Disparities in Unmet Need for Care Coordination: The National Survey of Children’s Health

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WHAT’S KNOWN ON THIS SUBJECT: Care coordination has been proposed as a key mechanism for increasing quality and reducing costs of care. Little is known about the degree to which disparities exist in care coordination or whether having high-quality primary care attenuates disparities.

WHAT THIS STUDY ADDS: A considerable proportion of parents reported unmet care coordination needs for their children, especially parents of children with special health care needs. Black and Latino children also may have more unmet needs because they received family-centered care less often.

abstract

OBJECTIVE: To determine (1) the proportion of parents who report a need for and receipt of effective care coordination for their child, (2) whether unmet care coordination needs differ by children with special health care needs (CSHCN) status and sociodemographic characteristics, and (3) whether having a personal provider or family-centered care mitigates disparities.

METHODS: This study was a cross-sectional analysis of the 2007 National Survey for Children’s Health, a nationally representative survey of 91,642 parents. Outcome measures were parent report of need for and lack of effective care coordination. We also examined the effect of parent report of having a personal provider and family-centered care. We conducted weighted bivariate and multivariate analyses.

RESULTS: Forty-one percent of parents reported their child needed care coordination. Among those who needed care coordination, 31% did not receive effective coordination. CSHCN (41%) were more likely than children without special health care needs (26%; \( P = .001 \)) to have unmet care coordination needs. Latino (40%) and black (37%) children were more likely to have unmet needs than white (27%; \( P < .001 \)) children. These patterns remained in multivariate analysis. Having a personal provider decreased the odds of having unmet need for care coordination but did not attenuate disparities. Receiving family-centered care mitigated disparities associated with race/ethnicity but not with health status or health insurance.

CONCLUSIONS: A considerable proportion of parents reported their child needed more care coordination than they received. This was especially true for parents of CSHCN and parents of black and Latino children. Interventions that enhance family-centered care might particularly contribute to reducing racial/ethnic disparities.

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In the United States, there is tremendous interest in improving the frequency with which patients experience health care that is well coordinated.\textsuperscript{1–4} Care coordination is “the deliberate organization of patient care activities between two or more participants... involved in a patient's care to facilitate appropriate delivery of health care services.”\textsuperscript{5} Clinicians, researchers, and policymakers all maintain that increasing care coordination is essential for improving health care processes and outcomes, particularly for medically or socially complex populations.\textsuperscript{1,2} Recently, the need to improve care coordination has been codified into law as a central tenet of the 2010 Patient Protection and Affordable Care Act.\textsuperscript{6,7}

Studies have associated poor care coordination with delayed access to care, inferior quality of care, ineffective use of resources, inflated health care costs, and patient and provider dissatisfaction.\textsuperscript{7–10} However, there is no nationally representative study on the degree to which inequities may exist in the receipt of care coordination for children with special health care needs (CSHCN), black and Latino children, and those with lower socioeconomic backgrounds. Reports of unmet need for care coordination within these groups could help identify who should be targeted for improvements.

Two other tenets of high quality of primary care have been associated with improved pediatric health outcomes: (1) having a personal provider (ie, a doctor or nurse who knows the child well) and (2) receiving family-centered care (ie, care that treats the patient and family as integral members of the care team and is grounded in the consideration of patients’ and families’ preferences and values).\textsuperscript{19–22} These 2 factors should be taken into account when assessing whether care is well coordinated or whether disparities can be mitigated.

Our study therefore aims to determine the following: (1) the proportion of parents who report a need for and receipt of effective care coordination for their child, (2) whether unmet care coordination needs differ by CSHCN status\textsuperscript{23} and sociodemographic characteristics, and (3) whether having a personal provider or family-centered care mitigates disparities in care coordination. We hypothesized that unmet care coordination needs exist for children in general and are particularly pervasive for children with special health care needs. We also postulated that black and Latino children and children in families with lower incomes will report more unmet care coordination needs than others. Last, we posited that having a personal provider and receiving family-centered care will decrease the odds of parents indicating unmet need for care coordination.

