

Medical Child Abuse and Medical Neglect

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Practice Gap

Medical child abuse and medical neglect are part of a spectrum of conditions that can lead to significant morbidity and mortality in children. Recognition of these forms of child maltreatment is crucial to preventing harm. Medical personnel should have a familiarity with and a framework for diagnosing and treating these 2 entities.

Objectives

After completing this article, readers should be able to:

1. Recognize medical child abuse and medical neglect in primary care practice.
2. Know the options available to managing medical child abuse and medical neglect in primary care practice.
3. Understand the parent factors, child factors, and physician factors contributing to medical neglect.
4. Know when to report cases of medical abuse and medical neglect to Child Protective Services agencies.
5. Know what other community resources can be helpful when dealing with medical abuse and medical neglect.

INTRODUCTION

In 1992, D. M. Eminson and R. J. Postlethwaite published an important paper discussing the range of parental behaviors when interacting with the medical care system. (1) On one end of the spectrum is medical child abuse (MCA) (previously referred to as Munchausen syndrome by proxy [MSBP]), wherein parents exaggerate, invent, or induce symptoms in their children and seek unnecessary medical care for them. On the other end of the spectrum is medical neglect, wherein parents either do not seek necessary care for their children or do not follow necessary instructions and medications that practitioners give them to treat illness. This behavior can put their children's health at risk as well. In the middle of the spectrum are parents who respond appropriately to their children's symptoms and seek medical care in a timely manner. Eminson and Postlethwaite (1) included in the "normal" range of the spectrum of care seeking parents who were "rather lackadaisical about symptoms or treatments" and "parents who were overly anxious about trivial symptoms."

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ABBREVIATIONS

AAP	American Academy of Pediatrics
CAM	complementary and alternative medicine
CPS	Child Protective Services
MCA	medical child abuse
MSBP	Munchausen syndrome by proxy

Herein we consider the 2 ends of the spectrum of parent care-seeking behavior: MCA and medical neglect.

MEDICAL CHILD ABUSE

One of the tenants of pediatric medicine is to trust parents. In learning to interview families, physicians rely on the parents' history while assuming that "parents know their children best." Most physicians are taught to trust parents' instincts and to pursue parents' concerns. This forms the basis of the pediatric physician-patient relationship, an implicit understanding that the patient (or in this case, the caregiver) will present concerns about his or her child truthfully and accurately and the physician will use that information as the basis for medical decision making. When this relationship goes awry due to a caregiver's distortion or falsification of the medical condition of a child, MCA must be considered.

Roesler and Jenny (2) defined MCA as "[a] child receiving unnecessary and harmful or potentially harmful medical care at the instigation of a caretaker." Although MCA is not a new entity, the shift away from the former term *MSBP* is a significant and important shift in the way we think of this condition. The term *medical child abuse*, similar to *physical abuse* or *sexual abuse*, focuses on the harm done to the child. Whereas *MSBP* focused on the motivation of the parent, MCA identifies what (*abuse*) and how (*medically*) a child has been harmed. In this way, instead of trying to determine the motivation of the parent in deceiving the medical care establishment, the physician can focus on how best to treat the child. (2)

The first description of Munchausen syndrome was in 1951 by Richard Asher, a physician who published cases of physicians being duped or hoodwinked by their patients. (3) He wrote, "Here is described a common syndrome which most doctors have seen, but about which little has been written. Like the famous Baron von Munchausen, the persons affected have always travelled widely; and their stories, like those attributed to him, are both dramatic and untruthful. Accordingly, the syndrome is respectfully dedicated to the Baron, and named after him." (3) In 1977, Roy Meadow identified deceptive parental behavior as abuse in a paper titled "Munchausen Syndrome by Proxy: The Hinterland of Child Abuse." (4)

Since 1977, the term *MSBP* has largely been used to define this condition. With growing recognition of the problem, alternative names have been coined, including *pediatric condition falsification*, *factitious disorder by proxy*, *child abuse in the medical setting*, and *caregiver-fabricated*

illness. (5) We choose to use the term *medical child abuse*, which puts the focus squarely on the harm to the child.

As with any disease, there is a spectrum of MCA. Physicians are often confronted with parents insisting on antibiotic drug therapy for a likely viral illness or anxious parents who their children to the emergency department for a minor cough. Few would view this as MCA. When a parent insists, however, that her child needs a gastrostomy tube despite testing to the contrary or when a parent is found contaminating her child's central line with feces, this constitutes child abuse. In making the diagnosis of MCA, careful consideration should be given to what harm has been inflicted on the child. Harm in cases of MCA must be looked at broadly to include harm from unnecessary testing or painful procedures (eg, radiation or sedation), from being isolated (eg, removal from school, confined to a wheelchair), and from being portrayed as sick. Although it might be challenging to convince outside agencies that these forms of harm are as significant as the harm from a femur fracture, exposing these harms is critical for the protection of the child.

