


Clinical Care Coordination in Medically Complex Pediatric Cases: Results From the National Survey of Children With Special Health Care Needs

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Abstract

This study uses a secondary analysis of the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) to describe care coordination (CC) for children with medical complexity (CMC). Chi-square test, *t* test, and multivariate logistic regression statistical tests are used to determine the relationships and differences between sources of CC and factors associated with receiving clinic-based CC for CMC and their family. Among CMC, 66.47% received no CC support and 25.73% received clinic-based CC. In multivariate models, families reporting dissatisfaction with communication between health care providers or reporting family-centered care were less likely to receive clinic-based CC. Families were more likely to receive clinic-based CC if they had younger children, lower household income, and greater school absenteeism. Clinic-based CC is associated with improved communication between health providers but must become more family-centered and minimize student absenteeism for the CMC population.

Keywords

child health services; health survey; patient care management; care coordination; functional disability

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Introduction

Children with medical complexity (CMC) are a small (1% to 4% of all pediatric patients) but diverse population of pediatric patients who account for approximately one third of all pediatric health care costs.¹ The predominant medical diagnoses of CMC are chronic and/or severe conditions that can cause functional limitations, including cardiovascular defects, severe neurological conditions, and include cancer patients or cancer survivors with multiple system disabilities.² Because of these challenges, CMC require increased access to health care services, such as routine intensive care, in-home caregiving, frequent doctor visits, multiple anesthesia treatments, and medical technology.^{3,4}

To meet the care needs of CMC, many providers use a process called care coordination (CC), which integrates and delivers health care resources to the patient and family. Family involvement is integral to CC for CMC, as CMC are dependent on their family and caregivers for basic daily activities: transportation and

scheduling of medical appointments, coordination of required care, and financial/insurance support. Furthermore, work by Coller et al⁵ indicate that the more medically complex a child is, the more challenging care coordination efforts become for the patient and family. With this in mind, our study defines CC in the context of CMC and occurs when “care planning decisions are communicated and actively discussed with the family and members of the child’s care team within the context of all the child’s health problems and issues.”⁶

Currently, among the biggest issues affecting CMCs’ quality of life are inconsistencies and lack of communication in their care.^{1,7,8} Families of CMCs also experience increased financial burden, work loss, and poor continuity

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of care in dealing with the challenges associated with their child's health status.^{7,9,10} CC has been shown to improve communication and reduce financial burden for patients and family, but it is unknown how sources of CC affect CMC quality of life.^{11,12}

To better understand CC for CMC, this study describes the sources of CC assistance and the prevalence of CC support for CMC using a population-representative, national US sample. Additionally, this study examines the relationship between CC source and CC dynamics, CMC and family impact, and household factors. Finally, we investigate which factors are independently associated with receiving clinic-based CC. These variables have not previously been examined using a population-representative, national US sample. This study provides a better description of CMC using CC, impacts of CC on CMC and family, and suggestions for improving CC for the US CMC population.

Methods

This study is a secondary data analysis of the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), a survey designed to examine the physical, emotional, and behavioral health of US children with special health care needs.¹³ The NS-CSHCN is a telephonic survey that is conducted by the National Center for Health Statistics (NCHS) at the Center for Disease Control and Prevention under the direction of the Maternal and Child Health Bureau using the State and Local Area Integrated Telephone Surveys approach.¹³ Trained interviewers conducted the survey to 372 698 children from 196 159 households and asked families a series of questions to identify their children as having special health care needs. If the family member answered "yes" they have a child in their household (under the age of 18 years) that they believe has special health care needs (if more than one, they were asked to randomly select one child as their subject) during their randomly selected call, they would be taken through the survey by the interviewer. If they did not identify any of their children as one with special health care needs, some sociodemographic data were collected and the survey was ended. The NS-CSHCN classified 40 242 children with special health care needs from all 50 states including the District of Columbia. Sampling is representative of the US population of non-institutionalized children with special health care needs ages 0 to 17 years.¹³

This study uses criteria similar to Kuo et al's to define our population of children with medical complexity (Table 1): "A need for medical care, evidenced by a positive response to the medical care question on the National

Table 1. Pediatric Medical Complexity Classification, NS-CSHCN 2009-2010^a.

