Children's Hospital of Philadelphia PolicyLab

Inequities in Time Spent Coordinating Care for Children and Youth with Special Health Care Needs

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In the United States, caregivers of children and youth with special healthcare needs (CYSHCN) must navigate complex, inefficient health care and insurance systems to access medical care. We assessed for sociodemographic inequities in time spent coordinating care for CYSHCN and examined the association between time spent coordinating care and forgone medical care. This cross-sectional study used data from the 2018-2020 National Survey of Children's Health, which included 102,740 children across all 50 states. We described time spent coordinating care for children with less complex SHCN (managed through medications) and more complex SHCN (resulting in functional limitations or requiring specialized therapies). We examined race-, ethnicity-, income-, and insurance-based differences in time spent coordinating care among CYSHCN and used multivariable logistic regression to examine the association between time spent coordinating care and forgone medical care. Over 40% of caregivers of children with more complex SHCN reported spending time coordinating their children's care each week. CYSHCN whose caregivers spent >5 hours/week on care coordination were disproportionately Hispanic, low-income, and publicly insured or uninsured. Increased time spent coordinating care was associated with an increasing probability of forgone medical care: 6.7% for children whose caregivers who spent no weekly time coordinating care versus 9.4% for <1 hour; 11.4% for 1-4 hours; and 15.8% for >5 hours. Reducing time spent coordinating care and providing additional supports to low-income and minoritized caregivers may be beneficial for pediatric payers, policymakers, and health systems aiming to promote equitable access to health care for CYSHCN.

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