Epidemiology

Little is known about the true prevalence of MCA. Some studies report the incidence to be 0.5 to 2.0 cases per 100,000 in children younger than 16 years and closer to 2.8 per 100,000 in children younger than 1 year. (6)(7) This likely represents the more severe end of the spectrum because many less severe cases of MCA go unrecognized. Lack of recognition of the condition, unwillingness to consider the diagnosis, and having a high threshold for diagnosing MCA make it likely to be grossly underreported. (8)(9) One study from the UK and Ireland showed that when physicians decided to report a suspicion of *MSBP*, 85% of them had a greater than 90% certainty that the child was a victim of *MSBP*. (7) Most primary care pediatricians will report seeing at least 1 case of MCA in their career, and our experience in a large academic children's hospital is on the order of 20 to 30 cases per year. Whether due to a true increase in prevalence or a greater recognition of the problem, the incidence of MCA seems to be increasing.

Males and females are subjected to MCA equally. (7)(9)(10)(11) Younger children are most likely to be victims of MCA, with a mean age at diagnosis of 14 months to 2.7 years. (6)(7)(10)(11) As children get older and become more independent they are less likely to be victimized. If the abuse has been long-standing, the child might take on the sick role on his or her own. Siblings of victims are also likely to be abused, especially if there is no intervention. (7) Mortality rates for MCA of 6% to 9% have been reported. (7)(9)(10)

Female caregivers are the most common offenders. Reports range from 85% to 98% female predominance. (7)(11)(12) Perpetrators are more likely to have had a history of abuse themselves. (12)

Diagnosis

The diagnosis of MCA is especially difficult and takes an astute clinician to raise concern. The average time from onset of symptoms to diagnosis of MCA in 2 studies has been shown to be between 14.9 and 21.8 months. (9)(10) Clinicians must remember that as many as 30% of children diagnosed as having MCA have an underlying illness, often making the distinction between a true medical condition and MCA difficult. (9) MCA should not be thought of as a diagnosis of exclusion, with emphasis on pursuing an alternative diagnosis first. As with other uncommon diagnoses, putting it on the differential diagnosis is the first step toward diagnosis. (5)

The search for a diagnosis should focus on whether “. . . the child is being hurt by unnecessary care” and not, “Does the caregiver fit the profile of an abuser?” Indicators that should alert the physician to possible MCA include 1) a diagnosis that does not match the objective findings; 2) inconsistent histories, signs, and symptoms that are present only in the presence of 1 caregiver; 3) failure of the child’s illness to respond to normal treatments; 4) caregiver insists on invasive procedures; 5) caregiver does not express relief or pleasure when told that his or her child does not have a particular illness or improves; 6) caregiver or siblings have a

history of unusual or unexplained illness; and 7) doctor shopping. (13)

Similar to many other illnesses, no single test will confirm the diagnosis of MCA. The key elements to making a diagnosis include a thorough review of the medical records and a multidisciplinary team meeting with the child’s medical providers, social workers, and teachers. The goal of the record review is to document the symptoms and illnesses that are being reported and compare that with the objective findings from the testing, clinical visits, and other therapies that the child has received. The American Academy of Pediatrics (AAP) Committee on Child Abuse and Neglect in their 2007 report recommended using the following 3 questions as an aid in making a diagnosis of MCA (2): 1) Are the history, signs, and symptoms of disease credible? 2) Is the child receiving unnecessary and harmful or potentially harmful medical care? 3) If so, who is instigating the evaluation and treatment?

Because these cases may require reviewing several years of medical records, an organized approach using a standardized recording tool is advised (Fig). It is especially important to pay special attention to signs and symptoms being reported that are difficult to verify by medical providers, such as apnea, pain, feeding intolerance, food allergies, and diarrhea. In cases in which medications are prescribed, documenting an expected response is important. In some instances, testing is possible to confirm drug levels or medication adherence. This can include testing for common medications such as polyethylene glycol with mass

Suspected Medical Child Abuse Chart Review							
PATIENT NAME:				CHARTS REVIEWED:			
MRN:				BIRTH HISTORY:			
DOB:				SOCIAL HISTORY:			
DATE OF RECORD REVIEW:							
REVIEWER:							
REQUESTING PROVIDER:							
PRIMARY CARE PROVIDER:							
DIAGNOSIS			PROCEDURES			CARE PROVIDERS	
DATE	LOCATION	REASON FOR CONTACT/ VISIT TYPE/PROVIDER	REPORTED SIGNS/SYMPTOMS PER CAREGIVER	OBJECTIVE OBSERVATION BY MEDICAL PROVIDER	CONCLUSION/ DIAGNOSIS	TREATMENT/ INTERVENTION	COMMENTS
SUMMARY							

Figure. Suggested template for medical record review in cases of suspected medical child abuse.

spectrometry in cases in which parents report constipation in the face of increasing laxative dosing. (14) At our institution we have noted an especially heavy burden of cases of MCA being referred from specialties where symptoms are often self-reported, such as difficulty eating, seizure activity, apneic spells, and chronic vomiting, all symptoms that are difficult to independently confirm. These specialties include gastroenterology, neurology, pulmonology, and genetics. In addition, caregivers tend to seek out diagnoses that are exceedingly hard to disprove, such as mitochondrial disorder, Ehlers-Danlos syndrome, or pediatric autoimmune neuropsychiatric disorder.

