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Role of Medical Social Workers in Identifying and Managing Medical Neglect Among Children with Chronic Diseases

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ABSTRACT: Medical social workers play a vital role in identifying and addressing medical neglect among children living with chronic diseases, as these children require continuous medical supervision, regular follow-up appointments, appropriate medication administration, and adherence to complex treatment plans. Medical neglect may occur when caregivers fail to provide essential medical care, delay seeking appropriate treatment, discontinue prescribed medications, or repeatedly miss medical appointments, potentially resulting in disease progression, preventable complications, and increased hospitalization. Medical social workers are particularly important in recognizing the early warning signs of neglect through comprehensive psychosocial assessments, family interviews, medical record reviews, and collaboration with healthcare professionals. They evaluate various contributing factors, including parental knowledge and awareness, financial difficulties, limited access to healthcare services, family instability, cultural beliefs, caregiver stress, and inadequate social support. Distinguishing intentional neglect from situations in which families face socioeconomic or psychological barriers is essential to ensure accurate assessment and appropriate intervention. Beyond identification, medical social workers contribute significantly to the management and prevention of medical neglect through coordinated interventions, family education, psychosocial support, and multidisciplinary collaboration. They provide caregivers with information about the child's chronic condition, the importance of treatment adherence, medication schedules, warning signs of complications, and the consequences of interrupting medical care. Additionally, they facilitate access to healthcare services, financial assistance, transportation support, community resources, and specialized social care programs to overcome barriers that may interfere with appropriate disease management. In cases involving persistent or severe medical neglect, social workers collaborate with physicians, nurses, psychologists, child protection services, and relevant legal authorities to develop individualized safeguarding plans that prioritize the child's safety and best interests. Regular monitoring, follow-up assessments, and documentation of interventions are also essential for evaluating improvements in caregiving practices and ensuring continuity of care.

INTRODUCTION

Medical neglect occupies a paradoxical position within child maltreatment research and practice because it is recognized as a potentially lethal form of harm yet remains inconsistently defined, understudied, and frequently overshadowed by physical and sexual abuse (1). The American Academy of Pediatrics describes medical neglect as a failure by a parent or caregiver to recognize obvious signs of serious illness or to follow physicians' instructions once medical advice has been sought, resulting in harm or risk of harm to the child (10). Child maltreatment generally, including neglect, is associated with immediate injury, impaired development, and long-term physical and mental health consequences that persist into adulthood (2). Systematic reviews have demonstrated that neglect, like other forms of maltreatment, is associated with elevated risks of depression, anxiety, substance misuse, and chronic health problems across the life course (3). Prevalence studies further show that neglect is the most common form of child maltreatment globally, although reporting and definitional differences make cross-national comparison difficult (4). Within this broader landscape, medical neglect is distinctive because it occurs at the intersection of caregiver behavior, health system access, and clinical judgment, and because its harm often accumulates gradually before producing an acute and preventable crisis (5).

Children with chronic medical conditions are not merely overrepresented among cases of medical neglect; they constitute the overwhelming majority of such cases (5). A review of referrals to the child protection unit of a tertiary pediatric hospital found that most medically neglected children had chronic medical conditions, and communication difficulties and resource barriers were present in nearly all cases (5). Children and adolescents with diabetes mellitus are among the most frequently reported groups, and medical neglect in diabetes may present as recurrent diabetic ketoacidosis, missed insulin administration, or failure to attend essential follow-up (6). Children with life-threatening complex chronic conditions are also vulnerable because their care depends on technology, multiple medications, and close coordination among subspecialists, and providers have reported that medical neglect concerns intensified during periods of health system disruption (7). Health literacy is a further critical factor

because low parental health literacy affects medication administration, recognition of warning signs, and navigation of complex services, all of which can mimic or contribute to medical neglect (8). In asthma, neglect has been linked to tertiary hospitalization and to failures in recognizing severe symptoms, adhering to controller therapy, and reducing environmental triggers (9). These clinical patterns show that medical neglect in chronic disease is not a single event but a process shaped by family resources, health system design, and professional response (10).

