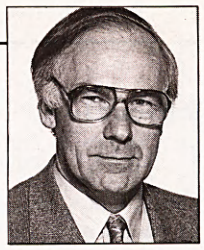
Who's to blame—mothers, Munchausen or medicine?



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This article is based on the Charles West lecture given at the Royal College of Physicians on 7 October 1993 by **S R Meadow**, Professor of Paediatrics and Child Health, St James's University Hospital, Leeds and President of the British Paediatric Association.

Who's to blame . . . ?

> 'Nobody who has not been in the interior of a family, can say what the difficulties of any individual of that family may be.'
>
> Jane Austen

Baron Munchausen (Fig 1) was an extravagant liar, relating fantastic accounts of his worldwide travels and a journey to the moon. It was because of the twin characteristics of telling false stories and travelling widely, that the late Dr Richard Asher (Senior Physician at the Central Middlesex Hospital) used the term 'Munchausen's syndrome' to describe patients with a particular form of abnormal behaviour [1]. Asher's addition to medical terminology has endured and is in widespread use throughout the world to describe the notorious hospital hopper who presents with a dramatic and untruthful story of illness in successive hospital accident departments in different cities. The term is applied more for men than for women, and is used more by those who are not psychiatrists than by those who are: psychiatrists have a more elegant and detailed classification for the somatisation disorders.

About 25 years after Dr Asher's paper I described two children whom I had encountered in my work as a paediatric nephrologist [2]. One was a six year old for whom the mother, throughout the child's life, had provided fictitious information about the child's symptoms and had tampered with her urine samples to cause false results and innumerable investigations for her daughter in different medical centres. It became apparent that when the urine samples were collected from the child by the mother, the samples disclosed microscopic haematuria whereas they were normal when collected solely by the nurses. Microscopic haematuria does not switch on and off but waxes and wanes. It is patients and parents who do the switching, and in this case the mother was switching her own urine (which disclosed haematuria and pyuria) for the child's.

The other index patient was a young boy who had presented from the age of six weeks with recurrent severe illnesses associated with hypernatraemia. Measurement of his sodium intake, excretion and total body sodium showed that he must be ingesting dangerous quantities of sodium chloride. We found that he would not eat or drink so much salt voluntarily, so it had to be his mother (who was resident in hospital with him) who was forcing it into him. The social services in the city where he lived found this difficult to accept; to make matters worse, when they asked me how these quantities of salt might be getting into the boy, I replied with naive sincerity that perhaps his mother, a former children's nurse, was administering it by nasogastric tube. It was all too much to believe: he remained with his mother, and died at the age of 15 months with a serum sodium of over 200 mmol/litre. These two cases were reported in the *Lancet* with the title 'Munchausen syndrome by proxy: the hinterland

Fig 1. *Frontispiece of the 1895 edition. Baron Munchausen: fantasist, traveller and raconteur.*

of child abuse' [2]. There was no doubt that the two children had been severely abused. The factitious illness had been invented for them by another person, a proxy, hence Munchausen syndrome by proxy.

That was over 15 years ago, and those involved with cases of factitious illness by proxy at that time will know what a difficult and lonely time it was, with incredulity and scepticism from social workers and other child protection agencies, from the courts, coroners, police and even from friends and close colleagues.

But times change and in the last 10 years Munchausen syndrome by proxy has been recognised as a serious form of child abuse occurring in all countries. At the beginning of 1993 there was a sensational murder trial in which a nurse was found guilty of 13 charges of murder, attempted murder or gross bodily harm to children on the paediatric ward in Grantham, and was proclaimed by the popular press to be 'suffering from the incurable disease of Munchausen syndrome by proxy'. In the same year, a child who seven years earlier had incurred Munchausen's syndrome by proxy abuse claimed damages against his mother, whilst a mother who, over a period of nine months, 10 years ago repetitively smothered her one year old son, has started to sue the paediatrician for failing to diagnose earlier the Munchausen syndrome by proxy abuse.

