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Carole Jenny and the Committee on Child Abuse and Neglect

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CLINICAL REPORT

Recognizing and Responding to Medical Neglect

Guidance for the Clinician in Rendering
Pediatric Care

Carole Jenny, MD, MBA, and the Committee on Child Abuse and Neglect

ABSTRACT

A caregiver may fail to recognize or respond to a child's medical needs for a variety of reasons. An effective response by a health care professional to medical neglect requires a comprehensive assessment of the child's needs, the parents' resources, the parents' efforts to provide for the needs of the child, and options for ensuring optimal health for the child. Such an assessment requires clear, 2-way communication between the family and the health care professional. Physicians should consider the least intrusive options for managing cases of medical neglect that ensure the health and safety of the child.

INTRODUCTION

Pediatricians are sometimes confronted in practice by children whose medical needs are being neglected. In the United States, medical neglect accounts for 2.3% of all substantiated cases of child maltreatment.¹ This represents the "tip of the iceberg," because only the most egregious and intractable cases are likely to be reported to authorities.

Medical neglect usually takes 1 of 2 forms: failure to heed obvious signs of serious illness or failure to follow a physician's instructions once medical advice has been sought. Either of these situations can be fatal in some cases or can lead to chronic disability.²

Several factors are considered necessary for the diagnosis of medical neglect³:

1. a child is harmed or is at risk of 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, so that reasonable caregivers would choose treatment over nontreatment;
4. it can be demonstrated that access to health care is available and not used; and
5. the caregiver understands the medical advice given.

In many cases, no harm will occur if the caregiver opts not to seek medical care for an ill child. For example, if children have high fevers caused by self-limited viral illnesses, they are unlikely to suffer adverse consequences if they do not receive medical care, even if they appear acutely ill. On the other hand, if a child with a stomachache caused by appendicitis fails to receive medical care, the results can be dangerous. However, when a procedure carries inherent danger or a drug has significant adverse effects, labeling a caregiver's reluctance to cooperate as neglect may be problematic.² In some situations, health care professionals may evaluate risks and benefits of drugs or procedures differently than families.

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The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

Key Words

medical neglect, health literacy, physician-patient relationships, cultural competency

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REASONS THAT FAMILIES FAIL TO SEEK APPROPRIATE MEDICAL CARE

Many factors can lead to children not receiving appropriate medical care. It is important to consider these etiologies in planning for the alleviation of the problem. The child can be seen as the center of an ecological framework within which lack of medical care may result from interactions among a variety of interdependent factors.⁴

Patient and Parent Factors

Poverty or Economic Hardship

Many families lack financial resources to care for children with acute or chronic illnesses. For some parents, taking time from work to care for sick children can lead to decreased income or even loss of their jobs.

Lack of Access to Care

The number of children in the United States who do not have health insurance is estimated to be between 8.7 and 11.1 million.⁵ Other barriers to access include geographic constraints (such as long distances to care and lack of transportation), lack of baby-sitters for siblings, lack of available health care professionals, and language barriers.

Family Chaos and Disorganization

Some families lack order and routine in their lives. Interactions are inconsistent and fragmented. Parents may be unable to respond to the children's needs in an effective manner. These families may have a difficult time responding appropriately to medical emergencies, and it may be even more difficult to meet the needs of chronically ill children who require ongoing medications and treatments.

Lack of Awareness, Knowledge, or Skills

Caregivers may not be aware of the signs or symptoms in their children that could indicate serious illness. They may not understand why a medication or treatment is prescribed or why it is important to follow through with their physicians' instructions.

Lack of Trust in Health Care Professionals

Some families may refuse advice because they lack trust in physicians or organized medicine because of what they have heard from friends or the media or because of previous negative experiences with the health care system.

Impairment of Caregivers

If a child's caregiver is developmentally delayed or mentally ill, he or she may not have the capacity to respond to the child's health care needs. Substance abuse can also interfere with normal caregiving. In cases in which par-

ents cannot comprehend the child's need for care, the children might need protection from a social service agency if they are in danger, even if the parents are trying to meet the children's needs.

Caregiver's Belief Systems

Some caregivers have belief systems that are inconsistent with Western medicine. A parent of a child who has a serious illness may decide to rely on untested remedies or alternative medicines. Some caregivers will seek healing through religion rather than medical care. The special case of religiously motivated medical neglect is discussed further below.

The Child's Attitudes and Behavior

In some cases, particularly in adolescents, the child will reject medical care and refuse to comply with medications, treatments, or diet. Children might assert their independence by not cooperating or use their illness to gain attention from their parents or deflect family conflict. Children may also be influenced by their peers and may not want to accept the fact they are ill and need treatment. They may feel they are more likely to "fit in" with others if they are not ill.

