues. The social and cultural background and knowledge of the parents and their family can be woven into the assessment and differential diagnosis.

The importance of collaboration with other professionals has been emphasised previously.³² Primary healthcare workers are ideally placed to raise suspicions since they have wider knowledge of the family and access to previous healthcare records. The paediatrician needs to communicate with and recruit the family doctor at an early stage, preferably by direct contact. This should prevent professionals confounding attempts to clarify the diagnosis, for example by referring the child for second opinions or submitting applications for benefits.

Where the diagnosis is reliant on the history, as is the case with seizures, it is particularly important that the possibility of fabricated illness should be considered from the outset. The abuse hypothesis must be considered and the evidence in favour or against genuine illness, the need to initiate early treatment, and the potential pitfalls and implications of inappropriate management should be carefully balanced. Hypothesis

testing as an approach to clinical problem solving should be a basis for training of doctors in paediatrics, and professional examinations should test this.

PRACTICAL GUIDELINES **How to avoid making a false diagnosis of epilepsy**

- The starting point is a meticulous history supplemented by carefully chosen diagnostic tests.
- Consider first the differential diagnosis of paroxysmal events (gastrooesophageal reflux, gratification phenomena, breath holding attacks, cardiac arrhythmia, syncope, metabolic disturbances, reflex anoxic seizures, and pseudoseizures).
- Look for clinical epilepsy syndromes with typical supporting electroencephalogram (EEG) findings.
- Ask the carer to video "episodes". Most families have the means to do this and some hospitals may be able to loan equipment.
- Do not start treatment until sure. As a minimum, seek independent corroboration of a parent's history or supportive EEG findings. It is rarely necessary to start anticonvulsant medication immediately and it is good practice to have EEG information beforehand.
- Be especially wary of making the diagnosis if the EEG is normal. Seek confirmation from purported witnesses early on in the course of investigation, preferably an independent third party.¹⁶
- Beware of the carer who uses the threat of harm coming to the child to influence clinical decision making.
- Consider hospital admission if the reported episodes are frequent. Cessation of episodes during periods of observation is suspicious.
- Actively seek to verify details given by the carer regarding the seizures or other aspects of history.
- Question discrepancies—children with severe, polymorphic epilepsy do not generally have normal neurodevelopment.
- Take and analyse blood and urine from any child presenting for the first time with a seizure—they may have been poisoned.²⁸ Ensure that the urine is screened for relevant substances, not just drugs of abuse. Store serum so future quantitative analysis is possible.¹³
- In the sick child glucose and electrolytes will usually be checked. An electrocardiogram should also be routine—it may provide a clue to poisoning with tricyclics.^{33–35}

- If poisoning is suspected, collect other body fluids (for example, vomitus or fluid from gastric lavage).
- Look for subtle signs of smothering (for example, petechial bruising to the face or nasal bleeding).
- Arrange appropriate supportive investigations including prolactin levels, raised glucose, and white blood count (following prolonged, generalised seizures), prolonged EEG or video-EEG records, pH studies, or tilt table tests.

How to make an early diagnosis of fabricated seizures

- Corroboration with the health visitor, general practitioner, and other members of the primary health team. Discuss with other health professionals who have had contact with the family. Be especially suspicious if the parent tries to frustrate these efforts.¹³
- Identify a temporal relation between symptoms and the mother's presence—this has implications for detailed nursing records if a child is having events as an inpatient.²⁸
- Take a detailed history, including family medical history and build this information into the eventual hypothesis.
- Look for evidence of risk factors for fabricated illness (for example frequent, medical contacts with no objective evidence of illness or typical perpetrator features).¹³
- Make arrangements to see and interview the absent father; he may be able to refute details that the mother has provided.
- Investigate thoroughly and promptly. Document relevant negative investigations.
- Covert video surveillance may rarely be needed but should not delay action to protect the child. Local protocols may already be established.
- Keep nursing records separately from the child so they cannot be tampered with. Ensure entries made by the mother are labelled as such (for example, fit charts).
- Where detail is secondhand or reported, indicate this in notes and nursing record.
- When the time comes for presenting evidence in court, meticulous notes will pay dividends.