Meanwhile, in Australia, a child psychiatrist who had been asked to help a family with a seriously ill child believed to have congenital glycerol kinase deficiency did some private detective work and showed that all the child's problems were the result of repetitive poisoning by the mother. Subsequently, the Medical Board of Australia, the equivalent of our General Medical Council, arraigned him for unprofessional conduct on the grounds that he had obtained the mother's medical records without her consent and also had interviewed her under another pretext.

Elsewhere, a 53 year old lady, in the course of consultation with a psychiatrist, admitted that she had killed her young son with salt nearly 20 years ago (not realising that both she and her son had featured in the *Lancet* as one of the first two examples of Munchausen syndrome by proxy abuse [2]). The psychiatrist felt bound to report her confession to the police. After the police had investigated her, they asked me whether it was possible that she could, as she said, have given it to the boy using a Ryle's tube.

The year ended with a television programme alleging that improper methods were being used to diagnose Munchausen syndrome by proxy, and that the condition was being over diagnosed. Times do change.

Definition

The term Munchausen syndrome by proxy has mainly been used in relation to children, though it may happen to the elderly, mentally handicapped and other dependent persons, and veterinary surgeons recount that some people impose it upon their pets.

In relation to children, the term can be used if the following criteria are fulfilled:

- the illness is fabricated by the parent or someone *in loco parentis*;
- the child is presented to doctors, usually persistently;
- the perpetrator (initially) denies causing the child's illness;
- the illness clears up when the child is separated from the perpetrator.

Characteristics

The abuse mainly affects young children who cannot speak for themselves. The false illness may last from a few months to several years before the deception is uncovered. The main presentations reveal that any system may appear to be affected, and multisystem disorders are often suspected (Table 1). The false diagnosis results mainly from the mother's story because we often have to base our diagnosis and management entirely on what she tells us (eg epilepsy, when we rarely see the seizures ourselves). A proportion of mothers substantiate the diagnosis with false signs, and a minority directly harm the child to cause signs of illness in the child. It does not need great imagination to work out ways in which the alleged disorders shown in Table 1 can be simulated. Haematemesis, haematuria and other bleeding episodes are created by the mother, usually using her own blood, by injuring herself or using a vaginal tampon during menstruation which she stirs into a sample of the child's vomit, faeces or urine. Sometimes raw meat is used as the additive.

Table 1. Presentation of Munchausen syndrome by proxy.

Common presentations	
Nervous system	Seizures, apnoea, drowsiness
Gastrointestinal	Vomiting, diarrhoea, failure to thrive, haematemesis
Respiratory	Apnoea, breathlessness, haemoptysis
Renal	Haematuria
Endocrine	Glycosuria, hypernatraemia, biochemical abnormality
Allergy	Rashes, diarrhoea, wheezing
Less common presentations	
Educational	Dyslexia, disability, special needs
Skin	Dermatitis artefacta
Orthopaedic	Locked joints
Cardiovascular	Sick sinus syndrome
Child abuse	False allegations

Children are made drowsy by doses of the common hypnotics and tranquillisers. Some drugs given by the mothers have also caused seizures, but the commonest form of factitious seizure is likely to be due to anoxia: the mother obstructs the child's airways to stop him breathing and a hypoxic seizure follows to which she draws the attention of the doctor or nurse. Examples of mothers adding sugar, salt, bicarbonate of soda or other cooking ingredients to samples of the child's blood and urine are numerous [3,4]. Many of these samples have kept some prestigious biochemical laboratories both busy and stimulated for a long time. Dermatitis artefacta is easy to diagnose when it is known to be happening, but notoriously difficult when it is not. Mothers have used caustic solutions on the skin, or repetitively rubbed their finger nail against their child's skin to cause vesicular lesions. There are innumerable examples of mothers injecting contaminated solutions into intravenous lines to cause recurrent septicaemia, inserting drugs down nasogastric tubes, diluting their baby's milk or sucking back the gastric contents via the nasogastric tube after a feed to ensure their baby fails to thrive. Several mothers have removed blood from central lines to make their children anaemic.

