Munchausen Syndrome by Proxy: balancing ethical and clinical challenges for healthcare professionals

Ethical consideration in factitious disorders

P. Tozzo¹, M. Picozzi², L. Caenazzo¹

¹ University of Padua, Department of Molecular Medicine; ² Insubria University, Department of Biotechnologies and Sciences of Life, Varese, Italy

Abstract

Munchausen syndrome by proxy is a relatively rare behavioral disorder affecting a child’s primary caregiver, typically the mother. Ethical dilemmas that physicians may face in such situations mainly concern the medical options for best protecting the child’s welfare, that are important, in clinical pediatric practice, because critical conflicts might arise between health professionals and parents. In such cases, the physician’s primary obligation is to protect the children involved, whose family environment may be essential to their wellbeing. Every ethical choice should be tailored to a given child’s story, which should be viewed as a whole, considering the possible consequences for the family balance, and taking the complexity of the emotional and psychological dimensions of children’s relationship with their parents into account.

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Introduction

The issue of clinical ethics in cases of suspected Munchausen syndrome by proxy (MSBP) is important in pediatric practice because critical conflicts might arise between health professionals and parents. Such cases give rise to a particular scenario in the patient-doctor relationship, when a child is brought to the pediatrician’s attention apparently carrying some sort of disease, and is very often accompanied by an abusive parent suffering from a psychiatric disorder.

The first aspect to clarify concerns who is really ill: it is the abusive caregiver (usually the mother) who has a psychiatric condition, while the child may have fabricated symptoms, sometimes induced by drugs, irritants or toxic substances, or may have no pathological conditions and merely be the bearer of nonexistent signs and/or symptoms reported by the caregiver. The illness in question (MSBP) is therefore not a pediatric condition, but the outward manifestation of an adult psychiatric disorder.

What distinguishes any analysis on the issues relating to this form of child abuse is the particular involvement of healthcare professionals: in cases of MSBP, the healthcare professional, and the pediatrician in particular, may unwittingly expose a child to potentially serious damage or injury (by prescribing unnecessary and sometimes invasive medical tests), but is also in a position to diagnose the adult’s condition and intervene to prevent further damage. What is particularly important, in our opinion, is the question of information, i.e. the balance that needs to be struck between what the health professional should and should not say to the child’s parents, and the moral justification for any practical decisions made in such cases.

For a better understanding of the considerations that follow, it may be wise to give a brief account of this form of child abuse.

The term “Munchausen syndrome” was first used in an article published in 1951 by Richard Asher (1), who described some clinical histories of patients - like the famous Baron Munchausen (2,3) - who reported imaginative, but scarcely credible details of diseases they experienced, consulting numerous doctors at various healthcare centers. Patients described their unusual symptoms with dramatic flair, and persisted in doing so despite repeated clinical interventions and after any evidence of organic abnormalities had been ruled out. The pediatrician Robert Meadow (1977) was the first to apply the term “Munchausen syndrome by proxy” in describing fictional diseases in healthy children being reported by adults (usually a parent) who invented or induced the child’s symptoms (4).

Over the years, Munchausen syndrome and MSBP have been classified in the group of conditions known as “factitious disorders”, which are characterized by physical or psychological symptoms that are deliberately produced or
feigned to cast the individual in the role of patient. Some Authors, as Flaherty and Macmillan (5) have suggested that a better term for MSBP would be caregiver-fabricated illness (CFI) in order to place the focus on the child affected rather than on the adult responsible. In the present paper, the term MSBP has been preferred because it is still used in the contemporary literature, and because our aim is to discuss the relationships not only between the doctor and the child, but also between the doctor and the adult involved.

The main issue to bear in mind, from both a clinical and an ethical perspective, is that this is not a “children’s disease”, but an adult psychiatric condition. It is of paramount importance for pediatricians to know about MSBP, and to be able to identify the signs and diagnose a case as promptly as possible. As in other forms of child abuse (6,7), so too in MSBP, the diagnosis should be timely and supported by objective data, always bearing the child’s best interest in mind.

