

Threats to the Medically Complex Child

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The maltreatment of children in the United States today has reached alarming rates, and estimates range from 1 in 8 children by 18 years old to 25% of surveyed children reporting caregiver maltreatment (Jackson, Kisson, & Greene, 2015; Wildeman et al., 2014). This is a public health crisis that affects those at the intersection of medicine, law, social welfare, and child advocacy. One of the most vulnerable groups of children subjected to maltreatment comprises pediatric patients with special health care needs. It is estimated that from 13% to 19% of children in the U.S. currently qualify as having special needs—children at increased risk for chronic physical, developmental, behavioral, or emotional conditions—as designated by the Maternal and Child Health Bureau in 1988 (U.S. Department of Health and Human Services [USDHHS], 2008). A 2005-2006 survey sponsored by the U.S. Maternal and Child Health Bureau and conducted by the National Center for Health Statistics (within the CDC) revealed that almost 14% of U.S. children met the definition for children with special health care needs (CSHCN) (USDHHS, 2008). Twenty-two percent of family households with children include at least one child with special needs (USDHHS, 2008). There is considerable variability in the specific needs of CSHCN—variation in medical complexity, functional limitations, and required resources (Cohen et al., 2011).

Children with medical complexity (CMC) are a distinct subpopulation of special-needs patients. Requiring the highest degree of medical intervention, CMC accrue the majority of health care resources and costs. CMC are patients with significant chronic conditions, including multisystem disease, severe functional limitations from a neurologic disorder, cancer, sequelae in multiple organ systems, and organ transplants with ongoing effects (Cohen et al., 2011). Advances in medicine have allowed

survival of these children far beyond past expectations, albeit with considerable disability. Subsequently, interventions such as medical technology, home nursing care, intensive therapy services, and high utilization of health care resources (Cohen et al., 2011) are common. Estimates of CMC prevalence range from 1% to 5% of the U.S. pediatric population, depending on definitions of health care needs and the number of medical diagnoses (Petska, Gordon, Jablonski, & Sheets, 2017; Berry et al., 2014).

CMC are set apart as specifically vulnerable, even within the context of special-needs patients. Severe limitations in activities of daily living and almost complete dependence on caregivers place these patients in precarious situations. The majority of CMC are unable to accomplish any independent tasks. They are entirely reliant on a multitude of others to carry out the basics of existence—nutrition, dressing, bathing, movement changes, medication administration, and hygiene. Without individuals to attend to these needs, such children would be unable to survive, let alone thrive. Many CMC are technology-dependent, relying on feeding tubes, tracheostomy tubes, respiratory machinery, wheelchairs, and other life-sustaining devices. Polypharmacy, the use of multiple daily medications, is frequently encountered with these patients. Caregivers, including in-home medical personnel, are necessary for medication administration. These factors combined create considerable vulnerability for the medically complex child.

Maltreatment and special needs, especially in the lives of the young, often intrinsically coexist. Maltreated children have increased risk of developing a disability, and CSHCN are more frequently abused and neglected (Corr & Santos, 2017). One study that focused on the prevalence of maltreatment occurring in CSHCN found this population to be 1.8 times more likely to be neglected, 1.6 times more likely to be physically abused,

and 2.2 times more likely to be sexually abused than children without special health care needs (Hibbard, Desch, & the American Academy of Pediatrics [AAP], 2007). A study of more than 4,500 maltreated children, conducted by Sullivan and Knutson (2000), described rates approximately 2 to 3 times higher. CSHCN were 3.76 times more often neglected, 3.79 times more often physically abused, and 3.14 times more likely to be sexually assaulted compared to non-CSHCN (Sullivan & Knutson, 2000). Within the health care sphere, maltreatment of the patient with special health care needs is repeatedly not recognized and diagnosed. The more medically complex the patient is, the more elusive the diagnosis of maltreatment may be. Characteristics of maltreatment in CSHCN as outlined by Sullivan, Knutson, and Ashford (2010) include the following:

1. Types of maltreatment—types in descending order of frequency are neglect, physical abuse, sexual abuse, and emotional abuse. Many children are victims of multiple types.
2. Victim gender—boys were identified to be more commonly neglected and abused in all forms of maltreatment.
3. Types of disabilities—behavior disorders, speech and language disorders, intellectual disability, and hearing impairments are the most frequently described disorders.
4. Disability and abuse associations—children with behavioral issues, speech and language disorders, and intellectual disability are all at increased risk for neglect and physical abuse. These groups, along with children diagnosed with attention deficit hyperactivity disorder (ADHD), are higher-risk targets for sexual abuse.
5. Age at first maltreatment—53% of abused children in the Sullivan and Knutson (2000) study were <4 years old when maltreatment was first identified.
6. Severity of maltreatment—children with multiple medical disabilities endured the most severe forms of abuse and neglect.
7. Duration of maltreatment—medically complex children endure longer (often years' worth) periods of maltreatment.
8. Perpetrators—generally, children with medical complexity were abused or neglected by known and trusted individuals. In cases of sexual abuse,

a perpetrator outside the family committed the acts 40% of the time.