Medical Complexity Classification	Frequency	Percentage	Cumulative
Not medically complex	35 977	93.43	93.43
Medically complex	2529	6.57	100
Total ^b	38 506	100	

Abbreviation: NS-CSHCN, National Survey of Children with Special Health Care Needs.

^aSummary of respondents meeting the criteria for having a child with medical complexity.

^bTotal is unweighted.

Survey of Children with Special Health Care Needs Screener; multiple needs across different domains, as evidenced by a positive response to at least three of the remaining four screener questions; and having seen at least two specialists in the previous year"^(pp.2192).¹⁴ We first coded a variable for respondents who answered "yes" when asked if their child used more medical care, mental health, or educational services than is usual for most children of the same age. We then included all respondents with positive responses to the 4 remaining NS-CSHCN screener questions to isolate the most medically complex children. To further satisfy the definition of medical complexity listed above, a variable was coded that restricted the sample to those respondents who reported seeing 2 or more specialists within the past 12 months. We combined the variable for special health care needs with the variable indicating 2 or more specialty doctor visits in a year to create the variable for medical complexity and isolate the most medically complex children in the NS-CSHCN (Figure 1).

The outcome variables for CC source are based on responses to the NS-CSHCN survey item that asks families what type of support they had for CC. The responses for CC support were categorized as follows: (1) clinic-based support (someone in a doctor's office), (2) family/social network support (someone in the family or social network), (3) both clinic-based and family/social network support, or (4) no support (no CC help at all; Table 2). To isolate any impact of clinic-based CC in bivariate and multivariate regression models, we made the CC outcome binary: (1) clinic-based CC versus (2) no clinic-based CC.

Constructs of interest for bivariate and multivariate regression models included CC dynamics, impact on child, impact on family, and household characteristics. Covariates that served as markers for these constructs were used when unable to directly measure these items given the nature of the survey. For example, for the impact on child we looked at unmet medical needs, absenteeism in school, and if the child's health conditions interfered with ability to go on outings.