Physician Factors

Pediatricians' Misunderstanding of Different Cultures

What some pediatricians may consider obvious medical neglect might be acceptable parenting practices in other cultures. It is important for pediatricians to have knowledge of the beliefs and practices of the families they serve.⁶ If children are in danger, interventions necessary to protect them are indicated even if the parents think they are doing the right thing. However, pediatricians should work to understand others so they can effectively educate parents while respecting different cultures. Some American Indian/Alaska Native cultures actively encourage adolescent children to make their own decisions about medical care. If the adolescent makes a potentially harmful decision, the parents must be informed about the consequences of that decision and urged to intervene with the child, whether through persuasion or overruling the decision.

Lack of Parent Health Literacy and Lack of Communication in the Medical Setting

Communication between pediatricians and parents can be affected by the parents' level of health literacy. Health literacy is defined by the US Department of Health and Human Services as "the degree to which individuals have capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."⁷ Parents often misunderstand complicated medical instructions and explanations of the justifications for treatment. Likewise, physicians

may not clearly communicate or adequately assess caregivers' comprehension of complicated medical instructions and justifications for treatment.⁸ This lack of understanding can lead to poor adherence by families. If parents and physicians do not speak the same language, this also can complicate communication. Pediatricians should be cognizant of the factors that limit effective communication with patients and parents and work to overcome those barriers.⁹ The American Academy of Pediatrics policy statement "Ensuring Culturally Effective Pediatric Care"¹⁰ provides excellent resources for pediatricians seeking information on cultural competency.

THE PEDIATRICIAN'S RESPONSE TO MEDICAL NEGLECT

When confronting a family in which a child is being medically neglected, the child's well-being should be the physician's first concern. Several management options are available to pediatricians. Generally, the least restrictive, most collaborative approach to the situation is the best. Whenever possible, the family should be assisted in understanding the need for obtaining necessary medical care. The management of medical neglect involves initially identifying the underlying problem that led to the neglect. Once this is done, the pediatrician has many options for rectifying the situation. The following suggested intervention options are listed from least restrictive to most restrictive.

1. If the parents are not fluent in English, access services in the community to facilitate translation.
2. Be sure the family's concerns are understood. The medical staff must understand the family's view of their child's medical condition and its proposed treatment. Recognizing the family as a partner in the decision-making process assures caregivers that their opinions are respected and opens the door to compromise and improved adherence.
3. Counsel the family about the need for care and educate the parents and patient. The parents should be educated about the dangers of the illness and the importance of seeking medical care and complying with treatment. The family's support should be enlisted in addressing the problem. Make sure the parents understand what medications are indicated, how they work, and when they are to be given. Special programs are available to teach parents and children about the management of some chronic illnesses such as diabetes and asthma.
4. In some cases, it will be helpful to expand the circle of caregivers who will help with the child's medical care. For example, the extended family of the child might be enlisted to assume some of the care responsibilities for the ill child.
5. Involve the family in the development of a medical plan. When physicians collaborate with their patients in the development of treatment plans, physicians and families can reach shared understanding of the etiology, prognosis, and treatment options. Engaging the caregivers throughout the planning process can empower families and enlist them in support of treatment plans.
6. When necessary, work with the family to develop a written contract that outlines exactly what care needs to be provided. Sometimes families have a difficult time keeping track of treatments, medications, and appointments, especially when they have a chronically ill child with complicated medical problems. A written contract that is agreed to by both the physician and the family can serve as a "blueprint" for the family to follow. It also provides the physician with documentation that the family understood and agreed to the care plan. If intervention is required later by social service agencies, this documentation can be helpful to demonstrate that the family was informed of the importance of the child's medical care. When contracting with families, physicians should make sure that the parents or caregivers can read and understand the care plan.
7. Enlist community resources to aid in caring for the child. Resources such as visiting nurses, transportation services, financial relief, and respite care should be used if needed and available. Some organizations that advocate for people with specific chronic illnesses will provide educational opportunities about disease management, support groups, or "peer counselors." Although organizing these interventions is often beyond the scope of pediatric practice, pediatricians should be aware of community resources that are available to support the families of their patients and be prepared to make appropriate referrals. The medical home must recruit and coordinate a multidisciplinary team to make decisions in complex cases of medical neglect. By gathering together the essential health and human services professionals involved in the case, treatment and rehabilitative regimens and services can be coordinated for the involved families. Enlist knowledgeable members from the family's cultural/ethnic/medical belief system to assist in understanding the actions of the family and to help the health and human services professionals meet the needs of the neglected child.
8. Arrange for directly observed therapy for children with chronic serious illnesses. Daily home visits by a nurse or paraprofessional could be considered in cases in which there is lack of compliance with medications. Roberts et al¹¹ reported on the use of directly observed therapy to ensure that HIV-positive children received their antiretroviral therapy. In

4 of 6 cases, this approach led to sustained decreases in the patients' viral loads and allowed the children to remain in their homes instead of being placed in foster care. Although this is an expensive alternative, it is less expensive than providing foster care for a medically complicated child.