9. Chronic illness or disability—20% of maltreated medically complex children have a parent with a chronic illness or disability, compared with 10% of nonspecial-needs children.
10. Single-parent families—a large portion of maltreated CSHCN (61%) lived in households with a single parent.
11. Site of abuse—the majority of abuse or neglect of a medically complex child occurs in the home or home of a perpetrator.

Medically complex children, the most vulnerable pediatric patients, convene in the center of child maltreatment risk. Their inherent susceptibility resides in the nature of their disability. Severe functional limitations, such as limited or no mobility and technology dependence, incapacitate the child to physically escape from a perpetrator. Limited or no communication prevents disclosure of the maltreatment, and intellectual disability impairs insight into another's abusive or neglectful actions (Nowak, 2015). Specifically, with respect to sexual abuse, children with medical complexity may be targeted owing to their high need of dependency on others. This high dependency may propagate excessive compliance and diminished understanding of offender motives (Nowak, 2015).

Children with medical complexity often place the highest burden of care onto caretakers. The demands are multifactorial and encompass emotional, physical, economic, and social factors. In particular, caregivers with limited social and community support feel overwhelmed and may lack healthy coping strategies, elevating the risk to abuse or neglect a child with medical complexity (Hibbard, Desch, & AAP). Among neonatal intensive care unit graduates, higher caregiving burden is associated with an increased risk for reports to child welfare (Nandyal et al., 2013). Parents and caregivers may suffer sleep deprivation, given the medical demands of the child (Sullivan, Knutson, & Ashford, 2010). Economic demands because of the child's needs may surpass the family's financial resources, especially for the poor. Transportation may be affected, and thus medical appointment adherence declines. Unemployment, particularly if a caregiver loses a job due to missed work from medical care for the child, lends secondary stress to

the fragile home life.

Children with medical complexity frequently have impaired cognition, developmental immaturities, and severe behavioral problems. Given these impairments, formation of the child-parent attachment is insecure, and negativity defines the dyad. Negative parental attitudes weaken the bond, and maltreatment is more apt to result (Corr & Santos, 2017). Noncommunicative children and children with behavioral concerns tend to not respond positively to traditional means of reinforcement. Discipline of such a child can be frustrating, and with a limited repertoire of behavioral control, parents often resort to physical measures (Hibbard, Desch, & AAP, 2007).

Various caregivers in the life of a medically complex child may expand the potential risk for abuse or neglect. Care from other adults exposes the child to more opportunities for harm; these care providers have not often formed any attachment to the child as a protective measure. If the child ventures beyond the home, risk for abuse or neglect rises with exposure to unfamiliar adults. CMC are often perceived, by community members, to have a higher tolerance for pain or to be unaware of pain and, therefore, are subjected to painful physical actions (Taraisman, 2016). Communal attitudes may exist that no one would victimize a child with medical complexity and, as a result, insufficient monitoring for abuse/neglect transpires (Taraisman, 2016).

Physical Abuse and the Medically Complex Child

Noted previously, childhood maltreatment, a pervasive trend in the United States, affects an estimated 1 in 8 children by 18 years old (Jackson, Kisson, & Greene,

2015). Maltreatment comes in many forms: physical, sexual, or neglect (Jackson, Kisson, & Greene, 2015). In 2010, the Child Abuse and Preventive Treatment Act (CAPTA) defined the term maltreatment as “child abuse and neglect,” which means, at a minimum, any recent act or failure to act on the part of a parent or caretaker, that results in death, serious physical or emotional harm, sexual abuse or exploitation, or an act or failure to act which presents an imminent risk of serious harm.” A select group of children may experience multiple forms of maltreatment, while others only one. Child abuse is the physical act of an adult upon a child, causing harm or potential harm. Actions such as hitting, biting, kicking, punching, slapping, shoving, throwing, shaking, smothering, burning, and other are

examples of intentional physical abuse.

Physical abuse may present with varying injuries, from mild to severe (Jackson, Kisson, & Greene, 2015). Frequently, an inconsistent history or no history at all may accompany the discovery of the corporeal injury. This is especially prevalent in nonverbal children or children with limited

intellectual functioning. Diminished or lack of verbal communication from the child prevents first-person knowledge of the abuse.

