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## Care Coordination, Medical Complexity, and Unmet Need for Prescription Medications among Children with Special Health Care Needs

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### Abstract

**Background:** Children with special healthcare needs (CSHCN) have multiple unmet healthcare needs including that of prescription medications.

**Objectives:** The objectives of this study were twofold: 1) to quantify and compare unmet needs for prescription medications for subgroups of CSHCN without and with medical complexity (CMC)—those who have multiple, chronic, and complex medical conditions associated with severe functional limitations and high utilization of health care resources, and 2) to describe its association with receipt of effective care coordination services and level of medical complexity.

**Method:** A secondary data analysis of the 2009/2010 National Survey of CSHCN, a nationally representative telephone survey of parents of CSHCN, was conducted. Logistic regression models were constructed to determine associations between unmet need for prescription medications and medical complexity and care coordination for families of CSHCN, while controlling for demographic variables such as race, insurance, education level, and household income. Analyses accounted for the complex survey design and sampling weights.

**Results:** CMC represented about 3% of CSHCN. CMC parents reported significantly more unmet need for prescription medications and care coordination (4%, 68%), compared to non-CMC parents (2%, 40%). Greater unmet need for prescription medications was associated with unmet care coordination (adjusted OR 3.81; 95% CI: 2.70–5.40) and greater medical complexity (adjusted OR 2.01; 95% CI: 1.00–4.03).

**Conclusions:** Traditional care coordination is primarily facilitated by nurses and nurse practitioners with little formal training in medication management. However, pharmacists are rarely part of the CSHCN care coordination model. As care delivery models for these children evolve, and given the complexity of and numerous transitions of care for these patients, pharmacists can play an integral role to improve unmet needs for prescription medications.

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## Keywords

Children with medical complexity; care coordination; prescription medications; unmet healthcare needs

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## Introduction

Families of children with special healthcare needs (CSHCN)—those representing about 15% (or nearly 12 million) of U.S. children under the age of 18<sup>1</sup>—report multiple unmet healthcare and social needs.<sup>2</sup> The Maternal and Child Health Bureau (MCHB) of the Health Services and Resources Administration defines CSHCN as those “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health related services of a type or amount beyond that required by children generally.”<sup>3</sup> Recently, a subset of CSHCN with more complex medical conditions, referred to as children with medical complexity (CMC) has received increased attention from researchers and policymakers. CMC represent the most medically fragile group of children and are characterized by multiple chronic and severe medical conditions that are associated with severe functional limitations and high healthcare resource utilization.<sup>4</sup> Despite representing just less than 1% of all U.S children, it is estimated that CMC account for as much as one-third of healthcare spending for all children.<sup>5</sup>

The sphere of care for CSHCN is extensive, and as a result, they often receive care that is fragmented and poorly coordinated resulting in family stress, unsafe care, and suboptimal health outcomes.<sup>6</sup> Families of such children also report lacking information and quality communication as well as difficulty navigating the healthcare system.<sup>7</sup>

Prescription medications play a central role in the overall treatment plan for CSHCN. This is especially true for the CMC subset of CSHCN, as these children are likely to receive numerous medications for the multiple chronic conditions they live with. Stone and colleagues, for example, reported that CMC take an average of at least 8 chronic medications.<sup>8</sup> Factors related to medical conditions of the child, the delivery of healthcare services, as well as the social circumstances of families of CSHCN may play a key role in determining whether CSHCN have their needs met for prescription medications.

While some studies have previously examined unmet healthcare needs—such as specialty<sup>2</sup> and dental care<sup>9</sup>—for CSHCN, to our knowledge, no study has specifically examined unmet needs for prescription medications for this patient population. Thus, the objectives of this study were to describe unmet prescription medication needs for CSHCN based on medical complexity as well as determine potential predictors of unmet prescription medication needs using data from a nationally representative survey of CSHCN.

## Methods

### Data Source

This study is a secondary analysis using data from the 2009/2010 National Survey of CSHCN (NS-CSHCN). The NS-CSHCN is a nationally representative telephone survey of

U.S. households that have at least one child under 18 years at the time of the interview. During data collection, an interviewer screened all children in the household for having special healthcare needs using a five-item instrument. If more than 1 CSHCN were identified in the household, one CSHCN was randomly chosen for the interview. Then, a parent or guardian with the most knowledge about the health and healthcare needs of the child in the household was asked a series of questions addressing various aspects of health and social care for the child including health and functional status, need and receipt of healthcare and social services, and impact of child's health conditions on the wellbeing of family members. At the conclusion of data collection, 40,242 CSHCN interviews were completed representing at least 750 CSHCN from each state of the U.S.