The identification of medical neglect requires a structured evaluation that distinguishes harm or risk of harm from ordinary nonadherence and that considers the net benefit of recommended care, the burden of treatment, the accessibility of care, and the caregiver's understanding of advice (11). Pediatricians have a role in prevention as well as recognition, and this role includes anticipatory guidance, family support, and collaboration with community resources before concerns escalate to child protection (12). Ethical analysis of parental refusals of medical treatment emphasizes that state intervention is justified when the harm principle threshold is met, meaning that the child faces significant risk of serious harm and the recommended intervention offers substantial net benefit (13). Children with medical complexity represent an emerging population for clinical and research initiatives because they require coordinated, family-centered care that addresses both medical and social needs (14). Caregivers of children with special health care needs report substantial financial, employment, and caregiving challenges that can interfere with sustained adherence and engagement (15). Health inequities further compound these challenges because children with chronic conditions from disadvantaged backgrounds face barriers in access, quality, and continuity of care (16). Adherence to pediatric medical regimens is multidimensional and is influenced by family functioning, regimen complexity, child development, and the quality of the provider-family relationship (17). Pediatric self-management frameworks emphasize that chronic illness care is a shared responsibility among children, families, and health systems rather than a simple matter of parental compliance (18).

Social determinants of health, including poverty, housing instability, transportation barriers, and food insecurity, shape the conditions in which chronic illness care takes place and must be part of any assessment of medical neglect (19). Racial and ethnic disparities in the evaluation and disposition of children with suspected maltreatment raise concerns that bias influences decisions about suspicion, reporting, and removal, and these disparities are directly relevant to medical neglect practice (20). Screening for social determinants of health in pediatric settings can identify unmet needs before they produce missed care, but screening must be linked to a response pathway rather than used as a substitute for clinical judgment (21). Health social work provides the professional framework for this response because social workers are trained to assess family ecology, mobilize resources, advocate within institutions, and mediate between supportive and protective mandates (22). Medical social workers are therefore not peripheral to pediatric chronic illness care; they are central to identifying the family in crisis, distinguishing poverty from neglect, and designing interventions that make safe caregiving possible (22). This essay argues that the role of medical social workers in identifying and managing medical neglect among children with chronic diseases is best understood as a continuum that runs from universal screening and family support to structured child protection collaboration, with the social worker acting as assessor, advocate, coordinator, and boundary-spanner across systems (10).

Conceptual Foundations: Medical Neglect, Nonadherence, and Chronic Disease

The conceptual boundary between medical neglect and treatment nonadherence is the first and most consequential distinction that medical social workers must navigate because conflating the two produces both false positives and false negatives (1). Nonadherence is common, multidimensional, and often rational from the family's perspective, since a caregiver may miss appointments because of transportation costs, administer medication inconsistently because of competing work obligations, or misunderstand instructions because of low health literacy (8). Medical neglect, by contrast, requires a judgment that the caregiver's failure to provide care has resulted in harm or risk of harm, that the recommended care would offer significant net benefit, that the anticipated benefit outweighs the burden of treatment, that access to care was available and not used, and that the caregiver understood the advice given (11). These criteria are not merely technical because they embody a moral distinction between inability and unwillingness, between circumstances that constrain caregiving and choices that disregard the child's welfare (13). Social workers are often the members of the clinical team best equipped to gather the contextual information necessary to apply these criteria because their training emphasizes family functioning, social determinants, and the lived experience of caregiving under adversity (22). The chronic disease context intensifies both the risk of neglect and the difficulty of defining it because chronic conditions require daily self-management, frequent monitoring, and repeated adjustment of treatment plans (17). For children, these tasks are developmentally beyond their capacity, and the responsibility for care falls on adult caregivers whose own resources, health, and supports may be stretched thin (18). When a child with type 1 diabetes