A more recent addition to this list of factitious illnesses has been false allegation of abuse: mothers have taught their child to give a realistic disclosure of, say, sexual abuse, have rehearsed her using tape recorders and injured her in ways to simulate that abuse. Such false allegations have occurred outside the context of divorce and custody disputes and seem to be another example of the need for mothers to focus attention on themselves, using their children to do so [5].

The consequences for the children range from repetitive and unpleasant investigations to a host of needless surgical and medical treatments. Several children have had to endure two or more years of parenteral feeding, diversionary gut operations, biopsies of many different organs and hundreds of venepunctures. Other children have been prescribed more than 30 different drugs for their non-illness, including courses of cytotoxic agents and steroids. Apart from the needless investigations and treatments, the mother's actions and those of the doctors may actually induce disease in the children. Repetitive smothering to cause a seizure is recognised increasingly often, and can result in brain damage and sudden death [6].

If the factitious illness is not detected early, it may persist through the school years, the child joining with the mother in a game to deceive the doctors, until eventually the child takes over the false illness story and presents with Munchausen syndrome as an adult. A few years ago such a young man repeatedly appeared at the accident departments of several teaching hospitals claiming that urine was coming out of his umbilicus. Almost without exception, the senior house officers wrote on the casualty card 'patent urachus—surgeons to see'. It is a remarkable testimony to our skills as medical teachers that they did so—if the same young man had gone to the local pub with the same story, the locals would have said 'you've got a screw loose'. More commonly, school-age children may be brainwashed into believing themselves to be ill and to be chronic invalids.

The children have often suffered other forms of abuse too. We found that nearly a third of 56 children who had incurred factitious illness abuse had failed to thrive in early life and nearly a third had suffered either previous physical abuse, neglect or inappropriate medication [7]. Only one-third had been free of other forms of abuse (Table 2). Over 40% of their siblings had incurred abuse (Table 3). It was ominous that 11 of the siblings had died suddenly and unexpectedly in early life, several categorised as sudden infant death syndrome. Early in the investigation of families, my hope was that the deaths had indeed been natural deaths and were a contributory factor to the subsequent maladaptive behaviour of the mothers. But after investigating more of these families in depth, it has become apparent that most of the sudden and unexpected deaths were caused by the mothers themselves, usually in the context of Munchausen syndrome by proxy abuse.

Perpetrators

From personal experience of over 300 families in which such abuse has occurred and also from the literature, it is clear that the usual perpetrator is the child's mother, in five per cent it is another female carer, such as a child minder or nurse, and in another five per

Table 2. Comorbidity for 56 children.

Comorbidity	No.	(%)
Other fabrication	36	(64)
Failure to thrive	16	(29)
Non-accidental injury/neglect/medicated	16	(29)
None of these	15	(27)

Table 3. Comorbidity for 103 siblings (43 families).

Comorbidity	No.	(%)
Munchausen by proxy	40	(39)
Failure to thrive/non-accidental injury/neglect/medicated	18	(17)
Died ? cause	11	(11)
None of these	59	(57)

cent the child's father. Certain features are particularly common in the perpetrators. As with artefactual illness in general, those with past nursing experience are over-represented—a desire to nurse and to be nursed are closely linked. A significant proportion (20–30%) themselves have marked somatisation disorders. Their child's false illness seems to be an extension of their own personal false illness, but it is common for them to alternate. The mother has a prolonged period of false illness until she then forces the illness on to the child for a year or more before she reverts to false illness herself.

The mothers' own family backgrounds usually reveal much unhappiness. When young, they lacked love and respect from their own mothers, and in some families there was also overt physical or sexual abuse [8].