Several factors of medical complexity intensify the physical abuse risk. Speech and language impairments present a 5 times risk for excessive physical force, while behavior disorders increase the likelihood by 7 times. For the child with intellectual disability, the risk is 4 times higher for all forms of risk and is 2 times greater in children with visual or orthopedic impairments (Sullivan & Knutson, 2000). Referring again the defining factors for children with medical complexity, the majority of CMC reside in these categories simultaneously. This serves to foster scenarios predisposed for caregiver frustration and forceful physical interactions. A severely



autistic child with a gastrostomy tube may repeatedly pull out the tube, requiring caretakers to replace it each time. Exasperation ensues and the caregiver forcibly inserts the tube, injuring the child. This scenario may repeat itself with a multitude of technology— replacement of a tracheostomy tube, insertion of a urethral catheter, cleaning and care of wounds. Attendants can use excessive force with a nonambulatory child, fracturing or dislocating bones. The nature of the medical conditions may inherently lead to physical trauma. Children with cerebral palsy often develop osteopenia (weakened bone strength), and any movement other than done with excessive care, may hurt them.

Case 1—Physical Abuse:

A 12-year-old male with Kallman syndrome (delayed or no puberty, no sense of smell), hearing loss, mutism, severe autism, intellectual disability, failure to thrive, short stature, and gastrostomy tube feeds presented to the special-needs clinic with human bite marks on multiple parts of his body. Prior to the abusive injuries, the child had been placed in a group home, with three other patients. These patients were all grown men with intellectual disability and inability to live independently. The patient visited the clinic that day to meet with his child psychiatrist and adjust his behavior medications. The group home staff member noted the patient had new “bruises” on his back, legs, and upper posterior thighs. Upon examination, the bruises were determined to be consistent with adult-sized human bite marks and in locations the child would be unable to reach with his own mouth. A full investigation ensued with Children Protective Services (CPS) and Adult Protective Services (APS), but the perpetrator was not discovered, and the child returned to the home.

The patient was followed, and it was documented that the bruising from the bite marks had mostly resolved, until return to the clinic 2.5 months later. At this visit, new adult-sized human bite marks were noted on bodily areas the patient would be unable to reach on his own. Referrals were again sent to CPS and APS. The child currently remains in the group home without positive identification of the offender.

Sexual Abuse and the Medically Complex Child

Sexual abuse of minors, according to the Child Abuse Prevention and Treatment Act (CAPTA), is defined as “the employment, use, persuasion, inducement, enticement, or coercion of any child to engage in, or assist any other person to engage in, any sexually explicit conduct or simulation of such conduct for the purpose of producing a visual depiction of such conduct; or the rape, and in cases of caretaker or inter-familial relationships, statutory rape, molestation, prostitution, or other form of sexual exploitation of children, or incest with children” (CAPTA, 2010). Again, cases of sexual abuse in the nonverbal or limited verbal child present an added degree of difficulty with lack of first-person reporting.

As with physical abuse, specific disorders raise the probability of sexual abuse. In descending order of magnitude, these disorders are behavior disorder (5.5 times more risk), mental retardation or intellectual disability (4 times more risk), speech and language condition (3 times risk), and all others being equal at twice the risk (Sullivan & Knutson, 2000). Predators will target medically complex children specifically because the children have neuromuscular conditions that alter or cease physical movement. Children with limited to no expression communication are preyed upon not only because they cannot alert someone at the time but also will not subsequently disclose. Early pubertal developmental is well documented in children with central nervous disruption or insult. Consequently, these children will develop secondary sexual traits, such as breast development and pubic hair, quite early. Findings such as this can give the appearance that the child may be older than the actual age. Younger patients can be targeted as well. If the patient has mild impaired intellectual disability, persuasion and grooming may be tactics leading to sexual abuse.

Case 2 – Sexual Abuse:

A 15-year-old female with mild intellectual disability, quadriplegic cerebral palsy, dependency on a wheelchair, bladder and bowel incontinence, and seizure disorder presented to a special-needs clinic and during part of the visit disclosed to the physician that she had been touched on her breast and inner thigh by a male PE teacher at her high school. The patient reported the touching had

occurred on the outside of her clothes, and it was not the first incident. The coach had touched her legs in a way on various occasions that made her feel uncomfortable. The mother noted that her daughter had stated the coach made her feel uncomfortable, but she did not disclose the fondling. A report was made to CPS and the patient was removed from the school. Subsequently, the PE teacher was fired from the high school.

