# Munchausen syndrome by proxy

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## ABSTRACT

Five children (3F:2M), in the age group 1 years to 11 years, with Munchausen syndrome by proxy are reported from the Sultanate of Oman. They were seen over a four years period from 1996-1999. In all these children, the mother came up with history of uncontrolled epilepsy. Carbamazepine was the most common antiepileptic drug used. One of these children remained hospitalized elsewhere for nearly 9 months, as a case of uncontrolled status epilepticus. It took 18 months to 6 years (mean 2.8 years) to establish the diagnosis and the mother was the offender in all. The main lead to diagnosis, was the disparity between history and clinical presentation to hospital. The carbamazepine levels were several times above the upper limit of therapeutic range. Munchausen syndrome by proxy very much exists here, but is possibly less recognized and needs immediate attention to formulate policies to identify and manage these children. It is necessary to create awareness even in the medical community, to recognise this problem. There is an urgent need to develop a child protection council at the national or regional level.

**Keywords:** Munchausen syndrome by proxy, seizures, antiepileptic drugs, drowsiness, counselling.

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Child abuse is emerging as a distinct entity in the Arabian Gulf, though previously considered a rarity, in this part of the world. After the initial report of child abuse, almost a decade ago from Saudi Arabia, more reports of Munchausen syndrome[1] by proxy (MSBP) and child abuse have appeared.[2-4] The term MSBP was first used to describe fabricated illnesses in childhood, by Meadow[5] in 1977 (also known as Meadow's syndrome). In a 2 year prospective study (1992-1994) to determine the epidemiological aspects of MSBP, non accidental injury and non accidental suffocation in the United Kingdom and the Republic of Ireland, the annual incidence was found to be 0.5/100,000 in children under 16 years of age.[6] From a total of 128 children, 55 (43%) suffered from MSBP. The 5 patients reported from the Sultanate of Oman were diagnosed from 1996 to 1999. It was initially challenging, for the health workers involved, especially the clinicians to go through the risks associated in diagnosing this condition in Oman for the first time.

## Case Reports.

***Patient 1.*** MMAK, a 6 year old girl was admitted on 23rd July 1996 for management of uncontrolled status epilepticus. The child was an in-patient in a different tertiary hospital since January 1996, being treated for uncontrolled epilepsy. She was born in hospital and on day five of life, was admitted to hospital with fever and fits. All investigations carried out were negative and an inborn error of metabolism and meningitis were ruled out. The child after 2 months on phenobarbital (PHB) was readmitted at 4 months of age with seizures. During this admission, metabolic work up for aminoacidopathies and organic academia were repeated and a brain computerized tomography (CT)

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scan was carried out. All the tests were normal. Around one year of age, in view of uncontrolled seizures, the child was sent abroad to the United Kingdom. All investigations including brain - magnetic resonance imaging (MRI) were normal and the child was referred back to the Sultanate on sodium valproate (SVA) and carbamazepine (CBZ). The child continued to have fits on and off and was being followed up at the same tertiary hospital. The parents also noted that there was developmental delay. She could sit at 8 months, walk at 2 years and speak monosyllables at one and half years of age. Until January 1996, the child was admitted several times at the same hospital for the control of seizures.

The last admission was in January 1996 when the mother reported frequent seizures and refused to be discharged from hospital until the child was completely seizure free. Subsequently the child was transferred to the Pediatric Intensive Care Unit (PICU) for control of refractory seizures. During this hospitalization, all drip sites on extremities had been exhausted and the child needed central venous line (Hickman cannula) for administration of various antiepileptic drugs (AEDs), intravenous fluids and other drugs. Unable to control the seizures in PICU, the child was transferred to the pediatric neurology ward of Sultan Qaboos University Hospital (SQUH). At the time of transfer the child was on ceftazidime and vancomycin for possible septicemia, CBZ, SVA, vigabatrin (VGB) and continuous midazolam (MDZ) infusion (3 mcg/kg/minute) for fits, 20% mannitol for possible raised intracranial pressure, iron, vitamins and salbutamol nebulization.

On examination, the child was responding only to painful stimuli. Cranial nerves were normal and fundal examination did not reveal any abnormality. Doll's eye movements were present. There were no localizing signs and other systems were normal. In addition to Hickman cannula for intravenous medication, the child also had a nasogastric tube, in place, for feeding. Various blood investigations including AEDs level were ordered. An electroencephatogram (EEG) was carried out which showed bilateral slowing.