METHODS

2007 National Survey of Children’s Health

We analyzed the 2007 National Survey of Children’s Health (NSCH), which was conducted by the National Center for Health Statistics to cover physical, emotional, and behavioral child health as well as family context and neighborhood environment.\textsuperscript{24} The NSCH is a telephone survey (\textless30 minutes) conducted in English, Spanish, Mandarin, Cantonese, Vietnamese, and Korean with a random-digit-dial sample in all 50 states and the District of Columbia. Participants were drawn from a randomly selected subset of telephone numbers from the National Immunization Survey sample by using State and Local Area Integrated Telephone Survey methodology.\textsuperscript{25} The parent/guardian of 91,642 children aged 0 to 17 years completed the interview, with a response rate of 46.7%.\textsuperscript{26}

The subjects of this analysis were parents of children who reported needing care coordination in the previous 12 months at the time the survey was administered. A child was considered to be in need of care coordination if the parent reported that the child had \textgeq 2 of the following: (1) preventive visit with a health care provider; (2) visit with a mental health specialist, or (3) specialist visit or need for specialist visit (not including mental health specialists).

The Boston Children's Hospital Institutional Review Board found the study exempt from human subject review.

Primary Outcome

We used a dichotomous variable to categorize whether a child had unmet need for care coordination. This variable was developed by the Data Resource Center for Child and Adolescent Health as a component of the patient-centered medical home (PCMH) and has been used extensively in this context.\textsuperscript{26,27} Receipt of effective care coordination has 3 components: getting as much help as needed with arranging or coordinating care, parental satisfaction with communication among doctors and health care providers, and parental satisfaction with communication between health care providers and non–medical service providers (eg, school). To meet criteria for receipt of effective care coordination (no unmet need), the parent must report “usually” receiving help coordinating child’s care when care coordination is needed and the parent must report being “very satisfied” with the 2 communication variables (when applicable). The outcome variable was unmet need for care coordination.

Independent Variables of Interest

CSHCN were included because we anticipated that they would have
increased unmet need for care coordination. The NSCH uses the CSHCN screener developed by Bethell et al. We also included in part of our analysis the presence of specific chronic conditions and number of reported chronic conditions. Parents had to answer whether their child currently had any of the following specific chronic conditions: anxiety; asthma; attention-deficit/hyperactivity disorder; autism; bone, joint, or muscle problems; brain injury or concussion; conduct disorder; depression; diabetes; hearing disorder; stuttering or other speech problem; Tourette syndrome; or vision problem not corrected with glasses.

Parent report of child’s race/ethnicity was categorized into the following groups: black/non-Latino, Latino, white/non-Latino, or other.

To meet criteria for having a personal provider, parents must have answered affirmatively to the following yes/no question: “A personal doctor or nurse is a health professional who knows your child well and is familiar with your child’s health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician’s assistant. Do you have one or more persons you think of as [child’s name]’s personal doctor or nurse?” The composite measure of receipt of family-centered care had several elements, all of which were required to be present (“usually” or “always”) to meet the following criteria: (1) health care providers spend enough time, (2) health care providers listen carefully, (3) health care providers are sensitive to your family’s values and customs, (4) you received specific information you needed from your health care providers, and (5) when you needed an interpreter, someone other than a family member helped you speak with health care providers (when applicable).

Additional Covariates
We adjusted for additional covariates previously found or likely to be associated with care coordination need. Child demographic covariates included gender and age. Household covariates included primary language at home (English, not English), family structure (2-parent household [biological/step/adoptive], mother-only household, and other [eg, grandparent as primary parent figure in household]), insurance status (private, public, none), and household income (<100%, 100 to <200%, 200 to <400%, ≥400% of the federal poverty level adjusted for family size). We tested the covariates for collinearity and included all in the model because the variance inflation factors were ≤1.7.

Missing values for adjusted poverty level were imputed by using sequential multivariable regression according to the Centers of Disease Control and Prevention and the National Center for Health Statistics. Missing values for the remainder of the covariates were imputed by using mean imputation methodology. Dummy variables flagging whether the value was imputed were created for those variables that had >1% missing data.

Analysis
Analyses incorporated sampling weights with the use of Stata survey procedures (StataCorp, College Station, Texas), following National Center for Health Statistics analysis guidelines. We first determined the percentage of parents reporting need for care coordination. Among children in need of care coordination, we also determined the percentage of parents reporting unmet care coordination need. We used weighted χ² statistics to determine bivariate associations between each covariate and (1) need for care coordination and (2) for those with need, unmet care coordination need. Covariates included the following: child gender, age, race/ethnicity, type of health insurance, family structure, highest parental educational level, poverty level, and primary language spoken at home. We then examined the need for care coordination and percentage of unmet care coordination need for CSHCN. We also examined the association of unmet care coordination need and (1) number of chronic conditions and (2) presence of the specific chronic conditions listed above. We determined the percentage of children who were reported to have a personal provider and to receive family-centered care. We then built a multivariable logistic regression model to test the association between unmet care coordination need and covariates. The model included parents of children who met the criteria for needing care coordination. Two additional multivariate logistic regression models were built to test the effect of adding (1) report of having a personal provider and (2) report of receiving family-centered care.