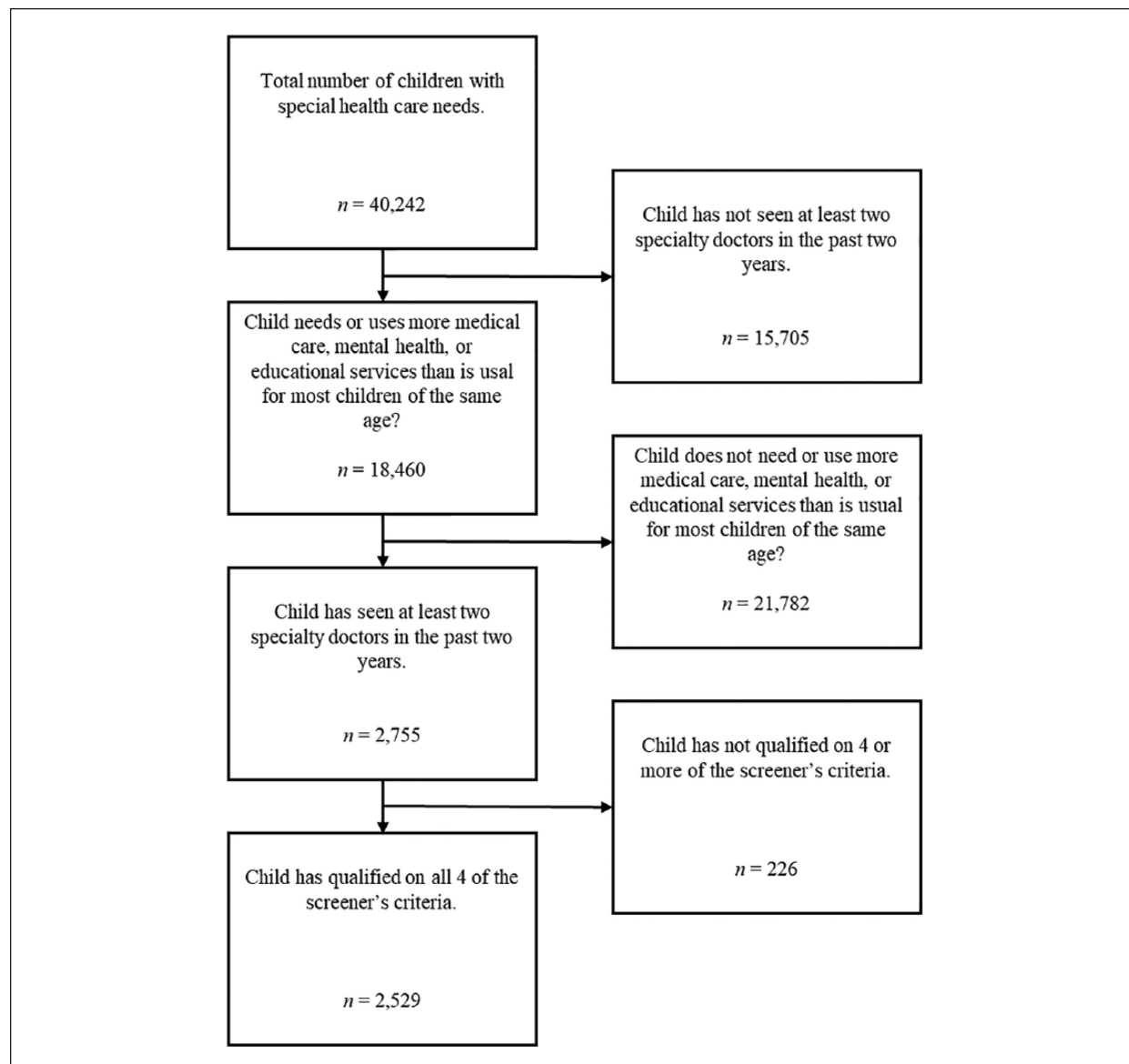


Figure 1. Flow diagram of criteria used to classify pediatric medical complexity from the NS-CSHCN Screener. Shown are the authors' criteria used to identify the most medically complex children from the NS-CSHCN. Starting with 40 242 respondents replying "Yes" to a question asking if their child had increased health care use, a final sample of 2529 children were collected who met study criteria.

All analyses were conducted in STATA v.13.1. Analyses were weighted using the "svy" command to account for the complex sampling strategy and to provide more accurate estimates. First, proportions were estimated according to the 4-category outcome measure of CC. Chi-square and *t* tests and statistical tests assessed differences in distribution across CC levels for CC dynamics, impact on child, impact on family, and household variables. Associations between

clinic-based CC support and the previously listed variables were explored using weighted bivariate analyses and multivariate logistic regression. Collinearity was assessed using tolerance values and a threshold of 0.1. Multivariate modeling proceeded in a forward stepwise manner with those entering the model having an alpha level of 0.1 in the bivariate associations and exiting the multivariate model if α level was $>.05$.

Table 2. Care Coordination Classification Among All Participants, NS-CSHCN 2009-2010^a.

Care Coordination Classification	Frequency	Percentage	Cumulative
Clinical support	4517	11.39	11.39
Family/social network support	2111	5.32	16.71
No support	31 380	79.09	95.80
Both clinical and family support	1668	4.20	100
Total ^b	39 677	100	

Abbreviation: NS-CSHCN, National Survey of Children with Special Health Care Needs.

^aSummary of care coordination type among respondents reporting receipt of care coordination for their child.

^bTotal is unweighted.

Ethical Approval and Informed Consent

Since the 2009-2010 NS-CSHCN data set is publicly available and de-identified, this study received exempt status from the Idaho State University Institutional Review Board.

Results

Among families reporting having a child with special health care needs, 6.57% met the criteria of CMC. The majority of family members within the CMC population reported receiving no support (66.47%) for CC. Other respondents received CC from clinic-based support (15.17%), both clinic-based support and family/social network support (10.56%), and family/social network support (7.80%).

Care Coordination Dynamics

Fewer than half of all families with CMC reported usually receiving as much help as desired arranging or coordinating care, which differed significantly by source for CC (Table 3). Receiving both clinic-based and family/social network support resulted in a higher proportion of families indicating usually receiving the help desired coordinating care (47.57%), compared with families who only reported family/social network (30.21%) or clinic-based (30.83%) CC ($P \leq .001$). Similarly, a higher proportion of families who reported no support for CC responded that they could have used extra help arranging or coordinating care (50.86%) compared with families with family/social network (45.64%), clinic-based (40.12%), or both clinic-based and family/social network support (37.03%; $P \leq .020$). Families with both clinic-based and family/social network support for CC had a higher proportion of being “very satisfied” with communication between their child’s doctor and other health care providers (61.19%) compared with those with clinic-based (51.46%), family/social network (51.89%), or no support (41.79%; $P = .004$). Conversely, the proportion of families who reported being dissatisfied with communication between their child’s

doctor and other health providers was highest among those who reported no support for CC. Finally, there were no significant differences between CC sources and reported hours per week spent by family providing and/or coordinating care for their CMC.