The blood results available at the end of the day showed an amazingly high level of CBZ – 52.2 mmol/L (normal range – 3.7 – 12 mmol/L) when the child was only on 10 mg/kg/day of CBZ. Surprisingly PHB and phenytoin sodium (PHT) were also detected in the blood in therapeutic range when she was not on any of these drugs. On interrogation, the mother denied having given any other medicines. The nurses were given standing instruction to observe all seizures and the duty doctor was asked to contact the pediatric neurology team before deciding to give diazepam, intravenous or per rectal. On day 3, the dose of MDZ was decreased and by day 7, the child could sit up though ataxic, and she asked for food. The MDZ infusion was stopped on day 9. On the same day, an attempt was made to remove the nasogastric tube which was met with stiff resistance from the mother. The CBZ level at this time was 10 mmol/L. Subsequently, 3 days later, the mother complained that the child had 3 prolonged seizures the previous night which was not noticed by the nursing staff or doctors. On examination, the child was drowsy, ataxic and aphasic. CBZ level carried out at that time was 23.7 mmol/L, which baffled us. She started improving by the 3rd day, but became unconscious again the next day. CBZ level went up to 25.3 mmol/L. At this point of time, the diagnosis of MSBP was strongly entertained. It was extrapolated that the mother had access to restricted drugs and was probably using the nasogastric tube to administer the drugs. By then all medications including antibiotics were being stopped.

On the 20th day of hospitalization, after informing the administrators, the nasogastric tube and Hickman cannula were removed, despite strong protests and dire threats from the mother. Simultaneously the belongings of the mother were searched and tablets of PHB and bottles of CBZ suspension were confiscated by the duty administrator.

Thereafter the child continued to improve and was discharged after 25 days of hospitalization on SVA, ethosuximide (ETX) and VGB. The parents were also counselled. Thus, after 7 months of hospitalization in 2 tertiary hospitals, with more than a dozen EEGs, half a dozen brain CT scans, 2 brain MRI scans and hundreds of needle pricks, this girl went home walking, happy and cheerful, leaving behind a bad dream. MMAK continues to attend the pediatric neurology clinic. She is on 2 antiepileptic drugs at the lowest therapeutic levels and has not had any major seizures after discharge. She attends school and is doing well in her studies. She still bears the scars of the central line and venesections.

***Patient 2.*** HSSH, a 11 yeas old girl was seen in February 1996 in the pediatric neurology clinic with history of headache and frequent falls of one year duration. There was no family history of migraine or epilepsy. Neurological examination was normal.

Routine biochemical tests and brain CT scan were normal. The EEG carried out, had shown sharp discharges and she was put on CBZ (10 mg/kg/day).

The child was admitted to the pediatric neurology ward in October 1996, November 1996 and January 1997 with history of worsening headache, falls and drowsiness. The CBZ levels were 18.8 mmol/L, 14.8 mmol/L, and 25.7 mmol/L. The parents were confronted. The mother blamed the hospital and medical personnel for this. The child was taken against medical advice after recovery.

Later it was found that the parents took the child to Egypt, Jordan and finally to Germany. Six months later, the mother visited the outpatient department and briefed the doctors about their visit to Germany. With the diagnosis of migraine, the German doctors

recommended SVA prophylaxis, which the child's mother was giving at her own free will.

***Patient 3.*** A 7 year old girl WMHH, was admitted with vomiting, drowsiness and ataxia to a peripheral hospital in July 1995. She was treated initially for pyogenic meningitis and later for acute encephalitis, although cerebrospinal fluid studies were normal. She was discharged after 14 days of hospitalization.

A month later, she was admitted again with the same complaints and an underlying inborn error of metabolism was thought of, and the child was referred to SQUH. A detailed neurological examination, in addition to baseline investigations including complete blood count, electrolytes, liver and renal function tests and baseline metabolic work up did not reveal any abnormality.

Subsequently a repeat metabolic work up revealed borderline elevation of leucine, isoleucine and valine. A double protein load challenge did not produce any symptoms. The child was empirically started on thiamine and blood samples were sent to United Kingdom (UK) for biotinidase assay. Six months later, the child was readmitted at our hospital in a drowsy state with vomiting and dehydration. Repeat metabolic work up including aminoacidogram was normal.

