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Analysis of Care Coordination in Medically Complex Pediatric Cases: A Secondary Data  
Analysis of The National Survey of Children with Special Health Care Needs.

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## Abstract

**Background:** Children with medical complexity (CMC) include those who suffer from chronic, severe health conditions, substantial health service needs, and functional limitations which are often severe and require high health resource utilization. Such children have shown to have better health outcomes with care coordination (CC) by clinics and/or families, though the broader impact of CC on the child and their families is understudied.

**Methods:** This secondary data analysis of children (ages 0-17 years) with medical complexity utilizes the National Survey of Children with Special Health Care Needs (NS-CSHCN) from 2009-2010 to describe CC for CMC, including sources of assistance for CC and how types of CC affect families of CMC. We examined CC in terms of sources of assistance according to the following categories: clinical support, family/social network support, both clinical and family/social network support, or no support. Data analyses included chi-square and t-tests to determine differences between CC dynamics, impact on child, impact on family, and household characteristic variables according to CC categories. Associations with receiving CC from clinics were explored using weighted bivariate analyses and multivariate logistic regression.

**Results:** Among the children with special health care needs, 6.57% were determined to be the most medically complex. Among CMC, the majority of parents reported receiving no CC support (66.47%), while others received CC support from clinical CC support (15.17%), both Clinical support and Family/Social Networks (10.56%), and family/social networks only (7.80%). CMC not receiving CC support were more likely to report that they could have used extra help arranging or coordinating care compared those receiving CC from family/social network only, clinical only, or both. In multivariate models, parent/guardians that were dissatisfied with communication among the child's doctor and other health care providers, and those receiving family-centered care were less likely to currently receive clinical CC. Those more likely to report currently receiving clinical CC had income below the federal poverty level, and a CMC that missed seven or more school days in the past month. In terms of age, clinical CC support is currently being used by younger CMC.

**Discussion:** These factors may assist clinical teams in identifying ways in which they can improve their CC efforts to impact the family positively. In addition to improving care, there is a need to reduce the number of CMC that do not have CC support to improve the quality of life of CMC and their families.

## Chapter I: Introduction

Children with medical complexity (CMC) are a fairly new patient designation referring to those children with multiple diagnoses and under the care of multiple pediatric specialists. Specifically, CMC includes those who suffer from: chronic, severe health conditions, substantial health service needs, functional limitations which are often severe, and high health resource utilization (Cohen, et al., 2011). Since there are varying specific definitions of medical complexity in terms of pediatric care, the factors from the above list are generally referenced in a majority of CMC definitions. Examples of medically complex cases include: multisystem diseases, severe neurological conditions with functional impairments, and cancer patients or survivors with multiple area disabilities (Cohen, et al., 2011).

Pediatric cases of medical complexity typically require routine intensive care, at-home caregiving, frequent doctor visits, multiple anesthesia treatments for care, and are technologically dependent requiring multiple specialist care coordination (CC) efforts. CC in the context of CMC in this paper is defined as; “care planning decisions that are communicated and actively discussed with the family and member of the child’s care team within the context of all the child’s health problems and issues” (Berry, Agrawal, Cohen, & Kuo, 2013). These patients are typically dependent on their families/caregivers for basic activities of daily living, transportation and scheduling of doctor appointments, coordination of required care, and financial/insurance support for payment of said care.

Approximately 4%, or 3 million US children, are medically complex with an increasing rate of 5% per year accounting for nearly 40% of Medicaid costs (Children’s Hospital Association, 2013). The biggest issues CMC’s face are inconsistencies and lack of communication that affects their CC, continuity of care, quality of life, and a development of national standards to support

care and cost improvements (Children's Hospital Association, 2013). These issues do not only affect the CMC's, they also affect their families by increasing the burdens of; finances, CC responsibilities, transportation, at-home caregiving, and ensuring continuity of care in the presence of changes and challenges associated with their CMC's care. The data set reviewed in this secondary data analysis is the National Survey of Children with Special Health Care Needs (NS-CSHCN) from 2009-2010.

The main aims of our study are to:

- 1) Describe CC for the CMC including sources of assistance and prevalence of support.
- 2) determine how CC dynamics, impacts on the CMC and family, and household factors vary according to level of CC.
- 3) Investigate which of these factors are independently associated with receiving clinical CC.

