Betrayal of innocence

Parents who deliberately make their children sick to gain attention are clearly child abusers. But how often are doctors getting it wrong? James Randerson investigates

IT WAS a bizarre child abuse case. Janet stood accused of repeatedly half-suffocating her baby, Lucy (not their real names), then rushing her to hospital claiming the infant had suffered an epileptic fit. The court heard that Janet did it because she revelled in all the attention the doctors were lavishing on her and Lucy.

An alert doctor had become suspicious and brought Lucy into hospital for two weeks' observation. Despite supposedly having had numerous fits at home, she didn't have a single seizure. The doctor suggested a procedure to investigate whether Lucy's fits were real, and Janet threatened to take the child home. The court decided she was carrying out a form of child abuse called Munchausen's syndrome by proxy (MSBP), in which a parent invents or induces their child's illness. She lost custody of Lucy.

But Janet isn't a child abuser and has never hurt her baby. The authorities realised they had made a terrible mistake when Lucy had epileptic fits while in foster care. Eventually she was returned to her mother. "It has been a living nightmare," says Janet.

Some doctors and lawyers believe Janet's case is far from unique. No one doubts MSBP exists, but the critics say the syndrome lends itself to wrongful accusations. The science underpinning the condition is seriously flawed, they say, and claims of MSBP can be made with little supporting evidence – sometimes by people with scant knowledge of the condition or no medical training at all. Some even say the term MSBP is so misleading it should be abandoned. Has the label led to a spate of miscarriages of justice?

MSBP was first described in 1977. Doctors were already using the term Munchausen's syndrome to refer to patients who repeatedly harm themselves or fake illness to receive care and attention from medical staff. (The name was a nod to the 18th-century German adventurer Baron von Munchausen, who was famous for his fantastical tales.) By contrast, parents with Munchausen's syndrome by proxy – almost always mothers – faked or induced symptoms in their children so as to receive the attention from healthcare workers vicariously.

The case described in 1977 was six-year-old Kay. The child seemed to periodically pass blood in her urine, but doctors failed to locate the source of infection. The child endured various medical procedures – including two gynaecological examinations under general anaesthetic – and was given numerous medicines, some with unpleasant side effects. Only when a doctor discovered that Kay's mother had been adding her own blood to the samples was the mystery solved.

Sometimes MSBP makes the headlines. In 1993, the nurse Beverley Allitt became infamous in the UK as a supposed example of someone with the condition after being convicted of killing several children in her care. (Although a subsequent government inquiry concluded that she was actually psychopathic). And paediatrician David Southall at North Staffordshire Hospital in Stoke on Trent triggered widespread shock and disbelief when he used hidden cameras in hospitals to catch mothers in the act of smothering their babies.

In the US, Kathy Bush of Coral Springs, Florida, made her daughter Jenny ill by, for example, giving her overdoses of medicines and putting faeces in her feeding tubes. By the time Bush was found out, eight-year-old Jenny had been hospitalised around 200 times and undergone about 40 unnecessary surgical procedures, including removal of her gall bladder, appendix and part of her intestine.

It is often said in medical journals that there should be more awareness of MSBP, and that doctors take too long to realise what's going on. The perpetrators are expert at hoodwinking doctors, says MSBP expert Herbert Schreier, head of child psychiatry at the Children's Hospital, Oakland, California. "These mothers know what they are doing." And the consequences of failing to recognise MSBP can be fatal: it is said that one in three children in such cases dies.

But what do we actually know about MSBP? Estimates of its prevalence in the population are scarce, but the most systematic study was in the UK during the early 1990s. It suggested that around one child in 100,000 under five years suffers MSBP abuse. Estimates of the number of court cases in the UK range from 70 to 200 per year.

But despite the publication of around 450 papers on the subject, there is major disagreement about what exactly the syndrome is. While psychiatrists see it as a mental illness affecting the mother, paediatricians define it as a form of child abuse. "You certainly can't diagnose it by diagnosing the mother," says Jo Sibert, professor of community child health at the University of Wales, Cardiff. But this is precisely what psychiatrists do. For them, what matters is what motivates the parent.