The child recovered in 2 days time with intravenous fluids and was discharged on biotin, as the blood assay from UK revealed low biotinidase levels. Even on thiamine and biotin, she got admitted a fourth time with drowsiness and ataxia. Finally, in November 1996 during her fifth hospital admission, a random toxicology screen revealed CBZ toxicity (14.9 mmol/L) cliniching the diagnosis. The source of CBZ was the child's younger sibling suffering from seizure disorder and he was on CBZ.

The diagnosis of MSBP was confirmed, by the child confessing to the senior nursing staff that her mother used to force tablets down her throat, whenever she wanted hospitalization. The mother was confronted by the medical social worker and was counselled. Accepting her crime partially, she was repentant about the entire episode. All drugs were stopped and the child went home happy. The child with her mother visited the doctors twice the following year and has remained asymptomatic thereafter.

***Patient 4.*** ISMB, a two and a half year old boy was first admitted at the age of 10 months with history of uprolling of eyes and stiffening of limbs. Clinical examination of the child was normal. Routine investigations were unremarkable. The EEG had shown bilateral sharp temporal discharges. CBZ was started and the child was discharged. He was later admitted twice with history of uncontrolled seizures. Five months later the child was re-admitted through the pediatric emergency department with history of fits and drowsiness. The CBZ level at that time was 15.0 mmol/L. With this result the mother was interrogated and surprisingly she broke down and accepted the allegation of child abuse. She confessed that the history of seizures were also totally false and fictitious. The boy was followed up for 2 years and was found to be developing normally with no complaints.

***Patient 5.*** AASK, a three year old boy was first admitted in a tertiary hospital at the age of 8 months with history of bleeding per rectum. His systemic examination was normal. All base line investigations including complete blood counts, serum electrolytes, hepatic and renal functions, stool microscopy, culture and occult blood and coagulation profile were normal. Proctoscopy and sigmoidoscopy done, did not reveal any pathology. Red blood corpuscle scintigraphy for intestinal bleeding was also negative. Three months later, the child was referred to University Hospital with history of repeated seizures. The mother was suffering from epilepsy and was on PHT from one of the peripheral hospitals. A detailed neurological examination of the child was unremarkable. Serum glucose, calcium, magnesium, urea and electrolytes were normal. EEG and brain CT scan carried out, did not show any abnormality. Considering the fact that the mother was an epileptic and the child has been having typical unprovoked seizures, he was started on CBZ.

A day before planned discharge, the mother complained that the child had bleeding per rectum early in the morning. The child was submitted to a battery of tests for bleeding per rectum again; however all of them were normal.

A repeat proctosigmoidoscopy was yet again negative. The next 2 years saw the child being admitted sixteen times in various hospitals including SQUH, with history of uncontrolled seizures.

It was during the last admission in April 1999 that the mystery started unfolding. The child was admitted through the pediatric accident and emergency department in an unconscious state apparently following a prolonged seizure. The Child was drowsy and had nystagmus. All the metabolic work up was normal except the CBZ level which was quite high (18.0 mmol/L). The child recovered in 3 days time after stopping CBZ. EEG carried out at that time showed, mild slowing. Five days later, the child again became drowsy and started vomiting.

To our surprise the CBZ level carried out at that time was 21.0 mmol/L. The nursing personnel, during one of the shifts found bottles of CBZ and other injections with the mother. At this point, mother was counselled and psychotherapeutic services were offered. After initial aggressive and abusive behavior, the mother started accepting the fact that her involvement in poisoning the child was being discovered.

Meanwhile the mother's medical records were

checked. She was hospitalized about 30 times in various hospitals including University Hospital, over the past 5 years with a myriad of symptoms – hematuria, bleeding per rectum, shortness of breath, headache, and uncontrollable seizures. All her investigations were normal except the EEG which had shown seizure discharges. A psychiatrist had evaluated her and found that she had lots of social problems at home and was incompatible with her husband.

The medical social worker also found that she had another child who had similar complaints and had been admitted to hospitals several times. She used to take her step children also, to hospitals with history of bleeding per rectum and repeated seizures.

One of the nursing staff later admitted that she had seen the mother mixing menstrual blood with the child's stool. While psychological and psychiatric rehabilitation was being arranged for the mother and child, they absconded from hospital and were seen in the local super market 2 days later.