experiences repeated episodes of diabetic ketoacidosis because insulin is not administered, or when a child with severe asthma is repeatedly hospitalized because controller medications are not filled, the clinical team faces a question that is simultaneously medical, social, and moral (6). The literature on medical neglect in diabetes emphasizes that the answer cannot be derived from glycemic control alone because poor control may reflect adolescent rebellion, mental health problems, fear of treatment, caregiver depression, or family chaos rather than indifference (6). Similarly, in asthma, medical neglect may present as a failure to recognize severe symptoms, nonadherence to management, failure to reduce exposure to allergens or tobacco smoke, poor nutrition leading to obesity, or allowing a young child to manage the illness without supervision (9). Each of these presentations requires a different response, and the social worker's task is to disentangle them through assessment rather than assumption (10).

Epidemiological and Clinical Significance

The epidemiological evidence establishes that medical neglect is neither rare nor marginal in pediatric chronic disease because children with chronic conditions dominate the population of medically neglected children (5). In the tertiary hospital review, medical neglect constituted a small proportion of all child protection referrals but involved caregivers who were either unwilling to follow medical advice or unable to provide necessary care, and communication difficulties were present in every case (5). In the United States, children with chronic medical conditions comprise approximately ninety percent of medical neglect cases, and type 1 diabetes is among the most frequent single diagnoses among children reported to child protective services for medical neglect (6). A retrospective review of children reported for medical neglect found that most had chronic illness, that Black and Hispanic children and publicly insured children were overrepresented, and that the profile highlighted the intersection of chronic disease, poverty, and racial inequity in the child welfare system (20). The clinical consequences of unrecognized or unmanaged medical neglect are severe and cumulative because children with chronic illness who experience neglect suffer short-term morbidity and, in some cases, long-term morbidity and death (5). In diabetes, failure to follow dietary and medication regimens can result in dehydration, acidosis, and hyperglycemia, and recurrent diabetic ketoacidosis is a marker of both medical danger and psychosocial crisis (6). In asthma, neglect accelerates the cycle of morbidity and stress associated with illness and contributes to emergency department visits, hospitalizations, and asthma-related deaths (9). For children with medical complexity, gaps in care can produce rapid and profound harm because these children depend on technology, multiple medications, and carefully coordinated specialty care (14). These clinical realities explain why medical social workers cannot treat medical neglect as a purely legal or child-protection matter because it is a health issue with measurable biological consequences and the timing of intervention matters enormously (22).

Table 1. Clinical presentations of medical neglect in selected pediatric chronic conditions

Chronic condition	Common presentation of concern	Clinical consequence	Social work focus
Type 1 diabetes	Missed insulin, recurrent diabetic ketoacidosis, missed follow-up (6)	Acidosis, hospitalization, long-term morbidity (6)	Assess caregiver understanding, mental health, and regimen burden (17)
Severe asthma	Unfilled controller medication, unrecognized severe symptoms, trigger exposure (9)	Emergency visits, hospitalization, asthma death (9)	Address housing triggers, health literacy, and care coordination (8)
Medical complexity	Gaps in technology care, missed subspecialty visits, medication errors (14)	Rapid deterioration and preventable hospitalization (14)	Coordinate multiple services and support caregiver burden (15)
Chronic rheumatic disease	Missed appointments and unmet social needs (21)	Flares, disability, and poor continuity (16)	Screen social needs and link to resources (21)

Psychosocial Risk Factors and Barriers to Care

Understanding the psychosocial risk factors for medical neglect is essential for social work practice because it determines whether the response will be supportive, protective, or both (10). Caregiver mental illness, particularly depression, is a well-