Talking with the medical providers is often helpful to tease out what has actually been told to the caregiver versus what is being reported. Often a provider may mention a possible diagnosis only to find out that the caregiver has subsequently adopted it and relayed it to other providers as a definitive diagnosis. These conversations must be conducted respectfully, remembering that the providers themselves have been deceived and may feel defensive about the care that they provided. Contacting the medical providers can also reveal previous concerns that were either buried in the medical records or never documented due to reluctance to put it in writing. Reaching out to medical providers outside one's own institution must be done with sensitivity to Health Insurance Portability and Accountability Act (HIPAA) regulations. All efforts should be made to obtain medical releases from caregivers. If this fails, a medical provider who in good faith believes that disclosure of protected health information is necessary to prevent or lessen a serious or imminent threat to the health or safety of the patient may do so under HIPAA regulations (HIPAA 45 CFR § 164.512[j][1][i]). This would include reaching out to unsuspecting medical institutions and providers if the caregiver is making motions at seeking care elsewhere.

Reaching out to the primary care provider can provide additional information. It is relatively common for the primary care provider to have had concerns but feel removed from the care of the child as the number of specialists involved in the child's care increases. In these cases, looping the primary care back into the medical home is critical to dispel misinformation provided by the caregiver and to prevent further harm.

Sometimes a hospital admission is necessary to directly observe a child's symptoms and the patient-caregiver interaction. When this is the case, it is important to have clear goals for the hospital admission as well as clear communication among the care team members to ensure that there is no manipulation or distortion of medical facts and opinions by the caregiver. It is crucial that meticulous documentation

occur to ensure a clear understanding of actual signs and symptoms being observed versus those being reported by the caregiver. Caregivers should be restricted from administering medications and feeds or from using medical devices without close nursing supervision. In rare instances, covert video monitoring during an inpatient medical stay may be necessary to confirm a caregiver's malicious actions. (15)(16) This takes significant resources, careful planning, and close coordination with other hospital departments, including nursing and hospital security. A well-developed hospital protocol and training of the individuals involved should be in place before covert monitoring is initiated.

There is often a level of enmeshment between the caregiver and the child that makes it difficult to make a diagnosis of MCA without separation of the caregiver from the child. In these cases, outside agencies such as law enforcement and/or Child Protective Services (CPS) are helpful in enforcing a therapeutic separation. Clear communication about the concerns of the care team and outlining explicitly how the child is in danger of further harm is essential to compel action. As complicated as these cases are for the medical providers, it is often more complicated for outside agencies to understand how a child could be in such harm when under such close medical care. The duration of separation can be variable but needs to be long enough to be able to see if symptoms persist in the absence of the caregiver and whether discontinuing unnecessary medication or therapies has any deleterious effects.

Finally, with the proliferation of social media sites and outlets for fundraising and sharing medical stories, many MCA perpetrators have engaged in online blogging. Although understanding the motivation of the perpetrator is not the goal, review of the online social media presence can be helpful in understanding how a child is being portrayed publicly and may reveal the perpetrator's motivation (eg, fundraising). (17)

If MCA is diagnosed and a protective plan cannot be negotiated with the parent, separation of the child from the caregiver should be pursued with the help of CPS. In making a report to protective services, the provider should focus on the harm done to the child, including physical abuse (eg, subjecting the child to unnecessary painful procedures, excessive radiation exposure), emotional abuse (eg, restricting the child to a wheelchair, convincing the child that he or she is sick), and risk of future abuse. In assessing future risk of harm, providers and protective services must assess the real possibility that the caregiver will escalate his or her behavior to prove the child's illness.

When MCA is confirmed, a meeting with the family, including the suspected perpetrator, should occur. Roesler

and Jenny term this meeting the “informing session.” (18) The goals of the meeting are to 1) detail the current medical condition of the child, 2) dispel any false claims of alternative medical conditions, 3) express concerns about the caregiver’s distorted perception of the child’s health, and 4) focus on a path forward toward normalization of the child’s medical condition. This session can be informative in seeing how the caregiver(s) reacts to the news that his or her child is not as ill as believed. Disappointment in the face of positive news about their child’s condition or refusal to accept the news is further evidence of MCA and should be reported to CPS. (13) Caregivers who do accept this news and agree to go along with the care plan still need to be under close monitoring to ensure that they do not stray from the plan or elope to another medical facility.

Prevention

Early recognition of the red flags of MCA is the best prevention. A fractured medical system, siloed medical records, the practice of defensive medicine, a strained child welfare system, and the proliferation of Internet blog sites and medical bulletin boards make prevention difficult. Reaching out to care providers early with concerns about MCA and lowering the threshold for reporting concerns to CPS can prevent the snowballing of unnecessary care and harm to the child.

Using the electronic medical record to alert other providers of concerns can be helpful. Some states have set up an emergency department information exchange system that can be used to provide important information about known medical conditions of a child as well as concerns for symptom exaggeration or falsification by a caregiver. Systems that alert institutions or health insurers to high-use cases that can be reviewed for MCA could also be helpful.