How to avoid unnecessary escalation of medical involvement

- Consider the possibility of fabrication or exaggeration at every stage.
- Be especially suspicious of those who are allegedly unresponsive to usual treatment.

- Caution if the child's epilepsy deteriorates at times of social stress.
- Check drug levels and toxicology on every admission with a seizure. Liaise with emergency departments to ensure this is part of their protocol. Low levels may indicate deliberate withholding of medication. Beware toxicity when medication is restarted in hospital; the cause of the child's poor epileptic control may be that the carer was withholding the medication previously (for example, carbamazepine).
- Resist attempts by the carer to escalate investigations or treatments or seek inappropriate second opinions.
- When parents insist on second or further opinions, share your concerns with the family doctor, social services, and the next specialist in line.
- Consider weaning anticonvulsant medication as an inpatient if fabricated epilepsy is suspected.
- Watch out for "recruitment" of colleagues by the carer and share information.

How to secure appropriate support for these children

- Where the diagnosis of fabricated seizures is suspected, the opinion of a psychiatrist is a valuable contribution in the assessment of the parent-child dynamic and degree of psychological disturbance the child has incurred.
- Document objective details that the child is suffering significant harm (for example, failure to attend school, exclusion from normal childhood, days in hospital, number of admissions and investigations).
- In less serious cases, try to shift the focus of the consultation from the child to the mother. Ask how they are coping and suggest appropriate referrals for themselves.
- If the parents cannot be dissuaded from their perceptions and actions that are harming their child with careful and sympathetic help, child protection procedures will need to be invoked.²⁸ The stage at which this intervention will be appropriate will depend on the degree of proof and the degree of danger that the carer's behaviour is creating for the child.¹⁴ The diagnosis is made on the balance of probabilities and delay in protecting the child should not occur.
- At some stage, even in less worrying cases, it will be necessary to point out to the carer that their behaviour is causing harm to the child and that they need to change. This will nearly always need to be preceded by a multiagency strategy discussion.

- In major illness induction situations or with a potentially violent perpetrator, the child may need to be protected at the same time as the perpetrator is confronted.
- Ensure that social services professionals are fully informed of the nature and implications of the abuse.
- A period in foster care may be necessary to show that the “episodes” cease when not in the care of the perpetrator.
- Where the doctor making the diagnosis is not an expert in child protection issues, a colleague with this expertise should be involved early and should assume ongoing consultant responsibility and arrange review.³
- It is essential that the doctor who has made the diagnosis is present at the strategy meeting and initial child protection case conference, as well as the paediatrician who will review the child, to ensure that an appropriate response occurs.¹⁴
- Siblings may be subject to fabricated illness or other forms of abuse and must be considered in the child protection process.³
- A commitment to long term follow up of the child by an expert in child protection is necessary in view of the recognised long term sequelae.³

CONCLUSION

Paediatrics and child health historically evolved from adult medicine because of a recognition of the need to look at our patients as children first and foremost, recognising their vulnerabilities, dependency, and developmental requirements. Children thrive on a holistic approach to health care, with maximum communication between the different professionals providing services. Increasing specialisation within the profession creates greater problems in communicating and coordinating care, with a huge potential for a “collusion of anonymity” which could prevent children from being protected from abuse. The training of future generations of child health professionals needs to address this, with a clear emphasis on child welfare and child protection issues in all specialities. It is not the exclusive role of specialists in either epilepsy or child protection to diagnose fabricated seizures. They can, like other fabricated illnesses, present to any one of us and all of us need these core skills.

Fabricated seizures, however, deserve particular attention from epileptologists, and general and community paediatricians. They are common, difficult to detect, easy to manage badly, and of great significance to the child if not detected early.

New curricula in medical schools recognise the concept of integrated medicine, which is a sound basis for preventing and arresting the harm to children that arises from child abuse. We all need to embrace this philosophy and incorporate these principles into our professional activities. Fabricated seizures present a stern test of our abilities in this respect.

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