documented barrier to sustained engagement with pediatric chronic illness care because a depressed caregiver may lack the energy to fill prescriptions, schedule appointments, or monitor a child's symptoms (17). Caregiver substance use, family chaos, intimate partner violence, and housing instability similarly disrupt the routines on which chronic disease management depends (19). Financial barriers are pervasive because families may be unable to afford co-payments, transportation, or time away from work, and public insurance may not cover all needed services (16). Health literacy is another critical factor because one in four parents has low health literacy, which affects their ability to understand medication instructions, recognize warning signs, and navigate complex health systems (8). Low parental health literacy has been associated with more medication errors, more emergency department use, and poorer asthma knowledge and outcomes, all of which can mimic or contribute to medical neglect (8). The social worker's assessment must also consider the caregiving burden specific to chronic disease because families of children with medical complexity perform nursing-level tasks at home, manage multiple medications with different schedules, coordinate among subspecialists, and absorb repeated disruptions to employment and family life (15). When a caregiver is overwhelmed, the resulting lapses in care may reflect exhaustion and insufficient support rather than a failure of love or commitment (15). Research on children with life-threatening complex chronic conditions has identified three themes that shape the risk of medical neglect: the relationship between the family and the medical community, the family's experience of being overwhelmed by medical demands, and insufficient support (7). Social workers who understand these themes can design interventions that strengthen the family's relationship with the medical team, reduce the burden of care through coordination, and mobilize concrete supports before a crisis occurs (22).

Structural and racial inequities are also central risk factors that social workers must assess without pathologizing families because poverty is not neglect and the failure to distinguish between the two produces both false positives and false negatives (20). Racial bias in clinical decision-making and child welfare reporting means that Black and Hispanic children are more likely to be evaluated and reported for suspected maltreatment even when presenting symptoms are similar to those of White children (20). Health inequities in chronic conditions further compound these risks because children from disadvantaged backgrounds experience barriers in access, quality, and continuity of care that make adherence harder and neglect more likely to be suspected (16). A social work assessment that ignores these structural dimensions will reproduce inequity rather than reduce it because it will treat constrained caregiving as personal failure (19). The appropriate response is not to lower the threshold for reporting in disadvantaged families but to apply the same careful, context-sensitive assessment to all families and to advocate for the resources that make safe caregiving possible (21).

Table 2. Psychosocial barriers and social work responses

Barrier	How it affects chronic illness care	Social work response
Low health literacy	Medication errors and missed warning signs (8)	Teach-back, simplified plans, and repeated education (8)
Transportation and cost	Missed appointments and unfilled prescriptions (19)	Resource linkage, transport vouchers, and insurance navigation (21)
Caregiver depression	Reduced monitoring and follow-through (17)	Screening, referral, and coordinated mental health support (22)
Medical complexity	Overwhelming care burden and fragmented services (15)	Care coordination and family-centered planning (14)
Racial bias	Unequal suspicion and reporting (20)	Structured assessment and equity-focused advocacy (20)

The Role of Medical Social Workers in Identification

Identification is the first and most consequential point of social work intervention because medical neglect is easily missed when clinicians focus narrowly on disease management and fail to ask why care is not happening (10). Medical social workers contribute to identification through psychosocial risk assessment, structured screening for health-related social needs, and clinical interviewing that elicits the family's explanatory model of the illness, their resources, their competing obligations, and their experience of the health care system (22). In emergency departments and inpatient units, social workers are frequently the

professionals who file child protective reports when a psychosocial assessment reveals suspicion of medical neglect and lack of proper guardianship, but they are also the professionals who can prevent unnecessary reports by identifying barriers that can be resolved through support rather than investigation (11). The distinction is critical because a social worker who discovers that a family missed repeated appointments because the only available subspecialty clinic is three bus transfers away has identified a transportation problem, not a neglectful caregiver, and the appropriate response is resource linkage rather than a child protective report (21). Effective identification requires both systematic screening and clinical judgment because standardized social needs screeners can identify food insecurity, housing instability, transportation barriers, and utility needs before they produce missed care (21). In a pediatric rheumatology clinic, an interprofessional team implemented a social determinants of health screener every six months for adolescents with chronic rheumatic disease, and most adolescents who screened positive met with the clinic's social worker at the time of the visit or shortly thereafter (21). Such models demonstrate that social work involvement can be proactive rather than reactive and that screening can transform the identification of medical neglect risk from a crisis-driven activity into a routine component of chronic illness care (22). At the same time, screening tools alone cannot determine neglect because they identify needs, and the social worker's assessment determines whether those needs reflect constrained caregiving or disregard for the child's welfare (10). The social worker's identificatory role also includes monitoring patterns over time because medical neglect in chronic disease rarely presents as a single dramatic event and instead emerges as a pattern of missed appointments, unfilled prescriptions, recurrent preventable hospitalizations, and unexplained gaps in care (5). Social workers who are embedded in chronic illness teams can track these patterns, communicate them to the medical team, and initiate a family assessment before the pattern escalates to serious harm (22).