Implementing standardized processes for certain procedures that are often associated with MCA can be used as a check step to prevent unwittingly being complicit in the abuse. Our institution implemented a multistep process for gastrostomy tube placement that has successfully prevented unnecessary placement of tubes in children. This includes identifying a medical home for the child, a team that will “own” the tube once it is inserted, and a mandatory inpatient stay to prove that the child cannot eat by mouth such that a gastrostomy tube is truly needed.

Stopping lateral referrals is central to preventing MCA. Lateral referrals from one specialty service to another increase the potential for unnecessary care and further remove the primary care provider from the center of the child’s care. When possible, caregivers should be referred back to their primary care providers for referrals to

specialists. In cases in which MCA has been successfully contained, empowering primary care providers to take control of the care of the child has been the single most effective strategy for preventing further harm. Open communication between specialists and the primary care provider is essential to ensure the fidelity of the information that the caregiver is providing.

Finally, increasing awareness of MCA can prevent caregivers from being complicit in the abuse. Educating providers on signs to look for and targeting education to specialties that see MCA commonly can trigger action at a much earlier stage in a child’s care, before injury being inflicted. Ultimately, good medical practice represents primary prevention of MCA.

Treatment

Treatment of MCA, similar to other forms of abuse, involves repairing the physical and psychological damage experienced by the child and, if possible, preserving the family if the safety of the child can be ensured. (18) The first step is developing a new course of treatment with the help of the medical care providers. A multidisciplinary team meeting is helpful in getting all the providers together and obtaining consensus among the providers that, in fact, MCA is occurring. This might lead to identifying more information that should be gathered, including additional laboratory tests or imaging. Once this is achieved, implementing the new care plan can proceed. Informing the family of the new care plan can occur during the informing session, described previously herein.

How and when to peel away certain medications or reintroduce foods can be challenging. Providers might be reluctant to wean therapies rapidly if they are worried that some of the falsified diagnosis could be correct. This is common in children with long lists of food allergies who go through painstakingly long periods of food reintroduction. Although it is important to be cautious, we have found that in most cases, peeling off therapies and reintroducing foods can occur fairly rapidly while the child is in the hospital and under close supervision. In general, stopping the most invasive and dangerous treatments should be done first. For example, removing a central line or gastric tube that is no longer necessary should occur urgently.

Similar to other forms of abuse, recognizing the psychological harm to the child is important to determining the best therapy. Anxiety, depression, and posttraumatic stress disorder can be seen in victims of MCA. Central to the treatment is restoring the child’s trust in the caregiver and the medical system. If the abuse has been going on long enough, affected children might have a distorted view of

their own health. Changing their perception of their health from “sick” to “healthy” can prevent future factitious medical utilization as these victims grow older and start accessing care on their own. (19)

Although the focus should be on treatment of the child, without treatment of the offending caregiver the risk of further abuse is high. Studies have shown that approximately 40% of MCA victims experience further abuse. (20)(21) A psychological evaluation of the offending caregiver by a trained practitioner who is familiar with MCA is often important for the courts. This will help show the level of insight into the harm caused by the caregiver’s actions and the risk of future harm.

Bools et al (21) pointed out 6 factors that have been shown to portend a more favorable outcome for children who have been victimized: 1) continuous positive input from the spouse and/or grandparents, 2) successful short-term foster care before returning to live with the offending caregiver, 3) the offender’s long-term therapeutic relationship with a social worker, 4) successful remarriage for the offending caregiver, 5) early adoption of the victim, and 6) long-term foster care placement.”

In cases where the offender agrees to go along with de-escalation of care and it is safe to do so on an outpatient basis, a successful day treatment program model has been demonstrated to work. Positive results in realigning the medical use patterns through a structured day treatment program that includes family, group, and individual therapy along with addressing medical issues have been reported by Roesler et al. (22)

Shreier (23) outlines indicators of successful treatment of the offender that include 1) the abuser admits to the abuse and has been able to describe specifically how he or she abused the child, 2) the abuser has experienced an appropriate emotional response to his or her behaviors and the harm he or she has caused the child, 3) the abuser has developed strategies to better identify and manage his or her needs to avoid abusing the child in the future, and 4) the abuser has demonstrated these skills, with monitoring, over a significant period.

MEDICAL NEGLECT

Definition

Medical neglect is defined by the AAP as “. . . either failure to heed obvious signs of serious illness or failure to follow a physician’s instructions once medical advice has been sought.” (24) According to the AAP, 5 factors are necessary to diagnose medical neglect (24): 1) a child is harmed or is at risk for harm because of lack of health

care, 2) the recommended health care offers significant net benefit to the child, 3) the anticipated benefit of the treatment is significantly greater than its morbidity, 4) it can be demonstrated that access to health care is available and not used, and 5) the caregiver understands the medical advice given.