We ran 3 sensitivity analyses. First, to address the concern that parental satisfaction with provider communication should not be included in the NSCH definition of effective care coordination, we reran our analysis based only on parental report of “usually” getting as much help as needed with arranging or coordinating care. Second, we examined the degree to which our findings differed if we included a physical versus mental health condition in models assessing family-centered care. Last, we analyzed whether the degree to which the number of chronic conditions a child may have (perhaps a proxy for illness severity) is associated with care coordination needs.

RESULTS
Overall, 41% of parents reported that they needed care coordination for their
child (Table 1). Of those in need of care coordination, 31% of children had unmet care coordination needs. In bivariate analysis, there was no significant difference by race/ethnicity in needing care coordination. Children with either private (41%) or public insurance (44%) were more likely than uninsured children (28%; \( P < .001 \)) to need care coordination. Black (38%) and Latino (40%) children were more likely to have unmet care coordination need than were white (27%; \( P < .001 \)) children. A lower percentage of children with higher household income had unmet care coordination need. In addition, children with public insurance (37%) or no insurance (49%) were more likely to have unmet care coordination need in comparison with children with private insurance (26%; \( P < .001 \)). Children who were from non–English-speaking in comparison with English-speaking households were more likely to have unmet care coordination need as were children from mother-only and other households in comparison with 2-parent households. Last, children without a personal health care provider were more likely to have unmet care coordination need than those with a personal provider (52% vs. 30%; \( P < .001 \)), and children not receiving family-centered care were more likely to have unmet care coordination need than those receiving family-centered care (50% vs. 11%; \( P < .001 \)).

Parents of CSHCN (72%) more often reported that their children needed care coordination than did parents of children without special health care needs (72% vs. 33%; \( P < .001 \); Table 2). Of those who reported need for care coordination, parents of CSHCN also were more likely than parents of other children to report unmet care coordination need (41% vs. 26%; \( P < .001 \)). The need for care coordination and the lack of effective care coordination among those who needed it was higher among children with multiple conditions. Among children with \( \geq 1 \) specific chronic condition, the percentage of children whose parents reported being in need of care coordination varied by condition from a low of 63% of children with asthma to a high of 95% of children with brain injury or concussion. In addition, the percentage of children with unmet care coordination need varied among conditions, with lows of 33% for children with diabetes and 37% for children with asthma to highs of 58% for children with anxiety and 62% for children with autism.

In multivariate analysis, among parents of children who met the criteria for needing care coordination, the associations between unmet need for care coordination and the sociodemographic covariates revealed in bivariate analysis remained, except that household income was no longer significant (Table 3). Black [adjusted odds ratio (aOR): 1.3; \( P = .001 \)] and Latino children (aOR: 1.5; \( P = .001 \)) had a higher odds of unmet care coordination need than did white children. In comparison with children with private insurance, uninsured children had higher odds of unmet care coordination need (aOR: 2.1; \( P < .001 \)). CSHCN had a higher odds of unmet care coordination need in comparison with children without special health care needs (aOR: 1.4; \( P < .001 \)).

The second model included parent report of having a personal provider (93%
of parents reported their child had a personal provider). Children with a personal provider had a lower odds of having an unmet care coordination need (aOR: 0.4; P < .001). However, the addition of having a personal provider did not change the measures of association substantially for the other factors associated with unmet care coordination need. The third model included parent report of receiving family-centered care (67% of parents reported that their child received family-centered care). Children receiving family-centered care had a lower odds of having an unmet care coordination need (aOR: 0.2; P < .001). Including family-centered care in the multivariate analysis attenuated the racial/ethnic disparities. However, including family-centered care did not attenuate disparities associated with health status or insurance status.

Our findings were robust to our 3 sensitivity analyses. The pattern of results did not change for any of the following: (1) changing the criteria for having effective care coordination to only getting as much help as needed with arranging or coordinating care, (2) including presence of a physical health condition and presence of a mental health condition, and (3) including the number of chronic conditions in addition to CSHCN status.