The present study began with an analysis of the relevant medical literature, identifying the ethical aspects involved in clinical practice with a view to contributing to their discussion.

The literature search was conducted particularly by consulting articles on MedLine and published in indexed journals available on PubMed, since the aim of our contribution was to offer some reflections on MSBP from the clinical standpoint that might be of help to health professionals dealing with this problem, considering the lack of specific literature on this topic.

Furthermore, the medical literature review is followed by some considerations on the usefulness of clinical ethics consultations in this area, which underscore the added value of such consultations in improving the quality of care for pediatric patients, by taking a structured approach to identifying, analyzing and advancing some ethical recommendations on the complex relationship between health professional, parents and pediatric patient in the setting of MSBP.

**Clinical background**

Munchausen syndrome by proxy is a relatively rare behavioral disorder affecting a child’s primary caregiver, typically the mother. The term “by proxy” emphasizes the relationship between the perpetrator and the victim of this form of child abuse: the adult has a pathological need to be cast in the role of patient through a third party (the child), to gain the attention of healthcare professionals. In 85% of cases of MSBP, the abusive adult is the child’s mother (8). In 80% of cases, mothers with MSBP had also fabricated their own symptoms earlier in life, and they often have other concomitant psychiatric disorders, such as personality disorders (typically antisocial, borderline and histrionic). The adult attracts attention by exaggerating or feigning symptoms of illness in the child. As reported by Fulton (9), MSBP perpetrators often have professional training or a strong interest in healthcare. A recent review on the role of the non-perpetrating parent in this pathological scenario indicated that this figure (usually the father) often has an entirely passive role, and tends to be absent, distant, uninvolved, and both emotionally and physically detached from the family system (10).

MSBP can present with a broad array of different signs and symptoms, ranging from moderate to very severe, and mainly consisting of: the simulation of signs and symptoms of various diseases of which the child does not really suffer; the exaggeration of symptoms of a disease of which the child does suffer; or the deliberate induction of signs and symptoms of disease in the child (11). The adult may falsify clinical records, contaminate biological samples (e.g. by adding blood or dyes to urine or feces to simulate hematuria or hematochezia), induce genuine signs or symptoms (e.g. by administering laxatives, applying irritants to wounds to cause suppuration or foreign body reactions), or fabricate a history suggestive of epilepsy (5,12,13). MSBP usually carries high rates of morbidity, family disruption, re-abuse, and harm to siblings, ultimately posing a real danger to the child’s life in the most serious cases (14). The mortality rate associated with this form of abuse varies in the published studies, with percentages ranging from 6% to 33% (15-17).

It is important to clarify who has the psychiatric disease, as defined in the DSM-V (18): in MSBP, it is the caregiver-perpetrator, while the child is the victim of their falsification of signs or symptoms. In some cases, the child may have fabricated symptoms (due to the administration of drugs or irritant/toxic substances); in others, they may have no real pathological conditions because any signs and/or symptoms are only reported, simulated or exaggerated by the abusing adult. MSBP is therefore not a child’s disease: it is the manifestation of a psychiatric condition in adult the caregiver-perpetrator.

Physicians have to seek clinical and scientific explanations for signs and symptoms that often seem inexplicable, and in doing so they may become involuntary accomplices to the perpetrator’s action. In an effort to provide clinical answers, they may submit the child to a number of medical tests that prove inconclusive, but gratify the perpetrator. Pediatricians striving to arrive at a diagnosis by means of medical examinations, instrumental tests, or surgical procedures may prompt the perpetrator to make the symptoms worse in order to retain the physician’s attention. Healthcare professionals may as a consequence unwittingly expose the child to potentially even severe injury every time they prescribe further unnecessary diagnostic tests or surgical procedures for the victim.

Recognizing a case of MSBP is therefore essential in order to ensure its prompt diagnosis and prevent any further consequences of this form of abuse, deriving both from the perpetrator’s actions and from the side effects of any unnecessary medical or surgical procedures.