### Study Sample

Multiple criteria are used to define children with medical complexity. Many structured clinical programs in U.S. children hospitals utilize criteria for enrollment based on family identified service needs, dependence on medical technology to support daily life and functioning, and involvement of multiple specialists in the care of the child. Kuo and colleagues utilized such criteria to identify CMC from the NS-CSHCN and their studies served as the basis for categorizing CSHCN based on presence or absence of medical complexity.<sup>10,11</sup> To be considered as having a complex medical condition, a child must meet the following criteria: 1) a positive response to the CSHCN screener question indicating need or use of medical care, mental health or educational services than is usual for most children of the same age; 2) a positive response to at least 3 of the remaining 4 CSHCN screener questions (i.e. need for prescribed medicines; functional limitation; need for physical occupational, or speech therapy; and presence of emotional, developmental, or behavioral problems); and 3) visit to at least 2 specialists in the previous year. A detailed description of the CSHCN survey items is available elsewhere.<sup>10</sup>

### Study Variables

The outcome variable of interest for this study was unmet need for prescription medications. The NS-CSHCN has a series of questions that asked parents about healthcare needs that may be unmet. Among this list is unmet need for prescription medications. Parents were asked by interviewers if their child had a need for prescription medications and whether they received the needed prescription medications for their child over the past 12 months. Unmet need for prescription medications was defined as a parent responding "yes" to the question: "During the past 12 months, was there any time when [child] needed prescription medications" and answering "no" to the question: "If Yes, did [child] receive all the prescription medications that [he/she] needed?"

The independent variables were effective care coordination needs and medical complexity status. Effective care coordination need was constructed as a composite variable using six items from the NS-CSHCN, per the Child and Adolescent Health Measurement Algorithm used by the MCHB.<sup>12</sup> The six items addressed two key components of care coordination: help with care coordination when needed, and communication. Specific wording of the items has been published elsewhere.<sup>2</sup> Effective care coordination was met if 1) the family usually or always receives help coordinating care when needed, and 2) the parent/guardian was very

satisfied with communication between the specialist/specialty program and the provider if needed. The composite variable for effective care coordination then had two response categories: 1) all needs met, and 2) needs not met. For the medical complexity status variable, the overall sample was divided into two as 1) CSHCN without medical complexity and 2) CSHCN with medical complexity, as described in the study sample section above.

The covariates included are: demographic variables (age, gender), race/ethnicity, insurance, parental education level and household income, and primary language spoken in the house. These variables were identified and included for the analysis as they were shown to influence child health outcomes in previous studies.<sup>10</sup>

### Statistical Analysis

Descriptive statistics were performed to provide summary information on the outcome variable, main independent variables, and covariates. Simple logistic regression models were used to identify associations between the outcome and independent variables and covariates. Multiple logistic regression models were constructed to determine associations between the outcome variable (unmet need for prescription medications) and independent variables (medical complexity status, and effective care coordination) while controlling for the covariates. A 95% confidence interval was used and odds ratios were given. All statistical analyses were performed using STATA 14® (StataCorp, College Station, Texas) and the analyses accounted for the complex survey design and sampling weights.

### Results

Table 1 shows the characteristics of CSHCN with and without medical complexity. There were 40,242 CSHCN represented in the NS-CSHCN 2009/2010. Of these, 3% had medical complexity, while the remaining 97% did not. The difference in the proportions between the two groups of CSHCN were significant for the following variables: gender, age, insurance status, highest education level of parent, effective care coordination needs, and unmet need for prescription medications.

CSHCN with medical complexity had a statistically significant higher percentage of unmet effective care coordination needs compared to those without complex medical conditions (68% vs 41%). A similar trend was also observed with unmet need for prescription medications between the two groups—4.4% and 2% for those with medical complexity and without medical complexity respectively.

Table 2 shows results from the multiple logistic regression model with adjusted odds ratios (ORs) indicating risk estimates. Family report of unmet care coordination need was associated a statistically significant higher odds of unmet need for prescription medications (OR 3.81, 95% confidence interval (CI) 2.7–5.4). In a similar vein, CSHCN with medical complexity had higher odds of unmet need for prescription medications (OR 2, 95% CI: 1–4).