It is usual for the perpetrator's spouse to be unaware of the deception and to disbelieve the revelation. This itself says something about the quality of the partnership and the husband's less than participatory role in the upbringing and care of the child. Some of the marriages have been amongst the most bizarre and ill assorted that I have encountered. The perpetrating mother is commonly an alert, intelligent and socially more aware person than her rather feeble unenterprising husband. Alternatively, she is a worried, inadequate woman with a dependent personality, and has a particularly 'macho' partner who spends the evening in front of the television, reading *Gun Weekly*, whilst his wife cooks offal for his Alsatian dog.

Mothers with a marked somatisation disorder are particularly difficult to help and are unlikely to change their behaviour. Although most of them are not a danger to children other than their own, there are notorious exceptions [9], and someone who has severe abnormal illness behaviour verging on Munchausen syndrome should not be allowed to care for children or for elderly or mentally handicapped people.

It is uncommon for the mother to have a treatable mental illness, but most have a substantial personality disorder and fulfil the criteria for one or more personality disorder [8]. The commonest personality disorders identified were borderline, histrionic, dependent and avoidant. Not all mothers with marked personality disorders, however, harm their children.

An individual's personality usually stays for life, though it may mature and sometimes mellow with age. The actual expression of personality is most influenced by circumstances in life. The circumstances in the lives of these mothers precipitate their abusive behaviour; for some, it seems to begin during pregnancy, when resentment of changing circumstances and lifestyle produces hostile feelings to the child and often self-induced complications of pregnancy; for others, the unpleasant reality and difficulties of caring for a child, particularly when living with an unsupportive partner in difficult circumstances, engender considerable hatred for that child. In these circumstances, mothers act in ways which bring them personal satisfaction and they seem able to shut their eyes to the suffering they are causing their child. An ill child can generate support from relatives, and also alter the habits of an absent husband—sharing an ill child with your partner may be better than sharing nothing. The mother generally comes in contact with other parents of genuinely sick children, and if it appears to be a rare illness, the local community, newspapers and media give the mother self esteem. The ill child provides the mother with access to a large number of supportive agencies. Most paediatricians would admit that a paediatric unit is a disguised mental health facility which is readily available to families, and rather more acceptable than one with an alternative title. Health services in general provide readily available help, and for a modern family in trouble a medical illness is one of the few available tickets to such help: involve a child and it can be a first-class express ticket.

Schreier and Libow, child psychiatrist and psychologist, respectively, claim that the perpetrator harms the child because she is in love with the paediatrician [10]. As in a Restoration play:

> 'Through all the drama, whether damned or not, love gilds the scene and women guide the plot'.

It is not a ridiculous hypothesis and I am aware of families to whom this could apply.

I quote from a letter written by a mother who was resident with her three year old child at a famous children's hospital. Unknown both to the referring paediatrician and to those at the tertiary centre, she had been repetitively poisoning and suffocating her son for nearly three years. She wrote from the tertiary centre to her district general hospital paediatrician:

> 'When you spoke to me on Monday, you said maybe you were too close to us, and that maybe it was good that a complete new look at this whole situation would help. For my sake, please do not give up on us, I *need* you because as long as you are strong, I can be strong too . . . Please do not be afraid for my strength—as long as you are with me, I can cope. I desperately need to know that you are there, and I honestly believe you are . . .'

In another context this would be a love letter. The specialty of paediatrics has men and women with more than the usual allocation of kindness, tolerance and empathy. Such doctors are a haven for a lonely mother who cannot cope with child rearing.

It would be naive to suggest that there is a single reason for the behaviour of different mothers abusing different children in different circumstances. A minority are consumed by feelings of considerable hatred and violence to their child and may admit it years after the event. When they do so, they usually say that whilst they did hate their child when they were pressing their hand over the child's mouth and making him unconscious, or scarifying the skin, or starving or poisoning him, they nevertheless wished that someone would

take him away because they really wanted their child to be looked after and loved by somebody else.