In situations where MSBP is clinically suspected, early recognition of the risk factors and prompt action to avoid further abuse (such as invasive diagnostic tests) are essential to protect the child and prevent more serious consequences.

Due to the difficulty of unequivocally diagnosing this form of child abuse, healthcare professionals in some countries may resort to covert surveillance, including the use of hidden video cameras or one-way mirrors in hospital rooms. The pros and cons of such methods are ethically charged and have been hotly debated in the literature for the last two decades (19-24). The use of covert surveillance is permitted in some countries, like the USA and the UK, but not in others.
Ethical issues

Despite the effective management of MSBP posing several significant ethical and legal challenges, the mainstream bioethical and medicolegal literature lacks a proper analysis of the matter, although other forms of child abuse have been discussed at length. Given its unavoidable involvement of (and sometimes inadvertent perpetuation by) the medical profession, MSBP seems to warrant being considered separately.

When a case of MSBP is suspected, the health professional’s first priority is to arrive at a clinical diagnosis, so a thorough clinical examination of the child and a qualified analysis of the family’s psycho-social relationship should be conducted and documented. The ethical dilemmas that physicians may face in such situations are manifold. The issues to consider when making decisions regarding cases of suspected MSBP mainly concern the medical options that best protect the child’s welfare. Two main criteria can be adopted, both normative: one focuses on the child’s best interest, which should generally be pursued by both doctors and parents; the other on a so-called “substituted judgment”, which means that those who decide on a patient’s behalf should, as far as possible, make the decision that the patient would normally make if he was not incapacitated, evidently exercised in the case in point by who holds the responsibility and thus, usually and in most cases, by parents. The first criterion, namely the child’s “best interest”, can be applied on the grounds of the two bioethical principles of beneficence and non-maleficence. The second criterion is founded on one of the classical principles of bioethics - autonomy - in relation to decisions made by parents, and not by the child on whose behalf they act.

Relational challenges and the child’s best interest

The first aspect to consider is the medical doctor’s relational approach to the MSBP perpetrator and victim, and handling this relationship between child, parents, and healthcare professionals can prove difficult, differently from usual daily pediatric clinical situations (25). Clear and effective communications between the different healthcare professionals involved in a case may be crucial in the management of suspected cases of MSBP, especially in the early stages, when the abuse is only suspected and difficult to prove. This situation can cause anxiety and frustration among practitioners, contributing to their perception that a definite diagnosis is almost impossible to establish. Dealing with children believed to be victims of MSBP may make physicians doubt their ability to deal with their parents and understand the pathological parent-child relationship, which is often apparently loving and authentic. Unlike the situation in other forms of child abuse, mothers suffering from MSBP appear to be loving, caring and compliant, particularly in their relations with the medical team and other families in the hospital ward, and they seem to be extremely good caregivers. In this scenario, it may be helpful to take a more patient-centered care approach (focusing only on the child, even if the mother is a potential psychiatric patient) with a view to facilitating the emergence of evidence of the abuse by minimizing the role of the parent. It is particularly difficult to strike the right balance in such a situation because acting in what is clinically or ethically the child’s best interest may not coincide with what is most appropriate for the child’s psychological wellbeing at the time. The ‘best interest’ approach has been criticized by some Authors and is still not without its detractors (26,27). In adult care, seeking a patient’s ‘best interest’ means looking first at what the patient thinks (or has thought) about him/herself. The same approach is not applicable when the patient is a small child because most children will not have enough experience to know and explain what they think and feel. Since children are usually strongly dependent on their families, the interest of the family should be considered too when assessing the best interest of a given child. In cases of MSBP, the ‘best interest’ principle might be served most appropriately by balancing the complex interactions between the various interests expressed within a family, with a view to clinicians achieving maximal benefit and minimal harm. When making decisions regarding a child who is definitely a victim of MSBP, it might be relatively easy to conclude that it is in the child’s best interest to protect them from the perpetrator, and consequently from their family. The solution is not so clear-cut, however, in cases where the diagnosis is uncertain, and further clinical assessments are warranted. Medical doctors confronted with the latter, more dubious cases need to carefully consider the child’s medical, personal, familial, cultural and legal best interest (28,29). In everyday clinical practice the doctor sometimes cannot cope with the child’s care alone, because medical professionals may not have enough time, resources, expertise, or the right to access information on all the factors relevant to a case. In such situations, the medical professional who is the first to intervene should take responsibility for alerting all the other interested professional parties and, when obliged to do so by law, they should collaborate with representatives of relevant law enforcement authorities. The Italian Deontological Medical Code (Article 32) requires that the doctor take action for the total care of the vulnerable person (30). Their primary obligation is to the child, who lives in a particular family environment that is one of the factors essential to their wellbeing, even if it is not necessarily in their “best” interest to remain there. An
ethically appropriate decision can only be reached case by case, and each situation should be examined globally, bearing in mind the potential consequences of any action on the family’s relationships and structure, and on the child’s future development. So it may serve the child’s best interest if the healthcare professionals conduct further clinical investigations without the parents’ consent, giving more priority to the principle of charity than to that of autonomy.