In the unadjusted model, families were less likely to be receiving clinic-based CC if they indicated that they “sometimes” or “never” got as much care as desired arranging or coordinating care for their child (Table 4; odds ratio [OR] = 0.48 [95% confidence interval (CI) = 0.27-0.86] and OR = 0.04 [95% CI = 0.01-0.11], respectively) compared with families that “usually” got as much care as desired arranging or coordinating care for their child. Receiving clinic-based CC was independently associated with satisfaction with communication between the child’s doctor and other health providers; after controlling for age, income, and other variables in the adjusted model, families that were “very dissatisfied” with communication between the child’s doctor and other health providers were 79% less likely to be receiving clinic-based CC (adjusted OR [AOR] = 0.21 [95% CI = 0.07-0.66]).

Family Impact

When examining the source of CC and its impact on families with CMC, lower proportions of those receiving clinic-based (27.52%) and both clinic-based and family/social network support (22.29%) reported a time when family members needed mental health care or counseling related to the child’s medical conditions compared with families with family/social network (34.02%) and or no support for CC (34.65%; $P = .025$). Higher proportions of families with both clinic-based and family/social network (66.93%) or clinic-based support (69.14%) reported receiving family-centered care compared with those receiving family/social network (54.11%) or no support for CC (52.35%; $P = .001$). There were no significant differences observed across sources of CC support in terms of having experienced financial burden due to their child’s health, having

Table 3. Comparison of CC Characteristics, Impact on Families and Individuals, Among Medically Complex Children According to Source of CC Support in the United States, NS-CSHCN 2009-2010^a.

	Both Clinical and Family/Social Network Support for CC, n = 258 (Weighted %)	Clinical Support for CC, n = 386 (Weighted %)	Family/Social Network Support for CC, n = 214 (Weighted %)	No Support for CC, n = 1668 (Weighted %)	Chi-Square P Value
<i>Numbers in the below columns do not always add up to the total n due to missing data</i>					
Care Coordination					.524
How many hours per week do you spend providing and/or coordinating child's care?					
Less than 1 hour per week	19 (7.09%)	42 (8.92%)	16 (4.17%)	140 (7.40%)	
1-4 hours per week	57 (25.95%)	126 (25.86%)	71 (32.98%)	547 (26.86%)	
5-10 hours per week	35 (12.71%)	66 (14.28%)	35 (20.28%)	306 (18.19%)	
11 or more hours per week	135 (49.66%)	142 (49.07%)	82 (37.35%)	624 (43.46%)	
How often did you get as much help as you wanted with arranging or coordinating care?					<.001
Never	7 (4.05%)	11 (9.60%)	10 (10.63%)	416 (55.30%)	
Sometimes	43 (48.37%)	87 (59.57%)	50 (59.16%)	280 (33.71%)	
Usually	41 (47.57%)	47 (30.83%)	22 (30.21%)	88 (10.99%)	
How satisfied are you with the communication among your child's doctors and other health care providers?					.004
Very satisfied	150 (61.19%)	200 (51.46%)	102 (51.89%)	692 (41.79%)	
Somewhat satisfied	78 (29.41%)	144 (38.46%)	81 (33.04%)	596 (36.16%)	
Somewhat dissatisfied	24 (4.78%)	34 (9.29%)	19 (9.66%)	238 (12.28%)	
Very dissatisfied	6 (4.62%)	6 (0.65%)	10 (4.47%)	132 (9.07%)	
Impact on family					
Has there been any time when you or other family members needed respite care? (Yes)	83 (29.93%)	98 (29.56%)	73 (31.44%)	523 (31.12%)	.863
Was there any time when you or other family members needed mental health care or counseling related to the child's medical conditions? (Yes)	82 (27.52%)	100 (22.29%)	66 (34.02%)	567 (34.65%)	.025
One or more unmet needs for family support services? (Yes)	53 (21.73%)	91 (23.12%)	59 (34.19%)	485 (30.47%)	.093
Have you experienced financial burden due to your child's health needs? (Yes)	119 (45.77%)	190 (53.98%)	100 (56.82%)	905 (56.66%)	.242
Family member cut back hours or stopped working or both (Yes)	165 (62.02%)	245 (70.55%)	128 (63.84%)	1106 (67.47%)	.528
Child has family centered care (Yes)	179 (66.93%)	256 (69.14%)	135 (54.11%)	915 (52.35%)	.001
Impact on child					
Does the child's health conditions interfere with [his/her] ability to go on outings, such as to the park, library, zoo, shopping, church, restaurants, or family gatherings? (Yes)	30 (38.57%)	50 (48.3%)	18 (51.34%)	118 (58.18%)	.330