Unmet need for prescription medications was also associated with being uninured (OR 7.11, 95% CI: 4–13). On the other hand, fewer family reporting on unmet need for prescription

medications was associated with being white (OR 0.63, 95% CI: 0.42–0.94) and black (OR: 0.58, 95% CI: 0.37–0.92) compared to being Hispanic. Further, families with household incomes greater than 100% of the federal poverty level (FPL) had lesser odds of reporting unmet needs for prescription medications compared to those with income less than 100% of FPL (OR 0.57 95% CI: 0.36–0.90 for 100%–199% of FPL; OR 0.26 95% CI: 0.26–0.74 for 200%–300% of FPL).

## Discussion

Children with special healthcare needs (CSHCN) have multiple unmet healthcare needs, including that of prescription medications. More importantly, our findings suggest that those CSHCN with medical complexity are more likely to have unmet needs for prescription medications compared to CSHCN without medical complexity.

Although unmet prescription medication need is among the many other unmet healthcare needs of CSHCN with more complex medical conditions, it might be the most important factor impacting the health outcomes of these children, as many depend on multiple medications to maintain a basic quality of life. Because of the nature of their medical conditions—often involving multiple organ systems—CSHCN with more complex medical conditions take multiple medications. Further, many of these children frequently transition between the different parts of the healthcare system thus accentuating barriers to communication that may otherwise help identify unmet needs for prescription medications. For example, Looman and colleagues reported that 25% of families for whom their CSHCN with more complex medical conditions were enrolled in a structured clinic program reported visiting at least five specialists in the past 12 months.<sup>13</sup>

Such unmet needs for prescription medications may mean that children who need the medications most will not be able to adhere to their prescribed regimens. Consequently, this could trigger a major medical meltdown for the child with more complex medical conditions, thereby leading to emergency department visits and prolonged hospitalization.

Care coordination has been suggested as a key solution to improve patient outcomes in the population of CSHCN.<sup>14</sup> Several models of care coordination exist with respect to practice location (e.g., in pediatric tertiary care centers<sup>15</sup>), primary care settings<sup>14</sup>, or an integrated/collaborative care model.<sup>16</sup> The types of healthcare professionals that are tasked with the primary responsibility of coordinating care for CSHCN also varies across practice locations. These may include: physicians, nurse practitioners, nurses, social workers, case managers, or patient navigators. On the other hand, other healthcare professionals who have key roles in addressing unmet prescription medication needs, such as pharmacists, may work peripherally without direct and active engagement with the team involved in coordinating care.

This study's findings suggest that having an effective care coordination service is associated with less likelihood of unmet need for prescription medications among the population of CSHCN, and more so for those with more complex medical conditions. A professional who is in charge of the care coordination can develop a long-lasting relationship with the child's

family, which makes it easier to identify gaps in care including that of unmet prescription medications. Such models of care may also make it easier to develop an open and continuous channel of communication between the child's family and healthcare providers. And when problems arise, it may be easier to address them immediately. For example, Cady et al reported that provision of effective care coordination for families of CSHCN with more complex medical conditions can be achieved by the use of advanced practice registered nurses.<sup>17</sup>

### Study Limitations

The findings of this study must be interpreted taking the following limitations into consideration. First, unmet need for prescription medications was reported by parents or guardians with the most knowledge about the child's health status. However, it may be possible that there may be under or over reporting of a child's actual unmet needs for prescription medications. Further, as is common in any survey research, there may be a potential for recall bias since parents were asked to remember events that occurred during the previous 12 months.

Second, the sample size for CSHCN with more complex medical conditions was not large, and as a result, there may not have been adequate power to identify important relationships between the study variables. Third, simply dichotomizing the population of CSHCN as those with and without medical complexity may have resulted in misclassification of study participants. Specifically, the criteria we applied to identify CSHCN with more complex medical conditions are the ones used by many of the structured clinical programs in U.S. children's hospitals. And these classifications may not identify all children with more complex medical conditions, thus increasing the potential for misclassification of study subjects.

### Conclusion

Improving access to care coordination services will likely reduce unmet needs for prescription medications for CSHCN. Importantly, CSHCN with more complex medical conditions can benefit greatly from such services, given their severe and complicated medical conditions that require transitioning between multiple providers. As healthcare professionals with the most knowledge about medications, pharmacists can bring invaluable expertise to the healthcare team in identifying and addressing unmet needs for prescription medications for children with special healthcare needs.