Interprofessional Collaboration and Child Protective Services

Medical neglect in chronic disease cannot be managed by any single profession because the quality of interprofessional collaboration is a major determinant of outcomes (12). Physicians, nurses, social workers, subspecialists, school staff, and child protective services caseworkers each hold a piece of the information necessary to understand the family's situation and to design an effective response (11). Social workers are often the professionals who convene the team, translate between medical and child welfare perspectives, and ensure that the family's voice is included in decision-making (22). Collaboration between healthcare and child welfare systems is complicated by different legal thresholds for action, different professional cultures, distrust between systems, and legacies of harm that shape how families experience both institutions (13). These barriers can lead to either over-reporting, in which families are investigated for problems that could have been solved with support, or under-reporting, in which children remain in unsafe situations because professionals are uncertain about the threshold for action (11). Effective collaboration requires structural supports rather than goodwill alone because co-located services, shared care plans, cross-system confidentiality agreements, and regular interdisciplinary team meetings improve communication and child safety planning (12). Social workers can play a boundary-spanning role in these arrangements by ensuring that medical information is communicated accurately to child welfare agencies and that child welfare concerns are communicated back to the medical team in a way that informs clinical care (22). The social worker's ability to communicate openly and empathetically with families about the reporting process is also important because reporting medical neglect does not inevitably destroy the therapeutic relationship and, when done transparently and with continued support, can foster more cohesive teamwork and prompt families to address their problems (10). The goal of collaboration is not to punish families but to create a coordinated system of support and protection that addresses the root causes of neglect while safeguarding the child's immediate safety (13).

Management and Intervention Strategies

The management of medical neglect in pediatric chronic disease ranges from intensive family support to statutory child protection intervention, and the social worker's task is to match the intensity of the response to the severity of the risk and the modifiability of the barriers (10). At the supportive end of the continuum, social work interventions include care coordination, resource linkage, transportation assistance, health literacy-informed education, motivational interviewing, home visits, goal setting, text messaging reminders, and repeated contact with the family (22). Social work interventions that combine practical barrier resolution with repeated contact and culturally congruent support are more likely to improve adherence than single-session advice because adherence is a relationship-based process rather than an individual responsibility (17). In pediatric chronic illness, this means that the social worker does not simply tell the family to attend appointments or fill prescriptions but helps the family solve the practical problems that make adherence possible (18). When supportive interventions are insufficient and the child remains at risk of serious harm, the social worker must participate in more structured management plans because the child's safety may require escalation to child protective services (11). In diabetes, a medical neglect case plan should include

objective outcomes such as hemoglobin A1c measurements, frequency of home glucose monitoring, and emergency department visits, and the child welfare system should assess family functioning and in-home adherence before deciding whether substitute care is necessary (6). Directly observed therapy and medical contracts have been used in a minority of cases, and statutory agency intervention is required in a substantial proportion of medically neglected children (5). The social worker's role in these plans is to ensure that the family understands the plan, that the plan is feasible given the family's resources, and that the child's voice is considered in decisions that affect their living situation (13). The social worker also has a role in monitoring the plan over time, documenting progress or deterioration, and advocating for adjustments when the plan is not working (22).