The argument goes beyond semantics. Whether the term applies to the mother or the child goes to the heart of how you (or a jury) think about MSBP. For example, some lawyers have tried to use the diagnosis as a defence against prosecution – an insanity defence. And a claim of "MSBP made me do it" only makes sense if it is a mental illness.

Another serious consequence of this clinical turf war is that paediatricians and psychiatrists characterise perpetrators in different ways. Researchers in both disciplines have published lists of character traits or patterns of behaviour that they say perpetrators have in common. While there

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are some similarities between these lists, the two disciplines cannot agree on what behaviours in a mother should act as warning signs of abuse. Even within disciplines the various lists are contradictory.

So what should doctors look out for? According to the literature, an MSBP mother may be very involved in her child's care and spend large amounts of time in the hospital (see "Faking it", page 42). She typically builds close friendships with staff and is often knowledgeable about the child's condition. She may behave dramatically and draw attention to herself – or may seem calm and unconcerned about the child's illness. When challenged over her involvement she may become angry – or she may be calm and overly cooperative. "There's really no consistency in these symptoms," says Mark Roberts, a philosopher of science at the State University of New York, Stony Brook, who has researched the scientific basis of the syndrome. He says the lists amount to a catch-all diagnosis that can be made to fit virtually any woman.

Surprisingly, no one has looked to see how many mothers of genuinely sick children display any of these characteristics. Critics such as Roberts argue that for scientific validity, researchers should compare the behaviour of MSBP parents with control groups of parents of genuinely sick children. They say many of the supposed warning signs are extremely subjective and could equally describe a normal mother concerned about her child's care.

Even denying the abuse is seen as central to the MSBP diagnosis, so the mother is stuck in a catch-22 nightmare. "It's heads I win, tails you lose," says Tom Ryan, a defence lawyer who specialises in MSBP cases in Chandler, Arizona.

The science underpinning MSBP would not pass serious scrutiny in an undergraduate research methods class, says psychologist and MSBP sceptic Eric Mart of Manchester, New Hampshire. He argues that the medical literature is little more than a collection of clinical anecdotes with no attempts at confirmation. "There is a tendency to accept clinical lore as science," he adds.

Problems also stem from the syndrome's breadth, tarring mothers who have merely exaggerated their child's symptoms with the same brush as those who have done something extreme, such as poisoning. Exaggeration can have harmful consequences, triggering unnecessary medical procedures, for example, but it isn't supposed to be included in the MSBP definition. However, it can be difficult to distinguish between faking symptoms and exaggerating them.

One justification for lumping this wide spectrum of behaviour into one syndrome is the assumption that "exaggerators" and "inventors" move on to inducing illness. But there have been no scientific studies into how often that happens.

Even the supposed one-in-three death rate from MSBP may be scientifically baseless. The figure stems from a study of 13 children, four of whom died. But the cases had been selected for review specifically because of their severity. Nevertheless, the "31 per cent death rate" figure has been used in court to justify full withdrawal of parental rights from those convicted.

Recent events in court have begun to make MSBP's scientific foundations look even shakier. The scientist who coined the term MSBP is the controversial British paediatrician Roy Meadow, now retired. His evidence at the trial of solicitor Sally Clark in 1999 has been widely criticised and has placed his scientific credibility under intense scrutiny.

Clark was convicted of killing two of her children and served more than three years in prison before being released on appeal in January this year. As well as giving extensive evidence about MSBP at the trial, Meadow presented a now infamous statistic – that the chance of there being two cases of sudden infant death syndrome (SIDS) in the same family is 1 in 73 million. To reach this number, he had assumed that the two events are statistically independent – they have no potential cause in common – and so had multiplied the chance of a family experiencing one SIDS death by itself. He ignored the fact that there may have been features of the household environment or shared genetic factors that contributed to both deaths. Meadow seems to have little understanding of basic statistics, says Mart.

Meadow's scientific credibility is important because he wrote many seminal research papers establishing the validity of MSBP as a syndrome. What's more, he has been key to the successful prosecution of many MSBP cases, as an expert witness.

While one error does not automatically invalidate a scientist's entire career, making such a basic mistake when the stakes were so high suggests his previous work does need investigation. When contacted by *New Scientist*, Meadow refused to comment, or discuss any aspect of the science behind MSBP.