9. A partial hospital or day-hospital program may be helpful in cases in which family dysfunction and lack of patient compliance are issues. In some areas, partial hospital programs offer medical and mental health care for chronically ill children. Such programs offer family, group, behavioral, and individual therapy as well as education for parents and children about coping with illness.¹² These programs, when available, are useful in treating children and families with complex histories in which chronic illness has been managed inadequately because of social and psychological factors.
10. Refer families to child protective services agencies to ensure that necessary medical care is received. When other options are not available or have not been successful, it may be necessary to involve child protective services if the child is being harmed (or potentially harmed) by lack of medical care. The child protective services agency should understand what the nature of the child's medical problem is and why appropriate medical care is critical to the child's health and development. In many areas, the child protective services system has access to resources for family support that might not be available otherwise. In extreme cases in which the family is not able to cooperate, placing the child in foster care may be the only option.

MEDICAL NEGLIGENCE IN CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Children with multiple medical problems can present a challenge to any parents. These children often require multiple regular medical appointments, multiple therapies such as physical, speech, and occupational therapy, medical equipment monitoring, special diets, and multiple medications. When the families of chronically ill children have limited resources, the challenges they present can be overwhelming. The primary care pediatrician can be helpful in providing a medical home that coordinates care and avoids duplication of services. A partnership with these families is critical so that problems can be identified and dealt with early. It is critical to always review the care plan so that the family can concentrate on therapies and interventions that are most likely to be beneficial and so that marginally effective therapies can be eliminated.

SPECIAL RESPONSIBILITIES OF PEDIATRICIANS CARING FOR CHRONICALLY ILL CHILDREN WHO MISS MULTIPLE APPOINTMENTS

Some parents with chronically ill children fail to keep multiple medical appointments. Depending on the seriousness of the child's illness, lack of medical care could adversely affect the child's health. In some cases, physicians inform such parents in writing that they will no longer be able to provide medical care for the child. When families tie up and then do not use scarce appointment slots, clinics are often unable to serve other families effectively. In other cases, clinic staff will contact the parents and simply reschedule the child for another appointment.

In either case, pediatricians should consider whether the child is at risk of harm because of the acts of the parents. If so, other interventions should be considered, including asking a clinic social worker or other staff member to discuss the problem with the parents, requesting a home visit by a nurse, or, in extreme cases, referring the family to the local child protective services agency. The important point is that each case needs to be considered individually to ensure the well-being of each child.

For chronically ill and complex patients, the medical home becomes an important asset in dealing with the competing demands for the caregivers' time and attention. In partnership with the families, primary care pediatricians can assist them in developing reasonable care plans involving many subspecialties and disciplines, such as physical and occupational therapy.

Pediatricians should work with families to facilitate the availability of appointment times that meet the demands parents face, such as jobs, child care, and transportation.

DETERMINING WHETHER A TREATMENT OFFERS SIGNIFICANT BENEFIT

One of the 5 factors that constitute medical neglect is caregivers refusing recommended health care that offers significant "net benefit" to the child. In many cases, the question of net benefit of a therapeutic modality can be debated. For example, if parents refuse medical intervention for a newborn infant at the limit of viability, is it medical neglect? In many cases, we do not have data on the relative benefits of various therapeutic interventions, and in some cases what one person would deem beneficial, another might think is of no value.

When these situations occur, it is important that the caregivers and health care professionals have an opportunity to communicate openly about their values and opinions. It is critical that these discussions be documented in the health record and acknowledged by providers and families. Involving a hospital's ethics committee can be helpful in resolving instances of conflicting opinions.¹³

RELIGIOUSLY MOTIVATED MEDICAL NEGLECT

Medical neglect evaluations should focus on the child's needs rather than the caregiver's motivations or justifications. Religious objections, therefore, should not be granted fundamentally different status from other types of objections.¹⁴

Although competent adults have the right to refuse life-saving medical care for themselves, the US Supreme Court has stated that parents do not have the right to deny their children necessary medical care.¹⁴ The court made this clear in 1944 in *Prince v Massachusetts*.¹⁵ "The right to practice religion freely does not include the liberty to expose the community or child to communicable disease, or the latter to ill health or death. . . . Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children. . . ." ¹⁵ The American Academy of Pediatrics has taken a firm stance on the rights of seriously ill children to receive life-saving medical care even if their parents subscribe to religious beliefs that are antithetical to medical care.¹⁶

SUMMARY

Medical neglect of children can cause harm or death. The pediatrician's responsibility is to the child. If parents or caregivers are not meeting the child's medical needs, the pediatrician is encouraged to work to ensure that the family has adequate resources to care for the child. The pediatrician has several important roles in working on behalf of medically neglected children, including engaging the family, understanding the family's circumstances, explaining the need for therapy, and collaborating with professionals and resources within the community to ensure that the child's health is optimized.

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