Although all 5 criteria would be needed to establish a finding of medical neglect by CPS, Drs Stephen Boos and Kristin Fortin pointed out in a recent article that for medical purposes, only the first 3 criteria are relevant. (25) That is, a child should be considered medically neglected if care is needed and will be helpful. Even if there are extenuating circumstances, providers still need to plan for an effective intervention to see that the child receives the needed care. As with MCA, making a diagnosis of medical neglect is neither straightforward nor easy. In certain circumstances, input from an ethics team may be beneficial.

Statistics

The latest data reported by the US federal government are the results of the 2015 National Child Abuse and Neglect Data System, (26) which collects data on the cases of child maltreatment reported to CPS agencies in all 50 states in the United States, the District of Columbia, and the Commonwealth of Puerto Rico. In this study, 15,169 children were found to be medically neglected, accounting for 2.21% of all cases of maltreatment. Among the 1,670 child deaths attributed to abuse or neglect, 122 children died of medical neglect in 2015 (7.3% of deaths). (27) Welch and Bonner (28) studied 372 children who died of neglect in Oklahoma during a 22-year period. Medical neglect accounted for 9.7% of the child neglect deaths.

These data probably represent a small fraction of the number of children affected by medical neglect. Health-care providers are often hesitant to report chronically medically neglected children to state agencies. (29) Many are more likely to inform parents that the patient will be dismissed from the practice for too many missed appointments. In patients who are chronically or seriously ill, this routine is potentially harmful. A recent study of patients with type I diabetes compared patients who missed no endocrine clinic appointments with those who missed 2 or more appointments. (30) The patients who missed appointments were 3 times more likely to have an episode of ketoacidosis and 3 times more likely to have a hemoglobin A_{1c} level of 8.5% or greater.

A study from an Illinois children’s hospital found that 91% of the children reported to CPS had chronic medical conditions such as type I diabetes, prematurity-related medical conditions, seizure disorders, and asthma. (31) Ninety

percent were covered by public insurance. More than half of the families had previous CPS involvement.

Barriers to Access to Medical Care

In general, financial and nonfinancial barriers limit children's access to care. (32) Not surprisingly, families with higher incomes are more likely to have access to care and to have health insurance. (33) Racial disparities also affect access, with white people being more likely to identify a regular source of care than minorities. (33) Other barriers include low parental educational levels, larger family size, mothers working outside the home, level of social support, lack of geographic availability of providers, not having an identified primary care source, homelessness, and being in foster care. (34) Immigration status also affects availability of insurance and access to care. (35) Immigrant children are much less likely to get medical care than citizen children whose parents are also citizens.

Reasons that Families Fail to Seek Appropriate Medical Care for Their Children

Table 1 lists identified reasons that families fail to get needed medical care or fail to follow prescribed treatments for illness. (2) The factors include parent factors, child factors, and provider factors.

PARENT FACTORS: Many factors making it difficult for parents to seek health care for their children are obvious, including lack of education, personal problems, medical literacy, lack of social support, and poverty. Parents who feel respected and understood are more likely to be pleased with the medical care they receive. (36) Chaotic, disorganized families can be less likely to get effective medical treatment. (37) Parents who do not have a regular source of medical care for themselves are less likely to get regular medical care for their children. (38)

CHILD FACTORS: Parents of autistic children report that their children's anxiety, fears, and behaviors make medical encounters difficult. (39) Adolescents' need for control and independence can get in the way of medical care and compliance. Children with complex medical care needs often lack adequate primary care, and coordination of care between various providers can be a challenge. (40)

HEALTH-CARE PROVIDER FACTORS: Ability to communicate, cultural sensitivity, empathy, adequate time, and good listening are all factors that can affect patient compliance and satisfaction. (36)(41)

Special Dilemmas

Four particular topics that are controversial with respect to medical neglect are religious objections to medical care, use

TABLE 1. **Reasons that Families Fail to Seek Appropriate Medical Care for Their Children**

Parent factors
Poverty
Lack of health insurance
Geographic constraints
Lack of transportation
Lack of babysitters for siblings
Lack of available health-care providers
Language barriers
Family chaos and disorganization
Lack of awareness
Lack of knowledge
Lack of skills (especially regarding care of chronically or seriously ill children)
Lack of trust in medical providers
Availability of misleading information on the Internet
Intellectual disability
Substance abuse
Lack of parent health literacy
Misunderstanding or misinterpreting providers' instructions
Caretakers' belief systems
Religious beliefs
Belief in ineffective alternative medicine
Child factors
Failure of the child to cooperate with care
Peer influence
Self-consciousness, not wanting to appear ill to their peers
Fear of pain
Fear of medications
Health-care provider factors
Lack of knowledge about families' beliefs
Lack of knowledge about families' culture
Failure to communicate effectively
Language barriers
Lack of appropriate teaching materials in the practice
Inadequate time to explain the child's medical needs

of complementary and alternative medicine (CAM), vaccine refusal, and childhood obesity.