**Parental authority and autonomy**

The second important ethical issue in cases of suspected MSBP concerns parental consent and particularly the information that parents should be given. For healthcare professionals, the fundamental ethical dilemma in such cases is whether or not to conduct medical tests on the child (which may sometimes be invasive, painful and not without risk), with or without the parents’ consent, to clarify the child’s organic or fictitious signs and symptoms, even though such tests may prove unnecessary, and bearing in mind the risk of enhancing the abusive parent’s behavior and prolonging the harm to the child.

The legal assumption of parental authority can be characterized ethically as a parent’s responsibility for making decisions concerning their child, as it is generally assumed in our society that parents are typically the individuals most appropriate for protecting and raising their offspring. The principle of parental authority is based on the assumption that parents safeguard their children, and that parents share the responsibility for decisions regarding their children’s health until the latter are old enough to take care of themselves. The justification for parents making health-related decisions on behalf of their children relies mainly on the assumption that it is in the child’s best interest, and parents might opt for a short-term harm if they are convinced that it would be offset by longer-term benefits for their child (31,32). What we need to consider in cases of MSBP is that parents’ decisions may be even dramatically detrimental to their child’s current and future wellbeing.

Autonomy, information and consent are always important issues in patient care because, without them, it is difficult to promote other values such as trust, honesty, confidentiality, and respect for the individual - all facets involved in safeguarding a patient’s best interest. This is especially true in the case of minors, who form a vulnerable group in need of special protection. Autonomy is a complex principle that has developed from different sources, such as political philosophy and moral philosophy, and in medical care we tend to treat children as non-autonomous individuals, in the sense that decisions concerning them are made by adults - usually their parents. Some children (especially as they grow older) are experienced, intelligent, and thoughtful enough to make decisions regarding their medical care, but for those who are not the principle of respect for their autonomy is clearly not directly applicable. As Baines suggested (28), although parents have authority over their children, this authority does not have the same moral force as respect for their autonomy, so it may be inappropriate to transfer the full force of a child’s entitlement to autonomy to his/her parents. In cases of suspected child abuse, as in MSBP, respect for a minor’s right to autonomy can be interpreted in the sense of complying with their entitlement to be protected while they are growing up, which also means enabling them to develop an adequate decision-making capacity, and thus be able to exercise their autonomy in future. This line of reasoning leads to the concept of respect for a child’s autonomy ultimately meaning protecting them from harm or from any abusive action. In cases of suspected MSBP, therefore, parental authority should not prevail over the child’s development of their own values and individuality, which will ultimately enable them to exercise their autonomy.

Because MSBP is difficult to diagnose with certainty, healthcare professionals have to use a variety of methods to reach a reliable diagnosis, but informing parents about a diagnostic process that aims to unmask them, or even only giving the impression that they are suspected, can have devastating consequences. For instance, parents might have their child discharged from the hospital, which means further delaying the diagnosis as the child would be taken to other doctors, who would probably prescribe more tests and unwittingly expose the child to further harm.

