Child Abuse in Children and Youth with Special Health Care Needs

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Education Gap

As the number of children and youth with special health care needs increases, it is imperative that pediatricians garner the skills to identify patients at increased risk for abuse, to correctly differentiate child abuse and neglect from accidental injury or sequelae of specific disease processes, to appropriately report child abuse, and to integrate prevention strategies into the medical home for our most vulnerable patients.

Objectives

After completing this article, readers should be able to:

1. Detail the definition and epidemiology of children with special health care needs.
2. Describe the epidemiology of child abuse and neglect.
3. Review the prevalence of abuse in children with special health care needs.
4. Determine the psychosocial and environmental risk factors for child abuse and neglect.
5. Differentiate the findings associated with physical abuse from those of accidental injury or illness.
6. List unique barriers to identifying and reporting abuse in children with special health care needs.
7. Identify strategies to prevent child abuse in children with special health care needs.
8. Recognize the importance of a medical home for children and youth with chronic conditions and physical and cognitive limitations.

CASE

A 14-year-old boy with intellectual disability and moderate spastic cerebral palsy presents to the emergency department with 1 day of fussiness and pain. At examination, he is noted to be nonverbal and thin and has swelling and tenderness.
of his left thigh. On radiographs, he is noted to have diffuse osteopenia with cortical thinning, as well as a left midshaft femur fracture. When questioned about the injury, his parents report no history of trauma.

INTRODUCTION

Child abuse is defined as “all forms of physical and/or emotional ill treatment, sexual abuse, neglect, or negligent treatment or commercial or other exploitation, resulting in actual or potential harm to the child’s health, survival, development or dignity in the context of a relationship of responsibility, trust or power.” (1) Child abuse can be thought of in 4 broad categories: physical abuse, sexual abuse, psychological and emotional abuse, and neglect. In 2014, 702,000 children were confirmed victims of child abuse and neglect in the United States, and data collected via telephone survey of caregivers and children suggest that this number may be even higher. (2) Every year, about 4% to 16% of children are physically abused, and 1 in 10 is neglected or psychologically abused. During childhood, 5% to 10% of girls and up to 5% of boys are exposed to penetrative sexual abuse, and up to 3 times this number are exposed to any type of sexual abuse. (3)

While abuse is a pressing public health concern in the general pediatric population, there are specific patient populations who are at even higher risk for abuse and neglect. Risk factors for abuse have been divided into 3 categories: factors related to the child, such as special health care needs or a child who is the product of an unplanned pregnancy; factors related to the parent, such as a personal history of abuse, poor impulse control, or substance abuse; and factors related to the environment, such as poverty and social isolation. (4)

The Centers for Disease Control and Prevention identifies “special needs that may increase caregiver burden,” such as intellectual disability or chronic physical illness, as a major risk factor for child abuse. (5) Children with special health care needs are defined as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” (6) It is imperative to note that this definition is not based on specific diagnoses or functional status but rather on increased service use or need. Increased risk can be both biological and environmental. On the basis of this definition, the National Survey of Children and Youth with Special Health Care Needs in 2009 to 2010 demonstrated an overall national prevalence of 15.1% of children with special health care needs. Owing to advances in medical technology for all children and youth, as well as the improved survival of extremely premature infants, this number has increased over time and represents an increase from 12.8% in 2001 and 13.9% in 2005. (2)

The definition of children with special health care needs can encompass a wide range of abilities; however, this article will focus primarily on a subset of this patient population known as children with medical complexity, which comprises those with multisystem acquired or congenital disease and children with severe functional impairment secondary to a neurological condition. (7) These patients require an additional level of experience, expertise, and resources to achieve optimal health outcomes and are particularly fragile and vulnerable.