Our ultimate goal with this secondary data analysis is to investigate methods in which we can reduce CMC and family burdens involving CC. We want to explore means in which we can consolidate treatments or streamline care services as efficiently as possible while still maintaining the highest quality of life for the CMC as possible. This secondary data analysis will be innovative in that we will be focusing more on the families and how that responsibility of CC affects their dynamic, work, and financial standing. This focus has not previously been isolated with the NSCSHCN dataset; Thus, it will provide us with a better comprehension on how to improve the care for the CMC by understanding more about their primary support systems, their families.

The data metrics that we are most interested in with this secondary data analysis will include family dynamics, getting required services and CC, and insurance and finances. We will be

assessing income level, family structure, missed school days by CMC, how much care is provided by family members, and impact on family work life. As well as insurance type and adequacy of coverage, financial investment into care/burden, and CC limitations. All of the above listed variables theorized to be related to CC.



## Chapter II: Literature Review

Concerning CC and CMC, there is a multifaceted examination necessary to identify and consider the factors that influence an efficient and effective system. This CC system is one that has been shown to depend on access to care, an established care model, multilevel coordination efforts, and family financial and time contributions.

One of the factors that have been shown to influence the CC efforts is an established model of coordination as well as communication concerning the CMC. One study looked at the achievement rate of meeting all of the CMC's health care needs comparing primary care clinic visits versus shifting to tertiary care centers. This study defines tertiary care centers as medical homes, children's hospitals, and special needs programs/complex care services (Zuo et. al., 2016). What they found was that a significantly larger percentage of required health care services (check-ups, therapies, mental health care, respite care, and referrals) for the CMC were met after enrolling in a tertiary care center based program (Zuo et. al., 2016). Zuo et al. suggests that the increase in met health services needs was due to the ease of access to multiple specialists with expertise in complex care and the reduced hospitalizations due to that satisfaction of preventative health service needs (Zuo et. al., 2016). In support of what Zuo et al. have found, Rosen-Reynoso et al. identified that one third of CMC's had difficulties, delays, or were frustrated with the process of receiving coordinated care (Rosen-Reynoso et. al., 2016). They then stated that when the access to health-related services is not effectively coordinated and multiple barriers are met, there is an increased reliance on emergency services and have a significantly increased likelihood of hospitalization for preventable illnesses (Rosen-Reynoso et. al., 2016). What they suggest is more support services available to families to increase the ease of access for required health services.

One of the reasons for the difficulty of coordinated services was identified by Cohen, et al. by claiming that the lack of a universal definition of CMC and the absence a specific model for service delivery (Cohen, et al., 2011). They suggest that creating a model of care that consists of uniform definitions for effective communication among “providers who are adequately trained and resourced to serve the needs of the CMC, is essential for enhancing the quality of life and outcomes for these children” (Cohen, et al., 2011). Establishing a consistent classification system for CMC’s for the sake of communication efficiency was the goal of the study conducted by Coller et. al. They went on to classify medical complexity on 4 levels, class 1 being most complex with broad functional impairments that require extensive health care to class 4 being the least complex with physical impairments alone (Coller et. al., 2016). In addition to this classification system they implemented, they also found CC related inconsistencies. Among these inconsistencies, they found that class 1 and class 2 CMC’s had a more difficult time receiving all essential care services than classes 3 and 4 (Coller et. al., 2016). This result indicates that the more complex the case, the more challenging CC efforts are for the patient and family, enforcing the need for a more developed model for continuity of care and support services for CC.

Outside of access to care and the reliance of a model that supports an efficient coordination system, families make a considerable investment of finances and time to support their CMC. One study focused primarily on time investments by the family of the CMC. What they found was that 52% of families spent at least one hour per week on CC and 4% spending 11+ hours per week conducting the same task (Miller et. al., 2015). As for care provided at home, 34% spent at least more than one hour providing care with 8% spending 11+ hours and 14% of families had a moderate or high (6-10 hours and 21+ hours respectively) combined time

burden of CC and providing home care (Miller et. al., 2015). These results differed when finances and education were assessed, lower educated household spent more time on home care and coordination of care and those with inadequate insurance/low-income also had higher rates of home care and personal CC efforts (Miller et. al., 2015). They state that: "...factors associated with healthcare utilization are also associated with time spent by family members providing and arranging health care for their chronically ill children" (Miller et. al., 2015). What Miller et al. recommend to alleviate these issues among CMC families is to screen families for high impact time burdens and connect them to home care and CC services to reduce that time burden and improve the care for the CMC and reduce the strain on the family (Miller et. al., 2015). One study looked to compare the financial burdens among families between subsequent NSCSHCN surveys from 2001 to 2009-2010. What they found was that there was little to no change from 2001 to 2010 in that nearly 50% of families experience high out-of-pocket expenses, financial problem, and employment or caregiving burdens with those factors worsening with more complex cases (Ghandour et. al., 2014). What Ghandour et al. suggest is changing the financing of CMC treatments and that the method in which care is delivered may be the solution with the most potential to ease the financial burden (Ghandour et. al., 2014).