Religious Objections to Medical Care. Thirty-four US states (as well as Guam, Puerto Rico, and Washington, DC) have some kind of religious exemption for parents who refuse medical treatment because of their religion (Table 2). (42) Sixteen of those states allow exemptions for "recognized" religious groups only, and 2 specifically mention Christian Science. Another 16 states allow the court to order treatment despite the exemption. Fifteen states have statutes that prohibit criminal prosecution if a parent is denying medical care due to religious beliefs, including criminal and manslaughter cases. (43) Only 16

states have no religious exemption; parents whose children are seriously ill cannot neglect to seek medical care for them.

These laws are argued in courts under the First, Fifth, and Fourteenth Amendments. These constitutional amendments forbid prohibition of free exercise of religion, provide for due process to safeguard arbitrary denial of liberty, and ensure that no state can deny anyone equal protection of the laws. (44)

The AAP recommends that although parents' decision-making authority should be respected, pediatricians should report suspected religiously motivated medical neglect to state child protection authorities when treatment is likely to prevent death or serious disability or relieve severe pain. (45) The AAP also recommends that pediatricians support the repeal of religious exemption laws.

The Use of CAM. CAM is frequently used by patients alongside allopathic medicine, particularly when patients have chronic diseases or chronic pain, (46) although many patients do not disclose this to their health-care providers. (47) The National Academy of Medicine recommends that the same standards used to evaluate conventional therapies be applied to CAM. (48)

The AAP Section on Integrative Medicine recommends the following factors be considered when evaluating CAM therapies (49): the severity and acuteness of the illness; curability with conventional care; degree of invasiveness of the therapy that is recommended, eg, chelation therapy for autism; toxicities and adverse effects of conventional treatment; quality of evidence for efficacy and safety of the complementary therapy; the family's understanding of the risks and benefits of the CAM treatment; the family's voluntary acceptance of those risks; and the persistence of the family's intention to use complementary or integrative therapy.

Vaccine Refusal. Vaccine refusal or purposeful vaccine delay for children puts children at risk for preventable illnesses and can be associated with decreased herd immunity. Geographic clusters of increased parental vaccine hesitancy have been identified, increasing the risk for epidemic disease. (50) Forty-six states allow religious exemptions for vaccinations before entering school (Table 3). (51) Of these 46 states, 17 also allow personal exemptions as well as religious exemptions. One state (Minnesota) allows personal exemptions that do not mention religion. And 3 states (California, Mississippi, and West Virginia) allow no exemptions to their immunization laws. Courts have generally upheld challenges to laws requiring vaccination, and in cases where exemptions are codified, vaccine refusal has not been classified as neglect. (52)

TABLE 2. States with Religious Exemptions to Child Neglect Statutes (42)

States and territories with exemptions in civil child abuse statutes when medical treatment conflicts with the religious beliefs of the parent

Alabama	Indiana	New Mexico ^a
Alaska ^a	Kansas	Nevada
Arizona	Kentucky	Ohio
California ^a	Louisiana ^a	Oklahoma ^a
Colorado ^a	Maine ^a	Pennsylvania ^a
Connecticut ^b	Michigan	Utah
Delaware ^a	Minnesota	Vermont
Florida	Mississippi ^a	Virginia ^a
Georgia ^a	Missouri	Washington ^b
Iowa	Montana	Washington, DC ^a
Idaho	New Hampshire ^a	Wyoming ^a
Illinois	New Jersey ^a	

States with religious defenses to felony crimes against children (43)

Arkansas ^c	Minnesota	Utah
Idaho ^d	Mississippi	Virginia
Indiana	New Jersey	Washington ^e
Iowa ^d	Ohio ^d	West Virginia ^e
Louisiana	Oklahoma	Wisconsin

^aState statutes apply to "bona fide religions" only.

^bState statutes specifically mention Christian Science.

^cState has a religious defense to capital murder of a child.

^dStates have religious defenses to manslaughter.

^eStates have religious defenses to murder of a child.

TABLE 3. States Allowing Religious Exemptions from Mandatory Vaccination of Children Before Entering School (51)(52)

Alabama	Louisiana ^a	Oklahoma ^a
Alaska	Maine ^a	Oregon ^a
Arizona ^a	Maryland	Pennsylvania ^a
Arkansas ^a	Massachusetts	Rhode Island
Colorado ^a	Michigan ^a	South Carolina
Connecticut	Missouri	South Dakota
Delaware	Montana	Tennessee
Florida	Nebraska	Texas ^a
Georgia	Nevada	Utah ^a
Hawaii	New Hampshire	Vermont ^a
Idaho ^a	New Jersey	Virginia
Illinois	New Mexico	Washington ^a
Indiana	New York	Wisconsin ^a
Iowa	North Carolina	Wyoming
Kansas	North Dakota ^a	
Kentucky	Ohio ^a	

Minnesota allows a personal exemption from mandatory vaccines but does not mention religion in its statute. Three states have no exemptions from mandatory vaccines: California, Mississippi, and West Virginia.

^aStates also allowing personal exemptions from mandatory vaccines.