SCOPE OF THE PROBLEM

While it is difficult to estimate the rates of abuse in the general population, it is particularly challenging to enumerate in children with special health care needs. Defining the special needs population presents a challenge, as there are various definitions used for special health care needs and disabilities in the literature. Additionally, the prevalence of maltreatment in the United States is often challenging to calculate, as individual states use different definitions of “child abuse and neglect.” (8) Finally, it can be difficult to determine whether the disability is the precipitating agent for abuse or whether abuse caused the disability, and the potential for reverse causation cannot be excluded in population-based studies. Despite the difficulty in calculating rates of abuse in children with special health care needs, several studies indicate that children with special health care needs experience all types of abuse at higher rates than their peers. (9)(10)

A landmark study published in 2000 noted that children with disabilities were nearly 4 times more likely to be physically abused or neglected and more than 3 times more likely to be sexually abused when compared to children without disabilities. (9) Additionally, a study conducted by using forensic interviews showed that increasing levels of impairment were associated with an increased risk of sexual abuse. (11) Finally, in the first review to provide pooled estimates of the prevalence and risk of abuse against children with disabilities, it was estimated that up to one-quarter of children with disabilities will be a victim of child abuse or neglect in their lifetimes. (12)

With clear evidence that children and youth with special health care needs are particularly vulnerable to all types of abuse, it becomes imperative to understand the specific risk
factors for abuse and the unique challenges faced by this population, as well as the ways in which pediatricians can appropriately identify and prevent abuse.

**SPECIFIC RISK FACTORS**

Several studies have sought to identify reasons why children and youth with special health care needs are more vulnerable to abuse than their typically developing peers. Reasons for this disparity include societal stigma, negative traditional beliefs or ignorance within communities, lack of social support for caregivers, and heightened vulnerability as a result of the need for increased care. (12) Children and youth may have behavioral issues that are difficult to manage or may not be able to communicate abuse when it happens, which leads to the inability to report abuse when it occurs. Finally, parents and caregivers often lack adequate support systems, which creates an environment in which abuse is more likely to occur. Thus, risk factors for abuse that are unique to children with special health care needs relate to the child’s underlying diagnosis and associated limitations, the increased need for assistance in activities of daily living, and the increased caregiver burden associated with having a child with special health care needs.

Specific special needs have been correlated with increased risk for specific types of abuse. A longitudinal cohort study in two counties in New York demonstrated an increased risk of neglect among children with a low verbal IQ or who were anxious or withdrawn. They also found that children who required special education were at an increased risk of sexual abuse but that low IQ was not an independent risk factor for physical abuse. (13) A retrospective birth cohort study conducted in the United Kingdom provided the odds ratio for abuse on the basis of several different types of disability, including cerebral palsy, conduct disorder, speech or language disorder, learning disability, sensory disorders, and autism. (14) Findings suggest that children with cerebral palsy were at increased risk of physical abuse and neglect; autism and hearing or vision impairments did not predispose children to abuse or neglect in this study. Investigators in another study posit that children with special health care needs who are reliant on others for assistance with self-care may be at increased risk for sexual abuse specifically because they may be used to others touching their bodies and may be less able to recognize inappropriate contact or touch. (15)

Parental stress also plays a major role in increasing the risk for child abuse in children with special health care needs. Parents of children with special health care needs face unique challenges in caring for their children, including the burden of additional parenting tasks, such as arranging and attending frequent medical appointments, developing appropriate behavioral management plans in children who do not have the same level of understanding as their age-matched peers, parenting without clear benchmarks for success, integrating their child’s care with both medical and nonmedical needed services, and the feeling of having to parent under public scrutiny. (16)

In a clinical report entitled “Maltreatment of Children with Disabilities,” several parental stressors are identified that may contribute to child abuse in children with special health care needs:
1. Parents or caregivers may experience additional stress because children with disabilities may not respond to traditional means of discipline.
2. Children with disabilities place additional physical, economic, emotional, and social demands on their families.
3. Parents and caregivers who have a limited social support system may be at increased risk of maltreating their children with disabilities because they may feel overwhelmed. (8)

**IDENTIFICATION OF CHILD ABUSE**

The identification of child abuse can be difficult for the pediatrician, as patients do not always present with clear physical examination findings, particularly in the case of childhood sexual abuse. Guidelines exist for the identification of abuse in the general pediatric population, including appropriate diagnostic testing to evaluate for underlying medical conditions; these guidelines are summarized in the clinical report “The Evaluation of Suspected Childhood Physical Abuse,” published by the American Academy of Pediatrics (AAP) Committee on Child Abuse and Neglect. (4) However, unique challenges exist in the identification of child abuse in children with special health care needs. These challenges may be related to the patient’s medical condition or to factors involved in caring appropriately for these children.

Medical conditions that may mimic abuse in the patient with special health care needs include but are not limited to motor and balance issues, bleeding disorders, osteoporosis or osteopenia, self-injurious behavior, and developmental delay.