Another danger is that, more than other forms of child abuse, the vague and all-encompassing profile of an MSBP parent lends itself to malicious allegations. Fathers in custody battles have been known to make false allegations against their former partner. Even healthcare professionals have done so, as a defence against a patient's complaint of malpractice, says Ryan. He says he knows of more than 20 cases in the US where he believes a father or doctor has made a malicious allegation.

In the UK, psychologist Lisa Blakemore Brown of West Sussex, who has extensive experience of MSBP, says she is aware of more than 30 cases where allegations have only been raised after a parent has complained about a doctor.

Even local education authorities have made suspect MSBP allegations, she says, against parents fighting for funding for costly special-needs education for the sick child. *New Scientist* has spoken to a mother who believes her LEA has behaved in this manner. She cannot be named for legal reasons – her claims are difficult to prove, and the LEA denies any motives but the best interests of the child. But her story is grim. As well as denying her child the special education he needs, she says, the allegations have ruined her reputation in her local town. "It's like a modern-day witch-hunt," she says.

In both the UK and the US, most MSBP custody hearings take place in family courts (known as juvenile courts in the US) where proceedings are not open to public scrutiny. Significantly, these courts also use a lower standard of proof than criminal courts. In the UK and some American states, the prosecution must prove its case "on the balance of probabilities", not "beyond reasonable doubt". When the wrong judgment risks placing a child in danger, the courts understandably want to err on the side of safety. But this can mean that the accused effectively has to prove their innocence rather than the prosecution prove their guilt.

A recent court ruling in three test cases has offered some hope to British families pulled apart by false MSBP accusations. Last month three appeal court judges ruled that children could, in future, sue healthcare trusts and local authorities in cases where their parents are wrongly convicted of child abuse, including MSBP, though parents themselves have not been given this right. Whether the potential for legal consequences will deter doctors and social workers from making malicious MSBP allegations remains to be seen.

Lord Howe, opposition health spokesman in the UK's House of Lords, believes that the combination of closed family courts and shaky science behind MSBP has led to numerous innocent mothers losing their children. "To remove a child from his or her parents is one of the most draconian things a society can do," he told *New Scientist*. This means, he says, that in such cases the science should be unassailable, which is currently not the case. Howe says he has "grave doubts" about the validity of MSBP as a syndrome.

Some doctors believe we should abandon the label MSBP and equivalent terms such as "factitious disorder", and replace them with statements of known facts about individual cases. The label "is of no help diagnostically or therapeutically", says Colin Morley, professor of neonatal medicine at the Royal Women's Hospital in Melbourne, Australia. "It just raises the emotional temperature and blankets a reasoned, rational approach." ▶

Ryan agrees: "Why not call it what it is? Why give it this esoteric name which doesn't add to your knowledge?"

No one *New Scientist* spoke to said this kind of abuse doesn't exist – there have been many cases where it has been proven beyond doubt, and obviously health professionals who suspect it must investigate. But critics say groundless accusations of MSBP are ruining children's lives by condemning innocent parents. If parents really have fabricated or caused symptoms then doctors should simply describe what has happened, says Roberts. "Don't call it MSBP, call it child abuse."

Janet's conviction almost had terrible consequences for the rest of her family. She has since had a son with a congenital heart condition, and he nearly died when doctors who knew of the MSBP allegation doubted his symptoms were genuine. "I've got this label now and no one takes me seriously," says Janet.

Even now, Janet continues to be treated with suspicion by doctors. There is a yellow sheet of paper in her daughter's file that details the MSBP conviction. She has never read it but she has read the reaction on the faces of doctors who see her children for the first time. "They open the notes and there is this silence," she says. "After that I'm treated like a freak." ●

FAKING IT

Below are some of the characteristics of parents that are taken to be indicative of Munchausen's syndrome by proxy (MSBP). Sceptics say they could equally apply to innocent parents

- **Often has some medical training**
- **Knowledgeable about the child's illness**
- **Persistently pursues tests or procedures**
- **Rarely receives outside visitors**
- **Overprotective, doting**
- **Overinvolved, almost becoming part of the medical team**
- **Denies MSBP when challenged**
- **Resists psychiatric treatment**

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