During a later therapy session, the adolescent revealed that the coach had paid extra attention to her for months, calling her his “special girl,” and would stroke and fondle her. Reportedly, the coach would whisper “special things” into the patient’s ear, telling her how important she was to him. Given her quadriplegia, the patient was unable to move herself and completely dependent on the teacher to move her during this time. It was assessed that the teacher had groomed this adolescent to accept the abuse as special attention, and the abuse continued for many months before disclosure.

Medical Child Abuse and the Medically Complex Child

Medical child abuse (MCA), a complex form of maltreatment, most commonly involves the exaggeration, fabrication, and/or the induction of the signs or symptoms of illness by external methods. Medical child abuse results in overutilization of medical care, intervention, and resources (Berry et al., 2014) at the instigation and often insistence of the principal caregiver. Physically, the child is subjected to excessive medical examinations, blood draws, diagnostic imaging (often invasive), unnecessary surgical procedures, and administration of medication with potentially harmful side effects (Petska et al., 2017). In addition to the physical aspect of the maltreatment, emotional abuse and neglect can be present as well. The abnormal child-caregiver dyad in a case of caregiver-fabricated illness

produces extreme emotional distress for a child (Petska et al., 2017). The discrepancy of harmful actions by the caretaker in medical child abuse and the expected care-taking role of a loved one to a child creates internal emotional turmoil for the child. This may be heightened in a child with intellectual disability, complex medical needs, or multiorgan disease.

Children with medical complexity and medical child abuse victims frequently present with similar clinical presentations (Petska et al., 2017). Situations may transpire that lead to an inaccurate diagnosis of medical child abuse when not present or a missed diagnosis of MCA, coexisting in a child with medical complexity (Petska et al., 2017). There is significant enough overlap

between medical complexity and medical child abuse that up to 30% of MCA victims have an actual underlying medical condition (Petska et al., 2017). As with

other forms of abuse, the medically complex child suffering from medical child abuse is often unable to describe the maltreatment, due to speech and language disorders and intellectual disability. As opposed to children without medical complexity, a special-needs patient may have genuine symptoms present that are exaggerated by the MCA perpetrator or manipulated by intentional actions to worsen. A health care provider in this circumstance may escalate therapeutic interventions in an effort to help, thus unsuspectingly perpetuating the abuse.

Case 3 – Medical Child Abuse:

A 2-year-old female followed closely in the special-needs clinic was diagnosed as a victim of medical child abuse after at least 1 year of suspicion by the primary medical provider. The child was a former extreme premature infant who had a prolonged NICU stay and had diagnoses of subglottic laryngeal clefts, ventriculomegaly, bronchopulmonary dysplasia (BPD), and reflux. Medical child abuse was initially suspected at 10 months of age, due to more than seven hospitalizations for apneic episodes. The child abuse physician followed the child for

“ Medically complex children are the most vulnerable of special-needs children and have the greatest risk for maltreatment.”

1 year as the primary care pediatrician, and it was noted that the mother repeatedly notified the on-call providers in the practice of apneic episodes so severe that CPR was required. Upon further inquiry, the child always returned to baseline, and the mother was the only witness, despite having home nursing training. Seventeen office visits to the special-needs clinic alone are documented over a 1-year period of time. The mother maintained the use of supportive respiratory equipment and convinced multiple subspecialists to prescribe inappropriate medications, based on symptom report only; the lab testing was normal in these instances. The infant was admitted for a therapeutic separation from the mother, after it was determined that the mother repeatedly exaggerated symptoms, likely falsified symptoms, and maintained inappropriate treatments for the child.

While hospitalized and removed from the mother's care, the patient was weaned off her seizure medication after it was determined she did not have seizure activity. Her respiratory support machines were discontinued after studies indicated no need and the child required only one medication for her mild chronic lung disease. She is currently in the father's custody and has supervised visitation with the mother.

Neglect and the Medically Complex Child

Child neglect is the most common substantiated form of maltreatment reported to child welfare agencies (Jackson, Kisson, & Greene, 2015). The Children's Bureau, in 2004, reported that 60% of child victims suffered from a form of neglect (USDHHS, 2008). Neglect subtypes include educational neglect, nutritional neglect, physical neglect, supervision neglect, and medical neglect. When a child's medical needs are not met and the child is harmed or at risk of harm, the parent has medically neglected the patient. Boos & Fortin (2014) describe the various dimensions of medical neglect:

1. **Temporality:** neglect can be an isolated rare event, a recurrent but intermittent situation, or a chronic and ongoing issue.
2. **Potentiality of harm:** mistreatment may be remote, imminent, or actual.
3. **Probability:** when harm is not yet actualized, its likelihood and severity are subject to probability.