**Motor and Balance Issues**

Patients with motor and balance issues, such as poor coordination or wheelchair dependence, may present with many concerning skin findings for physical abuse. The pediatrician should differentiate between skin findings consistent
with an appropriate mechanism of injury and skin findings that raise red flags for abuse. Few rigorous studies have been conducted to examine variations in bruising patterns among patients with limited or restricted mobility when compared to their peers. One study showed a significant decrease in the number of skin markings in patients with no ability to ambulate when compared to patients with some ability to ambulate with assistance. (17) However, no additional differences in skin findings were noted. Goldberg et al (18) found that patients with clinically significant mobility limitations that required maximal assistance with transfers and self-care were more likely to have bruising than their peers but that the location of bruising differed (Table). Specifically, the lower legs were often bruised in children without disabilities but not in children who were wheelchair bound. In contrast, the feet, back and lumbar areas, and pelvis were more frequently bruised in children who were wheelchair dependent, and children with severe mobility restrictions were more likely to sustain bruises at older ages when compared to their peers. These differences were postulated to be secondary to the increasing difficulty in transferring these patients, particularly as they grow in size. (18) However, children with mobility limitations did not have a higher frequency of bruising at other sites, which raise concern for abuse in the general population, such as the neck, ears, chin, anterior chest, or buttocks. (4)(19)

These studies indicate the importance of accounting for specific mobility status in patients when determining whether a skin finding is consistent with the mechanism of injury described. A patient who is unable to ambulate is significantly less likely to have bruising of the lower extremities from a benign etiologic cause than a patient with some ability to ambulate independently. However, patients who are wheelchair dependent may develop lower-extremity bruising related to their equipment, particularly bruises at the site of foot and ankle splints. Therefore, it behooves the pediatrician to examine each case on an individual basis, and suspicion should be raised if the mechanism of injury does not align with the child’s mobility status.

**Bleeding Disorders**

Patients with bleeding disorders may present with unexplained bruising or bleeding, which raises concerns for physical abuse or abusive head trauma. It is important to consider bleeding disorders in the evaluation of children with suspected non-accidental trauma, especially at young ages. Platelet number should be assessed, and disorders of platelet function should be considered, especially in the context of medications, which may influence platelet activity. Nonverbal patients with bruising as the only finding concerning for abuse should always be screened for hemophilia and Von Willebrand disease; frequently, other screening for bleeding diatheses is undertaken. (20) In patients with a known bleeding disorder, the specific manifestations of that disorder should be taken into account when assessing the likelihood of nonaccidental trauma. For example, a patient with hemophilia may be particularly prone to bruising, but a finding of patterned bruising is always concerning for child abuse.

**Osteoporosis and Osteopenia**

Patients who have limited mobility or who do not bear weight are at increased risk for osteoporosis and associated fractures. Specifically, children with spastic cerebral palsy have been studied in depth to assess their risk for long bone fractures, which may be mistaken for physical abuse. These studies showed that children with cerebral palsy are at increased risk for accidental or nontraumatic long bone fractures, at a rate of about 4% per year. (21) Specific risk factors for fractures included limited mobility, feeding difficulties, anticonvulsant use, and history of prior fractures. (22) Children and youth with limited mobility should have preventive measures taken to foster adequate bone health and mineralization in the primary care medical home or in partnership with specialty care when indicated.

**TABLE. Bruising Patterns That Raise Concern for Physical Abuse**

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<th>POSSIBLY ACCIDENTAL PATTERNS</th>
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<td>Children without mobility limitations</td>
<td>Lower extremities</td>
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<td>Ears</td>
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<td>Children with limited mobility</td>
<td>Feet</td>
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<td>Pelvis</td>
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<td>Hands and arms (18)</td>
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Self-injurious Behavior
Children with special health care needs engage in self-injurious behavior more frequently than their typically developing peers, and this behavior is more persistent as children get older. (23) Risk factors for self-injurious behavior include a diagnosis of autism spectrum disorder, as well as specific genetic syndromes such as Prader-Willi, Lesch-Nyhan, fragile X, Cornelia de Lange, and Smith-Magenis.

Studies have demonstrated the usual topography of these injuries to most frequently include head-banging, eye-poking, and hand-mouthing, which can result in serious morbidity. (23) These injuries can be mistaken for physical abuse; thus, vigilance on the part of the primary care provider is important. On the other hand, there is some evidence to suggest that there may be an increase in self-injurious behaviors, particularly in children with autism spectrum disorders, when they are exposed to chronic maltreatment and abuse; (25) thus, increasing intensity of self-injurious behaviors always merits further investigation.

