Making Time to Coordinate Care for Children With Medical Complexity

Ryan J. Coller, MD, MPH, Mary L. Ehlenbach, MD

The American Academy of Pediatrics' current policy statement on care coordination[1] describes it as a "patient and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families." This framework underscores the aspiration to achieve optimal health and well-being by addressing the child's "interrelated medical, social, developmental, behavioral, educational, and financial needs."[1] Given the diversity and intensity of these needs among children with medical complexity (CMC),[2,3] and a broad vision of health for this population,[4] care coordination has become the focus of the rapidly expanding field of complex care.[5] Supporting the personnel and infrastructure to successfully coordinate care for CMC is a major sustainability challenge facing complex-care programs today.[6]

In this month's issue of *Pediatrics*, Ronis et al[7] report on time spent in nonbillable care coordination activities for 208 CMC over their program's first 2 years. In near real time, staff logged each coordination activity, the staff's professional role (eg, registered nurse, medical doctor), and the modality, target, and duration of the activity. The cost of coordinating the child's care was then extrapolated from the average salaries of staff delivering tracked activities. The authors observed that nurses and social workers accounted for the largest numbers of discrete activities, whereas physicians and nurse practitioners accounted for the largest share of coordination time. Across all team members, an average of nearly 5 hours per enrolled CMC was spent each month. Using generalized linear models adjusting for child age, sex, duration of program enrollment, and family income, they concluded that a conservative estimate of care coordination cost was $145 to $210 per child per month.

Consistent with many described pediatric complex-care programs, the authors' clinical model reflected a robust interprofessional team performing comprehensive care management and coordination activities.[5,6,8,9] The study's population was of high complexity and may reasonably be expected to represent what similarly structured programs experience. The clinical team deserves credit for the painstaking effort of quantifying the reality experienced by those who coordinate CMC care: caring for CMC is a tremendously time-consuming process.

The authors of this study have advanced the complex care field by taking a critical first step toward articulating the costly nature of coordinating care for CMC. That cost (in the form of time and opportunity) has traditionally fallen on families[10,11] or has been inefficiently absorbed by health care providers. The timing of this research is important because payers, providers, and systems seek alternative payment models to support critical non–face-to-face care.[12] Ronis et al[7] have laid the foundation for several important future directions and essential questions that will sharpen the focus on care-coordination costs.

Department of Pediatrics, School of Medicine and Public Health, University of Wisconsin–Madison, Madison, Wisconsin

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Address correspondence to Ryan J. Coller, MD, MPH, Department of Pediatrics, University of Wisconsin, Madison, 600 Highland Ave, Madison, WI 53792. E-mail: rcoller@pediatrics.wisc.edu

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First, estimated costs from this study likely represent a care-coordination "floor" because some common yet understandably difficult-to-quantify activities were excluded (eg, scheduling appointments, requesting insurance company previous authorizations, faxing records, and informal patient-specific discussions among program staff). At times, these can be some of the most important yet time-consuming coordination activities.[13] Additionally, had indirect costs such as employee fringe benefits, clinic overhead, and administration been included, the cost estimates would be even larger.

Second, CMC care-coordination time needs are dynamic. The authors confirm what many complex-care providers suspect: care-coordination needs are high during the initial enrollment period. Predicting dynamic patterns and trajectories of individual children and their coordination needs would be useful for increasingly precise program management. Similarly, characterizing how shifts in program structure influence program coordination time (eg, staff turnover) would inform program planning. Observing whether mature programs with well-trained staff and "steady-state" panel sizes have similar results would be a valuable corollary.

Third, Ronis et al[7] effectively quantify care-coordination time delivered, and the field would benefit from research to qualify care coordination time needed. How can the time delivered reliably match what is needed to achieve the optimal well-being sought through coordinated care? Efficient systems would avoid providing more or less. Moreover, what is the right amount of time, if any, families should spend on care coordination given their unique circumstances?

Finally, important efficiencies of scale may emerge when coordinating a large CMC panel within a complex care program versus coordinating care for a few CMC within a traditional practice where personnel may either not exist or lack proficiency with challenging coordination tasks. Complex care programs may allow others caring for that child to dedicate more of their time to direct patient care. Quantifying the magnitude of savings achieved through these and other efficiencies is another potential argument to support the investment in complex-care programs.

The field of pediatric complex care is young. Comparative effectiveness research involving diverse populations, a variety of care models, and meaningful patient and family outcomes is needed. Solving the care-coordination time equation and aligning payment to that solution ultimately depends on such research. The study by Ronis et al[7] is time well spent and a great start to solving that equation.

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ABBREVIATION

CMC: child(ren) with medical complexity

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