On the other hand, doctors conducting (even invasive) tests on a child without involving the parents in the decision to do so, in an effort to identify a case of MSBP, may be fearful of acting in violation of the parents’ right to be informed and of the child’s right to see their autonomy fully exercised by their parents. Liability concerns, in the event of a clinician making such a diagnosis in error, may be a chilling factor that adds to the difficulty of arriving at an early diagnosis of MSBP.

When MSBP is suspected, guaranteeing the child’s right to autonomy and the parents’ right to be informed about tests performed on their child must be balanced against the need to protect a child whose life may be in danger. The ethical choice to be made in such cases depends on which of these rights prevails from a moral standpoint. Respect for a patient’s right to autonomy is a fundamental healthcare obligation that should be strictly met whenever possible (33), but it is absolutely essential to preserve the child from the harm that might be caused by any continuing abuse, and the latter obligation seems to carry more moral weight.

**Information and therapeutic privilege**

Healthcare professionals have to decide whether to give parents suspected of having MSBP (or others empowered by them) any clinical information that might indirectly damage the child. They therefore need to establish whether it is ethically acceptable to withhold information concerning medical investigations they conduct to support the diagnosis of MSBP. To give an example, if doctors are suspicious of a parent reportedly finding blood in a child’s feces, urine, saliva, or vomit, they might have biological samples analyzed to check whether they actually contain traces of blood, and whether it belongs to the child. The latter involves ascertaining the child’s genetic profile from a reference sample (swab of saliva or blood sample) and comparing it with the genetic profile obtained from the biological sample potentially contaminated by the MSBP perpetrator - and obtaining parental consent for such tests is clearly likely to be difficult.
There are some legal exceptions to the rule of informed consent that enable healthcare professionals to proceed without obtaining any informed consent in the event of emergencies, incompetence and waiver. A controversial form of ethical exception to the need to provide information is the so-called ‘therapeutic privilege’, according to which a healthcare professional may withhold information on the grounds that its disclosure could be harmful (as in the case of emotionally or clinically fragile, vulnerable, or unstable patients), generate anxiety and stress, or even endanger the patient’s life by prompting irrational behavior.

In our opinion, performing tests to diagnose MSBP without informing the parents of their purpose and without obtaining their informed consent could be ethically justifiable under the provisions of therapeutic privilege. The reference to therapeutic privilege seems to be justified because some information is withheld from parents not only for their own good, but also for their child’s (and here lies the difference vis-à-vis the typical definition of therapeutic privilege).

What is important here is that the healthcare professional decides to withhold certain information because disclosing it would not place the parents in a position to make the most appropriate decisions in their child’s interest - and this is what justifies our reference to therapeutic privilege. Providing detailed information (e.g. telling parents that a mouth swab will be used for obtaining the child’s genetic profile) might make parents suspicious, and induce them to alleviate or minimize their child’s symptoms, take their child elsewhere, or otherwise potentially damage the victim. It is worth bearing in mind that MSBP perpetrators often have a good medical and scientific training, they are attentive and particularly adept at identifying dubious situations.

If a diagnosis of abuse in the form of MSBP has been confirmed, it is the doctor’s duty to take action in the child’s best interest, and protect the child from further injury or potential danger. It is therefore morally quite easy to justify the decision not to inform parents about the diagnostic process under these circumstances. The difficulties arise, both in practice and from an ethical point of view, in doubtful cases, when any uncertainty regarding the diagnosis casts doubts on the best course of action. Physicians are morally bound to juggle with the difficult balance between protecting the child from further harm and preserving their original family relations and their parents’ trust in the doctors would be preserved until other action should prove necessary.