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[www.childhealthdata.org](http://www.childhealthdata.org)

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**Table 1:**

Characteristics of CSHCN with and without the presence of a medical complexity

Variables	Non-CMC (n=39201, Unweighted) n (%)	CMC, (n=1041, Unweighted) n (%)
<b>Gender<sup>a</sup></b>		
Male	23,440 (60)	699 (67.2)
Female	15,692 (40)	341 (32.8)
<b>Age (years)<sup>a</sup></b>		
0–5	7,072 (18)	222 (21)
6–11	15,343 (39)	491 (47)
12–17	16,786 (43)	328 (31.5)
<b>Race/Ethnicity</b>		
Hispanic	4,355 (11.1)	124 (11.9)
Non-Hispanic, white	27,243 (69.5)	746 (71.7)
Non-Hispanic, African American	3,928 (10)	82 (7.9)
Other	3,675 (9.4)	89 (8.6)
<b>Insurance Status at Time of Survey<sup>a</sup></b>		
Private	22,937 (60.81)	378 (37.1)
Public	10,983 (29.12)	379 (37.2)
Public and Private	2,656 (7.04)	254 (24.93)
Uninsured	1,141 (3.03)	8 (0.79)
<b>Highest Education Level Achieved by Parent/ Guardian<sup>a</sup></b>		
Less than high school	2108 (5.4)	37 (3.6)
High school	5,881 (15)	126 (12.1)
More than high school	31,212 (79.6)	878 (84.3)
<b>Primary language spoken in household</b>		
English	37,741 (96.3)	1007 (96.7)
Other than English	1,460 (3.7)	34 (3.3)
<b>Household Income (% of FPL)</b>		
0–99%	6,702 (17.1)	197 (18.9)
100%–199%	7,509 (19.2)	213 (20.5)



Variables	Non-CMC (n=39201, Unweighted) n (%)	CMC, (n=1041, Unweighted) n (%)
200%–399%	12,254 (31.3)	318 (30.6)
400%	12,736 (32.5)	313 (30)
<b>Effective Care Coordination Needs<sup>a</sup></b>		
Not Met	11,751 (40.8)	704 (68.4)
Met all Needs	17,065 (59.2)	325 (31.6)
<b>Unmet Need for prescription medications<sup>a</sup></b>		
Yes	745 (2)	46 (4.4)
No	38,406 (98)	994 (95.6)

<sup>a</sup>Differences of proportions between CMC and Non-CMC population are statistically significant CMC=Children with medical complexity

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**Table 2:**

Predictors of Unmet Need for Prescription Medications

<b>Independent variable</b>	<b>Adjusted Odds Ratio</b>	<b>95% Confidence Interval</b>
<b>Care Coordination</b>		
All Needs Met	1	-
Needs Not Met	<b>3.81</b>	2.70–5.40
<b>Medical Complexity Status</b>		
Child Not Medically Complex	1	-
Child Medically Complex	<b>2.01</b>	1.00–4.03
<b>Gender</b>		
Male	1	-
Female	1.29	0.99–1.68
<b>Age (years)</b>		
0–5	1	-
6–11	1.09	0.70–1.70
12–17	1.46	0.99–2.14
<b>Race/Ethnicity</b>		
Hispanic	1	-
White, non-Hispanic	<b>0.63</b>	0.42–0.94
Black, non-Hispanic	<b>0.58</b>	0.37–0.92
Other, non-Hispanic	<b>0.55</b>	0.34–0.90
<b>Type of Insurance at survey</b>		
Private	1	-
Public only	1.35	0.87–2.09
Both public and private	0.47	0.23–0.97
Uninsured	<b>7.11</b>	4.03–12.56
<b>Highest education level achieved by parent/guardian</b>		
Less than high school	1	-
High school	0.59	0.31–1.09
More than high school	0.87	0.49–1.54
<b>Primary language spoken in household</b>		
English	1	-
Other than English	<b>0.16</b>	0.07–0.35

Independent variable	Adjusted Odds Ratio	95% Confidence Interval
<b>Household income (% of federal poverty level)</b>		
0–99%	1	
100%–199%	<b>0.57</b>	0.36–0.90
200%–399%	<b>0.43</b>	0.26–0.74
400%	<b>0.25</b>	0.15–0.44

**Bold:** p<0.05

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