Severe Obesity as Medical Neglect. Medical ethics require that medical care providers respect patients' and parents' individual autonomy and their right to self-determination. (53) There is debate about whether referring families of seriously obese children whose medical condition is not cared for effectively in the home should be referred to CPS for medical neglect. (54)(55)

Varness et al (56) proposed that referral to CPS would be warranted if 3 conditions are met: "1) A high likelihood that serious imminent harm will occur; 2) a reasonable likelihood that coercive state intervention will result in effective treatment; and, 3) the absence of alternative options for addressing the problem." They propose that severely obese (>99% of body mass index) and obese (>95% of body mass index) children with serious comorbid conditions that could be ameliorated by weight loss would be appropriate for CPS intervention. This should be done when the family fails adequate medical intervention regarding the child's weight.

Alexander et al (57) caution that each case needs to be evaluated individually, and the potential benefit of treating the child's obesity outweighs the potential psychological harm to the child and family that CPS intervention might cause.

The Pediatrician's Role in Managing Medical Neglect

To effectively manage medical neglect in pediatric practice, pediatricians must first be alert to detecting it. After that, the management of neglect might depend partly on the practice setting. In a clinic with social work support it will be easier to affect the factors leading to neglect, such as social chaos in the family, lack of resources or transportation, or fixed belief systems. Still, pediatricians can counsel families about the importance of remedying neglectful parenting.

Contracting with families to change the care plan should be a collaborative process. The contract should be explicit in terms of the expectations of the parents and of the care provider. It is important to understand the family's resources and limitations. A contract that makes impossible demands on the family is not likely to be effective.

Making successful reports to CPS agencies requires clear explanations of the problem using language that lay people can understand. The potential harms to the child should be listed, as well as a description of what has already been attempted to address the problem. In most cases, parents must be informed of the intention to involve CPS. This can be presented as a positive intervention to access resources and support for the family, rather than as a pejorative or judgmental action. The exception would be in cases where the family's knowledge of an impending report might put the child at risk for harm.

A common cause of reluctance to report child neglect is the threat of harming the doctor/patient/family relationship. Often physicians feel that the value of their continued involvement with the family outweighs the need to report family problems to public agencies. Certainly, the decision to report to CPS should not be taken lightly, and all the implications of that report should be considered. In the end, however, the best interest of the child and mitigation of potential harm to the child should take precedence.

CONCLUSIONS

MCA and medical neglect have many features in common, even while the 2 conditions are on opposite ends of a spectrum of behavior. One is an act of commission and the other is an act of omission. Yet, the management of the 2 conditions shares many things in common. In addition, the 2 conditions can be present in the same child/family at the

same time. In some MCA cases, reasonable recommendations for the medical management of the child's condition are ignored by the family, even while they are insisting on unnecessary tests and medications. This is particularly true if the family believes that their child's diagnosis is unknown or different than the diagnosis that has been made by competent providers.

Although responding to MCA and medical neglect can be stressful and time-consuming for health-care providers, it is important that these conditions be recognized to maximize the child's ongoing health. Once the diagnosis is made, an effective response by the treatment providers is a critical part of caring for the patient.

Summary

- Based on the strength of evidence D, the diagnosis of medical child abuse (MCA) should focus on the harm or potential harm to the child and not on the motivation of the caregiver. (2)
- Based on the strength of evidence C, no single test can diagnose MCA, and providers should maintain a high level of suspicion for MCA when reported symptoms are not congruent with objective findings, illnesses do not respond to normal treatments, and, despite a thorough evaluation, the caregiver continues to advocate for additional testing.(5)(9)(13)
- Based on the strength of evidence C, treatment of MCA involves repairing both the physical and psychological damage experienced by the child. Weaning unnecessary medications, revising problem lists, and removing physical restrictions placed on the child are all components of successful treatment. Although treatment of the offending caregiver is essential to prevent further abuse, the recidivism rate for offenders is high, with as many as 40% of MCA victims experiencing repeated abuse.(20)(21)
- Based on the strength of evidence D, prevention of MCA requires a coordinated approach among medical providers, use of technology to alert providers to concerns of MCA, standardized processes within hospitals to limit unnecessary procedures, and clear lines of communication among all medical providers. (2)
- Based on the strength of evidence D, medical neglect occurs when a child is harmed or is at risk for harm because of a lack of

health care and the recommended health care offers significant benefit and the benefit is greater than its morbidity.(24)(25)

- Based on the strength of evidence C, medical neglect composes approximately 34% of all cases of neglect in the United States yearly and is a significant cause of childhood morbidity and mortality. (27)(28)
- Based on the strength of evidence C, medical neglect is often multifactorial and can include societal barriers to access to health care, parental factors such as low health literacy, child factors such as childhood anxiety or autism that make medical encounters difficult, and health-care provider factors such as lack of cultural sensitivity.(2)(32)(33)(34)(35)(36)(37)(38)(39)(40)(41)
- Based on the strength of medical evidence C, some form of religious exemption for medical care is legal in 34 US states (as well as in Guam, Puerto Rico, and Washington, DC), with 15 states allowing exemptions in criminal and manslaughter cases. (43)
- Based on the strength of medical evidence D, vaccine refusal, complementary and alternative medicine, and severe obesity pose unique challenges when trying to make a case for medical neglect. Each case must be looked at individually, with focus on the potential harms and benefits to the child. (56)