The mother's partner in the abuse of these children is the doctor. Some will say that there is no such entity as Munchausen syndrome by proxy and that it is merely medical misdiagnosis and maltreatment. Some of the most painful experiences for the children result from the doctor's actions rather than from any direct action by the mother. The mother provides false information but usually leaves others to harm the child.

Does modern medical practice predispose to Munchausen syndrome by proxy?

Some will say that the more frequent recognition of Munchausen syndrome by proxy abuse reflects modern medical practice. However, this syndrome did not originate in 1977 when the term was first used. This is not a *new* form of human behaviour; what has been claimed to be new has simply not been recognised, reported or described in the past. It has been known for centuries that patients and their relatives sometimes exaggerate symptoms. Smothering and suffocation were vividly reported in Victorian times. There had been many accounts of non-accidental poisoning before the historic papers of Henry Kempe [11] and more recent reviews [4,12,13]. Nevertheless, it is reasonable to wonder whether there are factors in modern medical practice which predispose to factitious illness abuse. I believe that there are.

When I was appointed a consultant in 1970 some children's wards allowed parents to visit their children only on Wednesday and Saturday evenings between the hours of 5 and 6 pm. Such arrangements made continuation and escalation of factitious illness abuse by mothers impossible. Today, with unrestricted visiting and resident parents, it is all too easy.

Another factor is the present-day lack of contact between primary and secondary care doctors. Lay people are surprised that the general practitioner's (GP's) knowledge of a deviant family is not known to those being deceived by that family in hospital. There was more chance of the information being shared 30 years ago when GPs regularly visited their patients in hospital. Yet now it is common to find that the voluminous notes of a child who has been extensively investigated in different centres contain little or no information about the mother's own health, background or family.

We may not know the intimacies of another family, but we can talk to other family members and gain some understanding. In many of the abusing families, a few conversations with the relatives of either the child or the mother would have led to early recognition of abuse, prevented damage and death of children, and helped the family.

Increasing specialisation and technological advances also increase the risk of factitious illness through failing to consider the whole child in the context of the family. Some paediatricians are readier to order magnetic resonance imaging or a biopsy than to spend more time listening to the mother and dissuading her from yet further investigations of her child. The tendency for over-investigation and over-treatment as a result of pressure from parents and patients also facilitates Munchausen syndrome by proxy abuse. The records of children who have suffered factitious illness abuse reveal, on the one hand, how fearful doctors appear to be of missing organic disease and, on the other, of making a positive diagnosis of non-organic disease. The reason is less the fear of litigation than our medical training and approach to patients. In the massive records of children who have been proved to have suffered factitious illness abuse, there is commonly a page headed 'differential diagnosis' or, equally often, an acetate sheet on which are listed six or seven rare disorders, one of which is Munchausen syndrome by proxy, which has been used to discuss the child at a clinical meeting. The presenter has drawn a line through each of the possibilities, leaving only one—Munchausen syndrome by proxy. Despite that, no positive action has been taken, by way of excluding the mother, discussing the possibility of abuse with her or other family members, 24-hour monitoring of the child or covert surveillance. Presumably someone suggested yet another bizarre investigation or new management regimen rather than face up to the proper diagnosis which an informed, logical approach to problem solving had delivered.

Conclusion

Munchausen syndrome by proxy abuse is uncommon but serious because of its association with death, disability and suffering [14]. It is also important because it illustrates how parents and doctors sometimes act in ways that do not benefit children. It also raises difficult questions about the degree of trust one should place in the patient's or parent's story. Nevertheless, as physicians, we are most likely to arrive at the correct diagnosis and provide effective help if we listen carefully and *believe* the mother's story of the child's illness. I will still teach my students to listen to the mother because she will tell them the diagnosis. At the same time, we must allow a small corner of our minds to be sceptical and question the story to prevent children being exposed to factitious illness invented by their carers.

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