Table 3. Continuum of social work management in medical neglect

Level of concern	Social work action	Collaboration	Expected outcome
Unmet social need without harm	Screening, resource linkage, and follow-up (21)	Primary team and community agencies (19)	Barriers reduced and adherence supported (17)
Pattern of missed care with modifiable barriers	Care coordination, education, and home visits (22)	Subspecialists and family supports (15)	Improved continuity and reduced risk (16)
Serious harm or imminent risk	Structured assessment and child protective report (11)	Child protective services and legal team (12)	Child safety secured and family support maintained (13)

Ethical and Legal Considerations

The management of medical neglect raises ethical tensions that social workers must navigate with explicit reasoning and supervision because the obligation to protect the child from harm may conflict with the obligation to respect family autonomy, cultural values, and the therapeutic relationship (13). Parents may disagree with medical recommendations for reasons that are culturally meaningful, religiously grounded, or rooted in mistrust of the health care system, and the social worker must distinguish between legitimate disagreement and neglectful refusal (10). The threshold for state intervention is not always clear because clinicians may jump to suspecting neglect without adequately exploring contextual factors that explain the family's behavior (11). Social workers are well positioned to slow down this decision-making process, to gather the information necessary for an ethically defensible judgment, and to ensure that the least restrictive intervention consistent with the child's safety is chosen (22). The legal framework for reporting medical neglect varies across jurisdictions because social workers must know their state's child abuse laws, the definition of medical neglect that applies, and the procedures for reporting and collaborating with child protective services (12). The ethical challenge is not to avoid reporting when reporting is required but to ensure that reporting is based on a careful assessment rather than on discomfort, bias, or inadequate understanding of the family's circumstances (20). Social workers must also attend to racial equity because the decision to report carries serious consequences for families and communities and should be made with awareness of historical and contemporary bias (20). The harm principle provides a useful threshold for state intervention because it focuses attention on the magnitude of risk and the expected benefit of treatment rather than on professional discomfort or parental noncompliance alone (13).

Implications for Practice and Policy

The evidence reviewed in this essay supports several implications for practice and policy because medical neglect in chronic disease is both preventable and manageable when social work is properly integrated into pediatric care (22). Medical social work should be embedded as a core component of pediatric chronic illness care rather than an ancillary service accessed only after a crisis because social workers who are present in specialty clinics, inpatient units, and complex care programs can identify psychosocial risk early and build trusting relationships with families (10). Screening for health-related social needs should be routine and should be linked to social work follow-up because screening without a response pathway does not improve outcomes (21). Training in the distinction between nonadherence and neglect should be provided to all members of the pediatric team because families are sometimes reported for problems that could be solved with support while children at genuine risk are sometimes missed (11). Interprofessional collaboration with child protective services should be structured through shared protocols, co-located services, and cross-system training because collaboration based on goodwill alone is insufficient to overcome structural barriers between health care and child welfare (12). Policy should address the social determinants that make medical neglect more likely, including poverty, transportation, housing, and health literacy, because a child protection system

cannot compensate for a health care system that fails to address the conditions in which chronic illness care takes place (19). Finally, pediatric chronic illness care should adopt a family-centered model that recognizes caregivers as partners and that provides the practical and emotional supports they need to sustain safe caregiving over time (15).

CONCLUSION

Medical neglect among children with chronic diseases is a complex, consequential, and under-recognized problem that sits at the intersection of pediatrics, child protection, and social work. The evidence is clear that children with chronic conditions constitute the overwhelming majority of medical neglect cases, that communication difficulties and resource barriers are present in nearly all cases, and that the consequences of unrecognized neglect include preventable morbidity, hospitalization, and death. Medical social workers play an indispensable role in identifying this form of maltreatment, differentiating it from ordinary nonadherence, assessing the psychosocial and structural factors that shape caregiving, coordinating care across fragmented systems, and designing interventions that range from practical support to statutory child protection. Their work requires a sophisticated understanding of chronic disease, a commitment to family-centered practice, and the ability to hold together the supportive and protective dimensions of the professional mandate. The challenge for the field is to ensure that medical social work is adequately resourced, integrated into chronic illness care, and supported by policies that address the social conditions in which medical neglect occurs.

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