(continued)

Table 3. (continued)

	Both Clinical and Family/Social Network Support for CC, n = 258 (Weighted %)	Clinical Support for CC, n = 386 (Weighted %)	Family/Social Network Support for CC, n = 214 (Weighted %)	No Support for CC, n = 1668 (Weighted %)	Chi- Square P Value
Missed school days by child					.157
0-3 days missed	36 (9.11%)	77 (21.64%)	48 (24.04%)	393 (24.53%)	
4-6 days missed	31 (19.07%)	44 (15.09%)	40 (23.91%)	269 (20.02%)	
7-10 days missed	39 (21.06%)	46 (13.08%)	23 (12.17%)	211 (16.37%)	
11 or more days missed	79 (44.71%)	105 (45.77%)	50 (37.02%)	499 (35.53%)	
Any unmet need for any of 14 specific health care services or equipment					.063
No unmet needs	153 (60.09%)	232 (62.41%)	133 (55.44%)	886 (50.30%)	
1 unmet need for services/equipment	59 (24.84%)	84 (18.05%)	40 (19.31%)	367 (21.79%)	
2 or more unmet needs for services/equipment	37 (13.60%)	66 (18.78%)	37 (23.35%)	375 (24.66%)	
Household characteristics					.567
Family structure					
Two parent biological/adopted	140 (56.02%)	228 (62.39%)	120 (54.92%)	1063 (57.85%)	
Two parent step family	22 (9.36%)	35 (7.33%)	18 (7.10%)	127 (8.76%)	
Single mother, no father present	65 (26.97%)	75 (19.05%)	49 (32.39%)	340 (25.82%)	
Other	29 (7.97%)	41 (11.23%)	23 (5.58%)	116 (7.57%)	
Levels of income according to Federal Poverty Level (FPL) guidelines?					.026
0% to 99% FPL	71 (22.96%)	68 (19.80%)	41 (31.61%)	267 (22.54%)	
100% to 199% FPL	65 (31.68%)	91 (27.38%)	45 (24.32%)	343 (20.05%)	
200% to 399% FPL	71 (24.40%)	129 (33.84%)	59 (19.27%)	528 (28.74%)	
400% FPL or greater	51 (20.69%)	98 (18.99%)	69 (24.80%)	530 (28.67%)	
Adequacy of insurance					.563
Current insurance is not adequate	96 (40.03%)	96 (46.57%)	796 (46.09%)	144 (39.75%)	
Current insurance is adequate	155 (57.30%)	113 (52.30%)	836 (52.22%)	236 (59.42%)	
Uninsured	4 (2.67%)	3 (1.13%)	27 (1.69%)	3 (0.84%)	
Age (in years; mean [SE])	8.33 (0.51)	8.38 (0.40)	9.59 (0.55)	9.17 (0.21)	<.001

Abbreviation: CC, care coordination; NS-CSHCN, National Survey of Children with Special Health Care Needs.

*Summary of comparisons between type of care coordination reported by respondents and variables of interest using χ^2 analysis.

Table 4. Association Between Care Coordination Dynamics, Impact on Family, Impact on Child, and Household Characteristics and Receiving Clinical Care Coordination, NS-CSHCN 2009-2010 (n = 38 178)^a.