**DISCUSSION**

This study is one of the first to estimate nationally the degree to which parents reported needing care coordination for their children and the extent to which care coordination was already delivered effectively. Overall, 41% of all parents and 72% of parents with CSHCN reported needing care coordination. These findings confirm other studies that found care coordination to be a desirable attribute of a health care system, particularly for those with the greatest medical needs. It is also one of the first studies to report the frequency at which those needing care coordination indicate not receiving effective care coordination. It is concerning that parents of children with the greatest medical needs and minority groups, who historically have not received high-quality health care, also reported having more unmet care coordination needs more frequently than children without special health care needs and white children.

Care coordination was crucial for many CSHCN, and their greater unmet need for care coordination was likely related to the high number of services often involved in their care. Although the amount of care coordination that each child needed was not measured, we were able to show that the odds of reporting an unmet need for care coordination increased with an increasing number of conditions. Moreover, unmet need remained after adjusting for parent report of having a personal provider and receiving family-centered care. Thus, our study suggests that more can be done in primary care to facilitate care coordination for all children, but especially for CSHCN.

Our findings also revealed that although all CSHCN had higher odds of having unmet need for care coordination, not all CSHCN had similar needs; the need for and receipt of effective care coordination varied among chronic conditions. The differences seen in need for care coordination may be related, in part, to the likelihood of need for specialist involvement. For instance, consistent with general practice patterns, for children with conditions that are more likely to be treated exclusively by primary care providers (eg, asthma and attention-deficit/hyperactivity disorder),...
Although our study did not find racial/ethnic differences in the need for care coordination, it identified disparities in receipt of effective care coordination. Black and Latino children had a higher odds of having unmet need for care coordination compared with white children. This is consistent with other studies that suggest that racial/ethnic disparities in health care are pervasive, affecting not only whether patients can gain access to health care providers but whether they receive quality care processes even after they enter the health care system.22–25

Our study is also the first to find a differential impact of 2 different components of the PCMH, having a personal provider and receiving family-centered care. Whereas both tenets are considered essential components of the PCMH and associated with improved pediatric health care quality and outcomes,19,20,36–38 receipt of family-centered care not only was associated with decreased odds of unmet need but also attenuated racial/ethnic disparities. As a result, those interested in narrowing disparities while improving care generally may need to focus more on providing family-centered care, partnering with families as integral members of the care team and grounding care in families’ preferences and values. However, studies have revealed that black and Latino children are less likely to have family-centered care.30

Thus, although receipt of family-centered care might address the inequities in the delivery of care coordination, the overall underlying inequities in the care they receive remains. Further research is needed to better understand the barriers for receipt of family-centered care to inform intervention development and health policies on or for promoting care coordination.

The NSCH is the most recent and largest nationally representative survey of child health in the United States. However, there are several limitations. Data came from parent report, which could have caused misclassification if parents failed to recognize that their child needed care coordination. The NSCH definition of who is in need of care coordination has limitations. Parent report of receiving ≥2 health-related services or being in need of specialist care might either include children who do not need significant care coordination (eg, a child with an uncomplicated broken arm who saw an