Developmental Delay
It is important to take into account both a patient’s developmental age and his or her chronological age when assessing whether an injury may be the result of nonaccidental trauma. This is relevant with regard to motor development milestones but also with regard to cognitive milestones. Patients with intellectual disability may be more prone to accidental toxic or drug ingestion, as their physical ability to access potentially harmful substances in the home may be beyond their ability to understand the consequences of their actions. This is particularly true in patients with severe intellectual disability, cognitive delays, hyperphagia, or other genetic syndromes, such as Prader-Willi.

PREVENTION OF ABUSE
The AAP clinical report “The Pediatrician’s Role in Child Maltreatment Prevention” provides guidance on child maltreatment prevention through strengthening families and promoting stable nurturing families. (26) At a minimum, pediatricians of children with special health care needs should consider providing disability-specific injury prevention recommendations to all families as part of their anticipatory guidance to help families minimize their child’s risk of injury. For example, the AAP Committee on Injury and Poison Prevention provides clear illustrated guidelines for the safe transportation of patients with technology dependence and specific medical needs to prevent serious injury.

Additionally, it behooves the pediatrician to develop strategies for recognizing overwhelmed parents who are at risk of harming their children. In fact, investigators in 1 study found that the single best way to protect children with special health care needs from abuse is to address the needs of their caretakers. This should include parental training in topics such as child behavior management, stress management skills, and respite care and community supports. (15)

The pediatrician need not work alone in a vacuum to prevent child abuse. Community partners can be extremely helpful in preventing parents from becoming overwhelmed and include, but are not limited to, home nursing agencies, child advocacy agencies, medical child care, school and educational settings, and community programs that provide home visiting and assistance in navigating the health care system to families of children with special health care needs. One national organization is Family Voices (http://www.familyvoices.org/), which provides resources and support to families of children with special health care needs and advocates for family-centered care. Indeed, the role of the medical home, or the provision of care that is “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective,” cannot be emphasized enough in the prevention of abuse of children and youth with special health care needs. (28)

CASE RESOLUTION
In light of the unexplained fracture, the provider becomes suspicious for potential physical abuse. A thorough physical examination demonstrates a nonverbal, wheelchair-dependent child with spasticity in all 4 extremities. A skin examination shows a small bruise on the lateral aspect of the left thigh, but no other bruises are identified. The provider notes that the patient has several risk factors for abuse, including special health care needs, limited mobility and communication, developmental delay, and multiple caretakers. However, the provider also recognizes that the patient is at increased risk for accidental femur fracture because of his limited mobility, spasticity, and low bone mineral density. As a mandated reporter, the provider reports her suspicion for abuse to child protective services. A thorough investigation of the home and family is undertaken. A more comprehensive interview with the family suggests that the patient’s femur fracture was most likely accidental and was sustained during a transfer from wheelchair to bathtub and that the patient’s parents feel overwhelmed by their child’s extensive needs. A referral is made to the local home-visiting intervention program to assist the family in managing their child’s care, and the child remains in the care...
of his family, without further concerns for nonaccidental trauma.

CONCLUSION

Children and youth with special health care needs are particularly vulnerable to all types of child abuse, including physical abuse, sexual abuse, emotional abuse, and neglect due to their increased medical, emotional, and psychosocial needs for care, as well as stressors on their caregivers. The pediatrician must be trained in differentiating abuse from injuries related to an underlying medical diagnosis. Additionally, pediatricians should work collaboratively within the context of the patient- and family-centered medical home and their available partners, recognizing patients and families with risk factors for abuse, with the goal of preventing child abuse in this particularly vulnerable patient population.