Variables	OR (95% CI)	AOR (95% CI)
Care coordination dynamics		
How many hours per week do you spend providing and/or coordinating child's care? (ref. Less than 1 hour per week)	—	—
1-4 hours per week	0.87 (0.52-1.46)	—
5-10 hours per week	0.68 (0.38-1.21)	—
11 or more hours per week	1.03 (0.62-1.71)	—
How often did you get as much help as you wanted with arranging or coordinating care? (ref = Usually)	—	—
Never	0.04 (0.14-0.11)	—
Sometimes	0.48 (0.27-0.86)	—
How satisfied are you with the communication among your child's doctors and other health care providers? (ref = Very satisfied)	—	—
Somewhat satisfied	0.53 (0.35-0.81)	0.82 (0.55-1.23)
Somewhat dissatisfied	0.32 (0.17-0.58)	0.60 (0.33-1.07)
Very dissatisfied	0.18 (0.91-1.37)	0.21 (0.07-0.66)
Impact on family		
Has there been any time when you or other family members needed respite care? (ref = No)	0.93 (0.65-1.35)	—
Was there any time when you or other family members needed mental health care or counseling related to the child's medical conditions? (Ref = No)	0.61 (0.44-0.85)	—
One or more unmet needs for family support services? (ref = No)	0.66 (0.45-0.97)	—
Have you experienced financial burden due to your child's health needs? (ref = No)	0.77 (0.57-1.08)	—
Family member cut back hours or stopped working or both (ref = No)	0.98 (0.70-1.37)	—
Child has family-centered care (ref = Yes)	0.51 (0.37-0.72)	0.63 (0.42-0.94)
Impact on child		
Does the child's health conditions interfere with [his/her] ability to go on outings, such as to the park, library, zoo, shopping, church, restaurants, or family gatherings? (ref = No)	1.74 (0.84-3.60)	—
Missed school days by child (ref = 0-3)	—	—
4-6 days missed	1.25 (0.69-2.25)	1.26 (0.69-2.32)
7-10 days missed	1.49 (0.84-2.63)	1.49 (0.82-2.71)
11 or more days missed	1.90 (1.21-3.00)	2.03 (1.27-3.24)
Not applicable (age <5 years)	2.46 (1.47-4.11)	2.19 (1.13-4.24)
Any unmet need for any of 14 specific health care services or equipment (ref = No)	—	—
1 unmet need for services/equipment	0.78 (0.54-1.14)	—
2 or more unmet needs for services/equipment	0.55 (0.36-0.85)	—
Household characteristics		
Family structure (ref = 2 parent biological/adopted)	—	—
Two parent step family	0.90 (0.53-1.55)	—
Single mother, no father present	0.84 (0.57-1.22)	—
Other	1.25 (0.63-2.48)	—
Levels of income according to Federal Poverty Level (FPL) guidelines? (ref = 400% FPL or greater)	—	—
0% to 99% FPL	1.36 (0.86-2.15)	1.94 (1.18-3.20)
100% to 199% FPL	2.11 (1.37-3.23)	1.44 (0.88-2.37)
200% to 399% FPL	1.51 (0.97-2.35)	0.89 (0.52-1.51)
Adequacy of insurance (ref = Current insurance is adequate)	—	—
Current insurance is not adequate	0.77 (0.55-1.07)	—
Uninsured	0.84 (0.27-2.57)	—
Age (in years)	0.96 (0.93-0.99)	0.98 (0.94-1.03)

Abbreviations: NS-CSHCN, National Survey of Children with Special Health Care Needs; OR, odds ratio; AOR, adjusted odds ratio; CI, confidence interval.

^aSummary of odds of respondents receiving clinic-based CC based on reported variables of interest in bivariate and multivariate models.

unmet needs for family support services, having the need for respite care among family, or having a family member cut back hours/stop working. In our unadjusted model, families were less likely to be receiving clinic-based CC if they had one or more family members receiving mental health care due to their child's health condition (OR = 0.61 [95% CI = 0.44-0.85]), had one or more unmet needs for family support services (OR = 0.66 [95% CI = 0.45-0.97]), or did not have family-centered care (OR = 0.51 [95% CI = 0.37-0.72]). In both the unadjusted and adjusted models, families reporting family-centered care were less likely to be receiving clinic-based CC (OR=0.51 [95% CI = 0.37-0.72], AOR = 0.63 [95% CI = 0.42-0.94]).