### TABLE 3 Adjusted Odds of Reporting Unmet Need for Care Coordination

<table>
<thead>
<tr>
<th>Variable</th>
<th>Odds of Unmet Need for Care Coordination, aOR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Model 1</td>
</tr>
<tr>
<td>Child gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>Ref</td>
</tr>
<tr>
<td>Male</td>
<td>1.0 (0.9, 1.2)</td>
</tr>
<tr>
<td>Child age</td>
<td></td>
</tr>
<tr>
<td>0–5 y</td>
<td>Ref</td>
</tr>
<tr>
<td>6–11 y</td>
<td>1.1 (0.9, 1.2)</td>
</tr>
<tr>
<td>12–17 y</td>
<td>1.0 (0.9, 1.2)</td>
</tr>
<tr>
<td>Child race</td>
<td></td>
</tr>
<tr>
<td>White, non-Latino</td>
<td>Ref</td>
</tr>
<tr>
<td>Black, non-Latino</td>
<td>1.3 (1.1, 1.6)**</td>
</tr>
<tr>
<td>Latino</td>
<td>1.5 (1.2, 1.9)**</td>
</tr>
<tr>
<td>Other</td>
<td>1.2 (1.0, 1.5)*</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
</tr>
<tr>
<td>0%–99% FPL</td>
<td>Ref</td>
</tr>
<tr>
<td>100%–199% FPL</td>
<td>1.0 (0.8, 1.2)</td>
</tr>
<tr>
<td>200%–399% FPL</td>
<td>0.9 (0.7, 1.1)</td>
</tr>
<tr>
<td>≥400% FPL</td>
<td>0.9 (0.7, 1.1)</td>
</tr>
<tr>
<td>Insurance status</td>
<td></td>
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<td>Private</td>
<td>Ref</td>
</tr>
<tr>
<td>Public</td>
<td>1.1 (0.9, 1.3)</td>
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<tr>
<td>No insurance</td>
<td>2.2 (1.7, 2.7)**</td>
</tr>
<tr>
<td>Flag*</td>
<td>1.6 (1.0, 2.6)*</td>
</tr>
<tr>
<td>Language spoken at home</td>
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</tr>
<tr>
<td>English</td>
<td>Ref</td>
</tr>
<tr>
<td>Non-English</td>
<td>1.4 (1.0, 1.8)*</td>
</tr>
<tr>
<td>Family structure</td>
<td></td>
</tr>
<tr>
<td>Two-parent</td>
<td>Ref</td>
</tr>
<tr>
<td>Mother only</td>
<td>1.3 (1.1, 1.5)**</td>
</tr>
<tr>
<td>Other</td>
<td>1.6 (1.2, 2.0)**</td>
</tr>
<tr>
<td>CSHCN</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Ref</td>
</tr>
<tr>
<td>Yes</td>
<td>2.0 (1.8, 2.3)**</td>
</tr>
<tr>
<td>Personal provider</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Ref</td>
</tr>
<tr>
<td>Yes</td>
<td>0.4 (0.4, 0.6)**</td>
</tr>
<tr>
<td>Family-centered care</td>
<td></td>
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<tr>
<td>No</td>
<td>Ref</td>
</tr>
<tr>
<td>Yes</td>
<td>0.2 (0.2, 0.2)**</td>
</tr>
</tbody>
</table>

After appropriate weights applied in accordance with complex survey design. *P ≤ .05, **P < .01, ***P < .001. FPL, federal poverty level; Ref, reference.

* Flag denotes a dummy variable flagging that the value is imputed (created for those variables that had >1% missing data).
orthopedist once) or not include children with significant need for coordination of non–medical care services (eg, a child with developmental delay followed by early intervention). More generally, the cross-sectional design of the NSCH prevents us from making causal inference.

Nonetheless, findings from our study support the emphasis that the 2010 Patient Protection and Affordable Care Act placed on the importance and need to improve care coordination for children generally, and for meeting the needs of CSHCN and narrowing racial/ethnic disparities in health care more specifically.

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UNREST IN THE SCHOOL CAFETERIA: The dietary preferences of my children have been different: for long periods of time one only ate bran flakes and refined sugar products, while another only ate meat. Since we paid for a school ‘credit card’ that students use for purchasing food from the cafeteria, we could scan an itemized list of what each child had purchased the previous month. While bottled water and bagels with cream cheese seemed popular for many years, each periodically bought the school lunch. What we did not know was whether our children actually ate the purchased lunch. As reported in The New York Times (N.Y./Region, October 5, 2012), students in many communities are not only boycotting school lunches, they are throwing the food away. Apparently, school lunches featuring smaller portions, fewer calories, healthier choices, and a slight increased cost are not popular. At issue is the Healthy, Hunger-Free Kids Act, which required public schools to follow new nutritional guidelines in order to qualify for additional federal aid. The act requires lunches to include fruits and vegetables, limit fat and sodium, and reduce the total number of calories. While pizza is still available, the portion size is smaller, and the meal includes a fruit and skim milk. It also costs a bit more than before: up 10 cents to $2.60. Many students have reacted by boycotting the lunch program. In some districts, participation in the school lunch program has dropped 70%. Other students simply throw the fruit or vegetables into the trash. Although student-directed videos depicting students acting weak from hunger have gone viral, all lunches must contain at least 750 calories. As most parents know, getting children to eat their vegetables can be challenging. Perhaps the best practice for the schools is simply to give the program more time. Children need to be exposed to vegetables over and over before finally trying and then liking them. I know from first-hand experience—even my carnivore now eats vegetables and fruits.

Noted by WVR, MD
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