1) they should run further (even invasive) tests to arrive at a certain diagnosis, possibly also with the aid of video surveillance. They have to judge the pros and cons of any tools they use to ensure that the benefits exceed the risks, relying on the “first, do no harm” principle and causing the child the least possible damage;

2) they should ensure the clinical care of their young patient, which essentially means assessing the family setting and relations before and after the child’s admission to hospital. Children who may have been abused need to retain their relationship with their parents (who, in cases of a still uncertain diagnosis, may or may not be perpetrators); the child’s ‘best interest’ should be sought and interpreted, striking the difficult balance between protecting them from further harm and preserving their original family context. It is important to apply the principle of beneficence, aiming to achieve the greatest possible benefit, not in a general sense, but for a particular child in a given family environment;

3) they should maintain a relationship with the parents because of the various possible scenarios: one or both parents may be involved in the MSBP, and one or both may be unaware of the child being abused by another member of the family or a person outside the family. Whatever the situation, the physician has to bear in mind that one or both parents may have a psychiatric condition, so they may be inadequate or incompetent decision-makers. The parents’ decisions may consequently be inappropriate, and it may be impossible to guarantee respect for their parental autonomy concerning decisions they make for their child.

Resorting to therapeutic privilege and withholding information from parents for the minor’s benefit may have two moral justifications in the scenario of MSBP, as already mentioned by Beauchamp and Childress (34). The need to avoid telling the parents derives from their incompetence, their inability to make informed decisions about their child, due to their psychiatric condition. When the mother is the perpetrator of the MSBP, withholding clinical information concerning her child can protect against the risk of her making decisions harmful to her child. The moral justification for not informing suspected MSBP perpetrators lies in that this is in the child’s best interest because it minimizes the risk of future harm to the child concerned. If we accept this moral justification, then - when MSBP is suspected - the need for the family caregivers’ informed consent can be overridden and their moral status subordinated to the child’s best interest.

Such ethical considerations cannot be totally disjointed from decisions to be made in the medicolegal context, particularly as concerns the physician’s duty to inform the judicial authorities and the appropriate timing of compliance with this obligation. A thorough analysis of this aspect of the problem of MSBP goes beyond the scope of the present paper, but it is worth mentioning here that the legal approach to the situation may be partially contradictory, making it necessary to justify the legal point of view in ethical terms.

A decision not to inform parents about tests conducted to establish a diagnosis of MSBP may be taken without involving the law courts by giving precedence to the principle of non-maleficence (given the uncertainty of the diagnosis). The child’s best interests would thus be protected, and their family relations and their parents’ trust in the doctors would be preserved until other action should prove necessary.

Conclusion

Healthcare professionals involved in cases of suspected child abuse should recognize and contain, without denying, their anxiety and concern, discussing cases in multidiplinary teams. They should learn from their own and other’s experience, bearing in mind the complex ongoing debate on the rights and duties of parents, the rights and duties of children, and the rights and duties of medical practitioners. Treating children who have been abused or exposed to violence is distressing, but clinicians need to be adept in dealing with the ethical dilemmas inherent in providing care to such children, making the best medical decisions on their behalf.
The numerous ethical dilemmas arising in the field of child abuse, and in the case of MSBP in particular, make decisions in the child’s best interest a challenge. Clinicians should have a good command of the ethical issues involved in order to provide the most appropriate and compassionate care for the child.

In such cases, the physician’s primary obligation is to protect the child involved, whose family environment may be essential to their wellbeing. Every ethical choice should be tailored to a given child’s story, which should be viewed as a whole, considering the possible consequences for the family balance, and taking the complexity of the emotional and psychological dimensions of children’s relationship with their parents into account.

The moral justification for not informing parents about the diagnostic workup when MSBP is suspected lies in the need to serve the child’s best interest and minimize the risk of the minor suffering ongoing and future harm.

Awareness of the ethical implications is the first step towards an appropriate care for children who are victims of MSBP, who need the support of healthcare professionals throughout the diagnostic process. Specific protocols, the discussion of clinical cases, and the open communication of their feelings will help doctors to deal more effectively with the families involved and ensure that treatment decisions are made in the child’s best interest.

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