Discussion. Child abuse means maltreatment of a child or adolescent by the caretaker, usually the mother, in majority of cases. Physical abuse constitute 70% cases and sexual abuse 25%.[7] Failure to thrive is noted in 5 percent. In USA, 1% children suffer some sort of child abuse with an annual incidence of 1200/million child population/year. About 4000 deaths every year in USA are related to child abuse. One third of these cases are under 1 year of age, one third in the age group 1-6 years and the remaining over 6 years of age.[7]

Child abuse, an unknown entity in this part of the world, is emerging slowly and has been postulated to be the result of modernization and industrialization, with import of ideas from advanced societies.[2]

Munchausen syndrome was a commonly used term, applied to adults who presented with false illness stories.[8] Munchausen syndrome by proxy was plagiarized and adapted to apply to children who were presented with a false illness story invented by someone else (a proxy).[5] The American Psychiatric Association, prefers the term "factitious disorder by proxy" and seeks to apply it to the perpetrator of the abuse, rather than to the abuse and has laid down criteria for the diagnosis.[9]

Almost any clinical picture can be fabricated but common presentations are epileptic seizures[10,11] and apnoea in infants, though fabrication of complex or rare diseases do occur.

All our children presented with symptoms of epilepsy. The diagnosis of epilepsy is based on history alone as it is rare to see a patient presenting with fits, unless the patient, by chance convulses in the hospital or has a prolonged fit like status epileptics. However, it was the disparity in clinical picture and drug level that prompted the doctors to diagnose these patients as MSBP. To establish the diagnosis in the first case was very difficult. The refractory nature of fits with toxic levels of CBZ and presence of AEDs like PHB and PHT, which were not being given to the patient, narrowed down the diagnosis to MSBP in the first case. The mother was very cooperative for any number of procedures and friendly to all the hospital staff, a feature noted in all such case.[2,7] On 2 occasions of CBZ toxicity in the ward, the mother had injected the drug through nasogastric tube. She threw tantrums and took objection to taking out the nasogastric tube & Hickman cannula. Based on these features, and finding unwanted drugs with mother, the diagnosis of MSBP became a distinct possibility.

After the diagnosis in the first case, it was relatively easy in the other 4 children, on account of inconsistency in history and toxic blood levels of CBZ. In patient 3, the child told the nursing staff, about her mother forcing medicines on and off, to produce symptoms in her. In patient 4, the mother partially accepted the administration of the drug. In patients 2 and 5, the mother did not admit giving CBZ. The confession of abusing the child is seen in a good number of cases but not all caretakers admit this.[2] An interesting observation is that CBZ alone was the drug in all the children. Additionally, it was noted that all such children were exclusively cared for, by mothers. The fathers of these children have rarely been seen. It is known that some sort of marital disharmony usually exists in such families.[2] A word of caution must be mentioned here: that is, not to make the diagnosis, unless all diagnostic criteria have been met after having excluded all other possibilities. It is not unusual to find children with AED toxicity, when they are on chronic treatment. The parents, sometimes learn with experience to increase the dose of the drug, in the event of a fit and hence could present with toxicity. This has to be borne in mind, before labelling it as MSBP, as this can be traumatic to the parents when such a situation does not exist and the parents may easily lose trust and faith in medical profession.

It has been recommended that only senior staff members should handle such cases. A direct friendly approach is always better than condemning the events. Social support should also be given whenever needed.[12]

On the other hand, doctors have to be more aware of this entity and should have a high index of suspicion.[2]

It appears from history of case 5, that mother herself has Munchausen syndrome[8] (MS) and her son MSBP, this co-existence has been reported in literature.

The outcome of patients with MSBP is ominous. In addition to emotional, psychological and physical trauma, such children are left with many other sequelae. Significant mortality has been reported

with MSBP. It has been 9% in one report,[11] 22% in another[13] and 50% in a third series.[4] As in Saudi Arabia, there are no clear guidelines in the Sultanate of Oman, to deal with such patients. A joint endeavour by the Ministry of Health, University Hospital and the Social Welfare Ministry is being established with the headquarters at one of the tertiary hospitals, to deal with these problems.

It is concluded that since the Gulf countries have societies akin to one another, the medical fraternity should constantly be on the lookout for MSBP & other child abuse cases. There is an urgent need to establish a uniform policy to deal with such cases. Perhaps establishment of a child protection council acceptable to all the countries in the Gulf of Arabia, would go a long way in finding a solution to this vexed problem.

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