Child Impact

With regard to variables relating to the impact on the child, over a third of families who had no CC support reported that their CMC missed 11 or more days of school (35.53%), while just under half of the families with clinic-based support reported the same (45.77; $P = .157$). In our adjusted model, as the number of missed school days increased, the likelihood of receiving clinic-based CC strengthened; families that reported 11 or more missed days of school were twice as likely to be receiving clinic-based CC in the adjusted model (AOR = 2.03 [95% CI = 1.27-3.24]). With regard to social outings, a greater proportion of families with no support for CC reported experiencing interruptions with the child's ability to go on outings, such as to the park, library, zoo, shopping, church, restaurants, or family gatherings (58.18%) compared with those with clinic-based support (38.57%; $P = .330$). When looking at the care burden experienced by families by examining the need for 14 specific health care services or equipment, nearly half of families with no CC support reported "no unmet needs" (50.30%), a lower proportion than families with other sources of CC support (clinic-based support [62.41%], family/social network support [55.44%], and both clinic-based and family/social network support [60.09%]). Similarly, nearly a quarter of families with no support for CC reported that their CMC had 2 or more unmet needs (24.66%), which was higher than those with clinic-based support (18.78%; $P = .063$). This agreed with findings in our unadjusted model, where families with 2 or more unmet needs for services/equipment were less likely to be receiving clinic-based CC (OR = 0.55 [95% CI = 0.36-0.85]).

Household Characteristics

Household characteristics of families with CMC differed across the sources of CC support by income, but

not by family structure or adequacy of health insurance. Families with family/social network or no CC support had significantly older CMC compared with those receiving just clinic-based or both clinic-based and family/social network support ($P \leq .001$). The families with no support for CC reported higher levels of income (57.41% at 200% or above the federal poverty level [FPL]) than those with other sources for CC ($P = .026$). The families with family/social network or both clinic-based and family/social network support for CC reported higher levels of having experienced financial burdens due to their child's health needs and had lower income (over 50% below 200% FPL). No significant differences were observed across the sources for CC support in reporting the adequacy of the families' insurance or the family structure. In the unadjusted model, families at 100% to 199% FPL were twice as likely to report receiving clinic-based CC support (OR = 2.11 [95% CI = 1.37-3.23]). Also, those families who had inadequate insurance (OR = 0.77 [95% CI = 0.55-1.07]) or were uninsured (OR = 0.84 [95% CI = 0.27-2.57]) were less likely to be receiving clinic-based CC compared with families with adequate health insurance. When examining CMC age, for every increase in years of age, families are 4% less likely to have clinic-based CC support (OR = 0.96 [95% CI = 0.93-0.99]). In the adjusted model, families in the lowest household income bracket were more likely to be receiving clinic-based CC support; and those at 0% to 99% FPL were 1.94 times (AOR = 1.94 [95% CI = 1.18-3.20]) more likely to be receiving clinic-based CC compared with those at 400% FPL or greater.

Discussion

This study provides evidence of the burden that can be alleviated by CC from families and caregivers of CMC. Specifically, in terms of CC dynamics between families and clinics, the families that reported receiving clinic-based CC support were more likely to not need extra help coordinating care, get the help they needed coordinating care, and report more satisfaction with communication between their doctors.

Considering access to CC services, approximately one third of parents/guardians report having difficulties, delays, or are frustrated with the process of receiving care coordination for their CMC.¹⁵ When access to health-related services is not effectively coordinated, there is an increased reliance on emergency services and increased likelihood of hospitalization for preventable illnesses.¹⁵ Zuo et al found that a significantly larger percentage of required health care services (check-ups, therapies, mental health care, respite care, and referrals) for CMC were met after enrolling in a tertiary care

center-based program.¹⁶ Thus, the lack of access to CC can place an unnecessary burden on the hospitals and tertiary care centers.

In our adjusted model, parents/guardians that were dissatisfied with communication among the child's doctor and other health care providers were less likely to be receiving clinic-based CC. Thus, receiving CC may result in improved communication between providers, as CC increases communication between providers, although the cross-sectional nature of this study precludes any causal inference. Nevertheless, rationale for expanding and strengthening clinic-based CC could improve the experience from the patient/family perspective.

