Addressing Medical Neglect in Children With Complex Chronic Conditions

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In this issue of *Pediatrics*, Cleveland et al report a cross-sectional analysis of a 2-state, multiyear database of linked child protective services (CPS) and Medicaid claims data to characterize the prevalence and associations of complex chronic condition (CCC) status across CPS outcomes.[1] This study demonstrates that having a CCC is associated with increased rates of CPS reporting, particularly for medical neglect, as well as higher rates of foster care placement. These findings are relevant to pediatric providers because most reports for medical neglect arise from the medical team, and clinicians are uniquely situated to support families and understand the nuanced context that leads to medical neglect concerns.[2,3] Collectively, we share our complementary perspectives as clinician researchers with expertise in foster care, child abuse, and medical complexity, and as a medical foster parent to highlight additional implications of these study findings for clinicians, researchers, and policymakers.

Medical neglect is multifactorial. Appropriately evaluating and responding to medical neglect concerns is challenging among children with CCCs (C-CCC) and must be thoughtful in approach. Although broad definitions have been published, clinicians caring for children within unique social and medical contexts may face uncertainty about when concern for medical neglect rises to the level of a CPS report. Two approaches to defining medical neglect have been described.[4] The first centers on caregiver omission, such that medical neglect is when a caregiver does not provide essential medical care.[5] The second approach focuses on the child's needs, such that medical neglect is when a child's medical needs are not adequately met.[4] It is no surprise that C-CCC are overrepresented in reports to CPS for medical neglect[6] because medical needs and corresponding caregiver demands far exceed those for children who require only routine well-visits.[7]

An American Academy of Pediatrics clinical report outlines 5 factors for clinicians to consider when questioning a diagnosis of medical neglect: (1) Is a child harmed or at risk of harm because of lack of health care? (2) Does recommended health care offer significant net benefit to the child? (3) Is the anticipated benefit of the treatment significantly greater than its morbidity? (4) Can it be demonstrated that access to health care is available and not used? (5) Does the caregiver understand the medical advice given?[8,9]

Although in some situations it can be clear that medical neglect is occurring, more often the nuances of medical care and social contexts will leave lingering uncertainty when evaluating for medical neglect in C-CCC.[3] When assessing the extent to which health care is accessible, it is important to consider the substantial and evolving caregiving, financial, and social challenges experienced by families with C-CCC without adequate system and community-level supports.[6,10–13] These challenges may include intensive daily caregiving without adequate nursing support or respite, unreliable transportation, insurance limitations, foregone employment, financial strain, and difficulty navigating complex systems of care without care coordination.[3,12,14–16] Each child's medical needs and corresponding

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RR Seltzer, A Cruce, and K Fortin conceptualized the manuscript, co-wrote the initial manuscript, and critically reviewed and revised the final manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

CONFLICT OF INTEREST DISCLOSURES: The authors have no conflicts of interest relevant to this article to disclose.

FUNDING: The authors have no funding relevant to this study to disclose.

Accepted for Publication Date: June 18, 2026

https://doi.org/10.1542/peds.2026-077262

COMPANION PAPER: A companion to this article can be found online at www.pediatrics.org/cgi/doi/10.1542/peds.2025-075190.

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To cite: Seltzer RR, Cruce A, and Fortin K. Addressing Medical Neglect in Children With Complex Chronic Conditions. *Pediatrics*. 2026; 158(3):e2026077262

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demands on caregivers differ, so it is not possible to set one standard for diagnosing medical neglect.

Another important consideration is whether strategies to minimize demands on caregivers have already been implemented. Would a report to CPS for medical neglect be warranted if implementing home and community-based supports (eg, home nursing, respite) or simplifying the care plan could help meet the child's medical needs? What if the family views net benefits of a treatment differently based on their values and child's underlying diagnoses? Should goals of care and broader quality of life considerations play a role in medical neglect determinations? The answer to such questions may differ based on the extent to which lack of recommended medical care places a child at imminent risk for morbidity or mortality. Uncertainty engenders variability in reporting and responding to medical neglect.

When a clinician does make a report for medical neglect, a common assumption is that CPS involvement or foster care placement will improve a child's safety, access to recommended care, and overall well-being. However, current gaps in data limit our ability to test this assumption, in part because of the lack of systematic identification and tracking of C-CCC in child welfare data systems.[17] Limited existing data largely focus on child welfare related outcomes and demonstrate that children with disabilities experience longer time in foster care, more frequent placement changes, a higher likelihood of congregate care instead of foster home placements, and a lower likelihood of reunification or adoption compared with peers without disabilities.[18] Longitudinal data regarding meaningful non-child welfare related outcomes pre/post CPS involvement, such as medication adherence, health care use, school attendance, and family participation, are even more limited. Additionally, children reported for medical neglect experience a high re-report rate to CPS.[6] Understanding the reasons for repeat reports is needed to improve system responses to medical neglect allegations and identify structural challenges that may be difficult to modify, contributing to a vicious cycle of repeat reporting for some families.

If foster care placement is considered a solution to medical neglect, then availability of medically appropriate placements becomes highly relevant. However, the availability of placements is scarce.[2,19] Placement gaps for C-CCC result in delayed hospital discharge and placement in more restrictive settings (ie, group home, residential facility) or even out of state, undermining family engagement and future reunification.[2,19]

Cleveland et al's study supports what we see in everyday practice, which is that C-CCC are at risk for medical neglect concerns and child welfare involvement. These families are tasked with navigating complex care plans and fragmented systems that are not appropriately designed or resourced to meet their needs. Yet, when concerns for medical neglect arise, the inclination is to focus on caregiver actions rather than consider how the health care and other child-serving systems of care have failed to set the child and family up for success.[3] Building from the study findings, we highlight considerations for clinicians, researchers, and policymakers.

Pediatric providers are well positioned to partner across health care, child welfare, behavioral health, education, and community serving systems to identify risks early and develop family centered plans of care that address barriers and stabilize families before escalation. Multidisciplinary approaches that include social workers, care coordinators, and health care providers may help families navigate complex treatment regimens and reduce unnecessary surveillance and punitive responses. Concrete strategies may include routine social needs screening, development of individualized care plans, embedded social work or nursing support within pediatric settings, and cross-system communication.

Additionally, there are opportunities for researchers to expand on this study's findings, including breaking down the data further by number of CCCs as a measure of complexity and by type of CCC to see if certain diagnoses or diagnostic categories are disproportionately driving medical neglect reports. Such data could inform more targeted outreach and interventions for certain patient populations. There is also a need to define and track child and family outcomes beyond traditional child welfare and health care metrics, such as family participation and quality of life.

Finally, there is a need to advocate for policies that support family caregiving in a more proactive rather than crisis-oriented punitive manner, such as expansion of home- and community-based services and family-strengthening social services (ie, tax credits, financial assistance, housing supports) designed to stabilize families and prevent avoidable child protection involvement among C-CCC.

Cleveland et al demonstrate that C-CCC are disproportionately represented in child protection systems.[1] The challenge for pediatricians is not simply identifying medical neglect but distinguishing between caregiver unwillingness and caregiver inability within systems that often fail to provide adequate supports. For many families, the pathway to safety may not begin with surveillance or foster care placement but with investments in the services and relationships that enable families to successfully care for medically complex children at home.

ABBREVIATIONS

CCC: complex chronic conditions
C-CCC: children with complex chronic conditions
CPS: Child Protective Services

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