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Medical Child Abuse and Medical Neglect

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1. A Child Protective Services (CPS) physician is conducting a case-based educational session at a conference for primary care providers. The topic of the conference is "Medical Child Abuse." The speaker presents case scenarios and gives the audience an opportunity to make a judgment on the need to file a report to CPS. Which of the following scenarios is suspicious for medical child abuse?
 - A. A 2-week-old baby with difficulty latching onto mother's nipple who is currently at birthweight.
 - B. A 6-month-old boy with formula intolerance and blood in the stool who is well-appearing.
 - C. A 15-month-old girl with new-onset apneic episodes witnessed by only 1 caregiver.
 - D. An 18-month-old boy with a high temperature and 10 minutes of seizure activity who has normal electroencephalographic and head computed tomographic scan results.
 - E. A 12-year-old girl with repeated vomiting and evidence of erosion of dental enamel who is of normal weight for age.
2. The mother of a new patient to your practice states that her 9-year-old daughter was diagnosed as having pediatric autoimmune neuropsychiatric disorder after a streptococcal infection 1 year ago. On physical examination today you note mild pharyngeal erythema and enlarged tonsils in an otherwise well patient. The mother shares a list of medications written by various physicians in a nearby town, some of which need to be refilled. Which of the following is the most appropriate next step in the management of this patient that will ensure an appropriate level of treatment?
 - A. Arrange for household members to be tested for streptococcal infection.
 - B. Ask the mother to complete a medical release that allows for exchange of medical information between you and former physicians.
 - C. Give a prescription for antibiotics and refer the patient to otolaryngology for prophylactic tonsillectomy.
 - D. Give a prescription for antibiotics to be filled if future signs and symptoms of pharyngitis occur.
 - E. Refer the patient for cognitive behavioral therapy.
3. A 14-year-old girl is brought to the emergency department (ED) for the fifth time in the past 2 months by her mother because of recurrent episodes of vomiting. The mother reports that the patient has a history of chronic pancreatitis and has missed school on and off in the past 4 months. Review of the electronic medical records showed that, other than evidence of dehydration, her evaluations were all negative. She received intravenous hydration on each of the ED visits and intravenous antiemetic and was discharged to follow-up with her primary care provider (PCP). The ED physician contacts the PCP who reports that the patient has been admitted to other hospitals and that the mother has been "doctor shopping" and demanding referrals to various specialists. On trying to get more history from the patient, the mother constantly interrupts to answer all questions and the patient appears withdrawn, with a flat affect and no eye contact. Medical child abuse is suspected. Physical examination results are normal except for dehydration and minimal weight gain from the previous visits. Which of the following is the most appropriate next step in management?
 - A. Admit the patient to the hospital for further observation and communicate the concern for medical abuse to the admitting team.
 - B. Discharge after hydration to follow-up with her primary care provider.
 - C. Discharge after hydration with referral to gastroenterology.
 - D. Refer the patient for outpatient psychological counseling to address her flat affect.
 - E. Repeat the previous evaluation of the vomiting with laboratory and imaging studies.

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4. The patient in the previous vignette is admitted and started on intravenous fluid hydration. Her amylase and lipase levels were normal. The admitting team consulted social services and child life therapy. A trend charting over 3 days correlated the vomiting episodes to the times that the mother was in the hospital. The patient had no symptoms and was less withdrawn when the mother was not around. Urine was positive for emetine, a metabolite of Ipecac syrup, strongly suggesting the diagnosis of medical child abuse. In addition to filing a report to CPS, which of the following is the most appropriate next step in management?
- A. Discharge the patient with the mother and arrange for home health nurse visitation twice weekly.
 - B. Suggest law enforcement immediately arrest the mother.
 - C. Hold a meeting as an "informing session" with the family, including the mother who is the suspected perpetrator, to discuss the patient's condition.
 - D. Obtain a court order to prevent the mother from entering the hospital.
 - E. Refer the mother to the psychiatry service for admission to an inpatient psychiatric facility.
5. A 3-year-old boy with a history of extreme prematurity and a seizure disorder is admitted to the PICU for the management of respiratory failure caused by pneumonia and severe malnutrition that requires nutritional rehabilitation. The patient's primary care provider (PCP) reports a nearly 2-year history of multiple missed primary care and subspecialty appointments, and poor adherence to prescription medications and specialty diets despite repeated PCP counseling to the patient's parents. In addition to the medical management required, which of the following is a reasonable intervention to address the cause of the clinical condition in this patient?
- A. Explain to the parents that the PCP will file a CPS report if the child misses another appointment after hospital discharge.
 - B. File a CPS report after a determination is made that at least 1 of the patient's drug levels is low.
 - C. File a CPS report after a determination is made that there are no medical reasons for the severe malnutrition.
 - D. Inform the parents that a CPS report of suspected medical neglect will be filed during this admission.
 - E. Recommend to the PCP to dismiss the patient from the practice given the long-standing nonadherence to medical advice.

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