We found that families receiving family-centered care were less likely to be receiving clinic-based CC. This is concerning, as CC focuses on involving and communicating with families through shared decision making. Specifically, shared decision making is pivotal to efficient CC, and is associated with decreased out-of-pocket costs and lower health care utilization rates.¹⁷ Another study found that family-centered care is related to a reduced need for coordination with CMC's school by parents, resulting in fewer absences and an improved adherence to referrals.¹⁸ These results relate to another of our findings: families receiving clinic-based CC had greater absenteeism at school. When the provider models family-centered care, parents have a say in when and where the appointments are scheduled and how the medical treatment will affect their child's behavior and/or performance in school.¹⁸ Interestingly, this study found that those CMC receiving clinic-based CC miss more school days than those not receiving clinic-based CC. This could potentially be credited to the severity of CMC conditions and physical limitations; patients in this population missing more days of school could require increased access to clinic-based CC. However, clinics should prioritize school absenteeism reduction in their CC programs. Interestingly, though not independently associated with clinic-based CC, there was a lower prevalence of parent/guardian's reporting that their child's health conditions interfere with their ability to go on outings, such as to the park, library, zoo, shopping, church, restaurants, or family gatherings when compared with those who have no CC support.

Families receiving clinic-based CC were more likely to live below the FPL. Given the cross-sectional nature of this study, this finding could indicate that additional CC services are being offered to those at low-income levels. In addition, it could also indicate a loss of income generating capacity as a result of needing to care for CMC. Access to CC for CMC in low-income households is important, as families with inadequate insurance/low-income also had higher rates of home care and personal

CC efforts.¹⁹ Furthermore, households with lower educational attainment spent relatively more time on home care and coordination of care than households with more income.¹⁹ Nearly 50% of families with CMC experience high out-of-pocket expenses, financial problems, and employment or caregiving burdens, with those factors worsening with more complex cases.²⁰ In the same study, a comparison of financial burden proportion among family respondents to NS-CSHCN surveys in 2001 and 2009-2010 found little to no change in financial burden of families of children with special health care needs. Financial support for households with CMC is needed to reduce the financial burden. Although CC may not sufficiently reduce financial burdens, it is worth noting that nearly half of the CMC families spent 11 or more hours coordinating their child's care and have experienced financial burden regardless of what level of CC support level they received. This is increased compared with all children with special health care needs, where nearly half (52%) of families of children with special health care needs spent at least 1 hour per week on CC and 4% spending 11+ hours per week on CC.¹⁹ In terms of time, 34% spent at least an hour providing care at home, with 8% spending 11+ hours.¹⁹ Thus, families of CMC make considerable financial and time investments to support their child despite CC. In addition, more than half of CMC families having a family member cut back or stop working due to the needs of their CMC.

In terms of age, clinic-based CC support was reported as being used by younger CMC. This finding may be due to having more CC needs at a younger age before CMC, their families, and clinics find a routine for management of care.

Though not significant in our final model, families who used clinic-based CC services had a significantly lower need for mental health care services or counseling due to their CMC's medical conditions compared with families that either coordinate care themselves or have no CC support at all. This may indicate that families who do not utilize the clinical team's CC services have an increased risk of mental health care needs and/or counseling. More research is needed on the impact that CC may have on alleviating mental health needs among family members.

This data analysis has limitations and strengths that should be noted. At the time of our analysis we used the latest available NS-CSHCN dataset from 2009-2010 and we acknowledge that pediatric CC efforts have likely grown and changed nationwide within the health system in the United States. Future comparisons of NS-CSHCN with our findings will be important to replicate. In addition, the cross-sectional nature of the datasets allows us to describe prevalence and associations

between variables and CC, but it does not allow us to consider the duration of CC received, or timelines including trajectories for impact on the child, family, or CC. Finally, due to the nature of self-reported surveys like the NS-CSHCN, the prevalence of CC can be poorly estimated for families of CMC. Clinicians, including pediatricians, often provide coordinated care to their higher need patients but these efforts may not be recognized by patients and caregivers and therefore inadequately captured by studies like ours. Strengths of this study include the utilization of a large, population-representative dataset of the most medically complex children in the United States, which allows us to compare population-level impact rather than a specific clinic's data.

Efforts to expand and improve CC are important in removing the burden on families with CMC's and minimizing the disruption that CMC encounter with CC. In addition to improving care, there is a need to increase access to CC to improve care, quality of life, and satisfaction among families.

Authors' Note

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Author Contributions

All contributed to the design of the study. RH, AP, and RL designed the study, conducted data analysis and wrote the first manuscript draft. JV, RT, EN, JN provided review of study design, analysis, and manuscript drafts. RL encouraged and assisted RH and AP in performing and interpreting the analysis and supervised the project.


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