Summary

1. Longitudinal epidemiologic surveillance data indicate that children and youth with special health care needs are a growing population in the United States, secondary to advances in medical technology and improved survival of premature infants. (2)

2. On the basis of strong research evidence, children and youth with special health care needs are at increased risk for child abuse because of increased need for care and additional parental and caregiver stressors. (8)(9)(10)

3. On the basis of some research evidence, as well as consensus, there are unique challenges to the identification of abuse in children with special health care needs, such as the differentiation of abuse from accidental trauma based on risk factors such as osteopenia, spasticity, higher rates of fracture or soft-tissue trauma, and limited mobility that requires transfers by assistive person, as well as recognizing abuse in nonverbal patients. (18)(20)(22)

4. The medical home model provides a framework for preventing abuse in vulnerable children while partnering with the community and families. (26)(28)

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Additional Resources for Pediatricians

AAP Textbook of Pediatric Care, 2nd Edition
- Point-of-Care Quick Reference
- Physical Abuse and Neglect - https://pediatriccare.solutions.aap.org/content.aspx?gbosid=245973

Parent Resources from the AAP at HealthyChildren.org

For a comprehensive library of AAP parent handouts, please go to the Pediatric Patient Education site at http://patiented.aap.org.
1. An 11-year-old boy with a past medical history of cerebral palsy, seizure disorder, and shunted hydrocephalus presents to the pediatrician’s office for a health supervision visit. He is followed up by multiple subspecialty services and receives routine physical therapy and home nursing visits. His medications include valproic acid, baclofen, and glycopyrrolate. Physical examination demonstrates a thin, nonverbal, wheelchair-bound boy in no distress. Neurological examination findings are clinically significant for generalized spasticity. The examiner notes a gastrostomy tube with no erythema or drainage and a well-healed ventriculoperitoneal shunt scar. Which of the following factors qualify this patient as a child with special health care needs?
   A. Diagnosis of seizure disorder.
   B. Having a shunted hydrocephalus.
   C. Need for nursing services and equipment.
   D. Number of medications.
   E. Ongoing physical therapy.

2. On further examination of this patient’s skin, several discrete, ecchymotic lesions are noted in the areas of the lateral pelvis, upper thighs, and feet. Which of the following should be considered when assessing this patient’s risk for child abuse?
   A. Bruising of the feet, thigh, and pelvis can be accidental in children with mobility restrictions.
   B. Ecchymosis in this pattern is pathognomonic for child abuse.
   C. This patient is at a lower risk of abuse than his healthy peer.
   D. Thrombocytosis can be an adverse effect of the patient’s medications.
   E. Workup for concomitant bleeding disorder is warranted.

3. A white 6-year-old boy with a medical history of fragile X syndrome and seizure disorder presents to the pediatrician’s office for a health supervision visit. His grandmother reports that he has recently been having difficulty in school because of inattention and frequent tantrums. The provider notes that he has missed his last few appointments, and his immunizations are not up to date. The patient lives at home with his mother, grandmother, and 3 siblings. On examination, he is noted to be an anxious, hyperactive child, who startles easily as the door is closed. He has a noticeably long face and protruding ears. On skin examination, multiple bruises are scattered on his abdomen and flank. Which of the following parental stressors puts this patient at most risk for child abuse?
   A. Caring for multiple children in the household.
   B. Coping with behavioral and intellectual disabilities.
   C. Functioning with a single-parent family structure.
   D. Management of the patient’s seizure medications.
   E. Missing his medical follow-up appointment.

4. A 15-year-old boy with a past medical history of repaired myelomeningocele presents to the emergency room for evaluation of right thigh pain of 3-day duration. He denies any history of trauma, fever, or recent illness. The patient is compliant with his routine catheterization and bowel management programs. He does require customized orthotics and a wheelchair to aid in mobility. Physical examination findings are clinically significant for scoliosis, lower-extremity paralysis, and sensory deficit. There is also mild swelling in the area of the distal right femur, tenderness with palpation, and passive range of motion. Which of the following factors most contributed to this patient’s condition?
A. Bony dysplasia associated with myelomeningocele.
B. Child abuse culminating in femur fracture.
C. Dysplasia of the articular cartilage.
D. Limited weight-bearing, resulting in osteoporosis.
E. Occult bacteremia, leading to osteomyelitis.

5. A pediatric practice serves as a medical home for a growing number of patients with special health care needs. Knowing that this patient population is at increased risk for child abuse, what anticipatory guidance would be most useful in the prevention of child abuse in this population?

A. Advise children with special health care needs to refrain from participation in sports and social groups.
B. Avoid placing children with special needs in medical child care.
C. Establish screening protocols for parental stressors and community resource needs.
D. Initiate efforts to transition to adult health care at the age of 21 years.
E. Recommend homeschooling for patients with special health care needs.
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DOI: 10.1542/pir.2016-0098

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