4. **Severity of harm:** harms vary from mild discomfort to fatalities.
5. **Etiology:** Rarely, ongoing medical neglect is the consequence of a single person's action or inaction. Medical neglect occurs at the intersection of the family's life and the medical system.

Neglect in the child with medical complexity manifests in various forms. The child requiring gastrostomy tube feeds may present with failure to thrive because nutrition is not being supplied. Pressure wounds and ensuing complications may develop in a nonambulatory child who is dependent on others to adjust positioning of bodily pressure points. A child needing multiple medications for a variety of chronic conditions may fail to receive these in a timely manner, or at all. Accordingly, the child may suffer worsening of physical symptoms such as seizures, muscular spasms, dystonic posturing, pain, or mental and emotional symptoms, including mood lability, depression, mania, or exaggeration of aggression.

Medical neglect is the failure to attain or a significant delay in attaining recommended health care services. It can also include noncompliance with medically prescribed treatments. Chronic illnesses place a higher demand on caregivers and families. More routine contact with the medical systems is necessary and families may miss appointments due to employment concerns. Medical fragility with multiorgan involvement raises the likelihood of poor outcomes, even with small departures from prescribed care (Boos & Fortin, 2014). The American Academy of Pediatrics has outlined criteria for the diagnosis of child medical neglect (Jenny & AAP, 2007):

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 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.
5. The caregiver understands the medical advice given.

Misperceptions of medical information, derived from family members, social media Internet sites, and self-directed Internet searches can foster an environment of distrust with the established medical system. Families may choose to opt for nontraditional interventions for their child's disorders and symptoms. Medical neglect still exists in such situations, if the above criteria are fulfilled.

Case 4 – Neglect:

A 2-month-old female infant presented to the special-needs clinic to establish care. The child had a severe upper airway anomaly requiring placement of a tracheostomy tube and use of a ventilator to maintain normal breathing. Along with her tracheostomy tube, a gastrostomy tube was also placed to ensure the child received adequate nutrition, as eating by mouth was difficult and potentially harmful for the infant. At the second clinic visit, it was noted the mother refused to have the patient weighed (had been weighed in another clinic earlier that day), and when mother's inappropriate feeding of the child was broached by provider, the mother reportedly became agitated and refused to heed the provider's advice. This occurred despite noted weight loss in the infant. Recommendations were again made to the mother, but the mother stated, "The babies in the NICU are too fat, and I will not let my daughter become fat." She also conceded that she had discontinued any gastrostomy tube feeds, giving only oral nutrition.

At each subsequent visit, the infant's weight gain was deemed inadequate, and every attempt to engage the mother was fraught with hostility. The mother refused feeding increases, despite stagnant weight gain. The mother had the patient's gastrostomy tube removed against medical advice. Upon further investigation, it was revealed the child was receiving no therapy interventions and not attaining any developmental gains. After multiple clinic visits, psychiatry was brought in to evaluate mother, but she refused. The mother then fired the special-needs clinic and the infant's pulmonologist, who both had discussed Child Protective Services involvement. The infant was evaluated by a community pediatrician who documented weight loss on two separate visits and subsequently hospitalized the child. During this hospitalization, the diagnosis of neglect was documented, the gastrostomy tube was replaced, and the child was removed from the mother's custody. She has

since been placed in medical foster care and is growing appropriately and gaining developmental milestones with therapy intervention.

Conclusion

The medically complex child lives in a sphere of vulnerability and fragility, a sphere fraught with diseases, disease complications, medications, therapies, technology and equipment, medical personnel, and caregivers. Within this sphere lies the hidden risk of maltreatment. This maltreatment comes in many forms: human bites in a defenseless, autistic mute child; the grooming and sexual abuse of a wheelchair-bound adolescent female yearning to feel special; a medically complex patient whose mother refuses to permit improved health; and an infant allowed to starve by a mother whose mental health obscures her own perception of appropriate growth of her infant. Individuals entering into the sphere of the medically complex child should remain vigilant in monitoring for and recognizing maltreatment. Caregiver education, caregiver respite, and other prevention strategies must be at the forefront of maltreatment intervention, particularly pertaining to children with medical complexity. Caregivers and families require respite time away from attending to the child's medical needs. The health care provider proactively should evaluate for and order appropriate in-home services, such as private duty nursing or paid personal attendant care. Medical treatments in conjunction with therapeutic behavioral counseling can address aggression or other problem behaviors. Consistent care provided by a pediatrician helps establish a trustful relationship within the medical system and allows for health literacy education. These are a few examples of proactive measures the health care system can adopt. Other fields intersecting with child abuse prevention must also design and implement protective practices within the scope focused on medically complex children.

About the Author

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