A study by Strickland et al. claimed that insurance and financial barriers are well established within current research and there has been payment reform models emerging benefiting both the payer and the patient, however CC is not yet well established (Strickland et. al., 2015). What Strickland claims shifts our mindset on CC effort away from the specific financial influence, rather focus on the other factors that influence CC that does not currently have reform models in place such as family and school influencers. Shared decision making (SDM) is one assessment that Smalley et. al. examined in CMC care management. SDM is

defined as; “a collaborative, respectful, partnership where both parties—the provider team and the patient, family, friend, etc.—are given the opportunity to share information; the expression of patient preferences and values is encouraged and considered; and both sides share responsibility in deciding the best care option for optimal health outcomes” (Smalley et. al., 2014). Placing an emphasis on promoting SDM is pivotal to efficient CC since the family will at least some part in the coordination of care effort due to its found effect on decreased out-of-pocket costs and lower healthcare utilization rates (Smalley et. al., 2014). What their study found was that two thirds of CMC families were involved in SDM on some level however 30% (mostly vulnerable and minority populations) did not receive adequate SDM opportunities (Smalley et. al., 2014). This relates to CC in that when the family has an open forum to communicate with their provider, the CC effort can be more efficient and barriers can be identified so that support can be provided where it is needed most. One of the venues where the CMC spends a majority of their time is in school, utilizing that as a resource for CC and how family-centered care (FCC) can improve the quality of life for the CMC. Barnard-Brak, Stevens, and Carpenter define FCC as care that follows the following criteria “[providers] spend enough time with patients, listen carefully, be sensitive to family values and customs, provide specific information; and help patients and families feel like partners” (Barnard-Brak, Stevens, and Carpenter, 2017). This relates to CC when we look at the results of the study, what they found was that FCC resulted in a reduced need for CC with school by parents resulting in fewer absences and improved adherence to referrals (Barnard-Brak, Stevens, and Carpenter, 2017). They explain that when the provider exemplifies FCC, parents have a say in when and where the appointments are scheduled and how the medical treatment will affect their behavior and/or performance in school (Barnard-Brak, Stevens, and Carpenter, 2017). As FCC is similar to SDM, it seems that the more the family is

involved in the process of care and coordination of care for the CMC, the more effective the efforts are on the CMC's quality of life as well as the reduced burden and stressors on the family.

The common theme among the literature reviewed is that in order to effectively coordinate care, the family needs to be integrated into the care process with the CMC and efforts need to be made to provide them support to alleviate their time, financial, and stress burdens. The NSCSHCN data contains information related specifically to CC, how that financial/time burden affects them, and what support (if any) is provided for the CC responsibility. It is with this data that we will assess the utilization of health care provided services, the availability of these services, and the effect it has on the family to support the implementation of services universally provided to support the CMC and their family.

### Chapter III: Methods

The focal population of interest for this study is children with high levels of medical complexity. We conducted a secondary data analysis of the National Survey of Children with Special Health Care Needs (NS-CSHCN) from 2009-2010. The NS-CSHCN is a telephonic survey that has been conducted three times, 2001, 2005/2006, 2009/2010 and is lead by the National Center for Health Statistics (NCHS) at the Center for Disease Control and Prevention (CDC) with direction from the Maternal and Child Health Bureau (MCHB) and uses the State and Local Area Integrated Telephone Surveys (SLAITS) approach ("The NS-CSHCN at a glance"). The 2009/2010 survey was conducted to 372,698 children from 196,159 households. Trained interviewers asked parents/guardians a series of questions to identify their children as one with special health care needs. If the parent/guardian answered "yes" they have a child in their household (under the age of 18) that they believe have special health care needs (if more than 1, they were asked to randomly select on child as their subject) during their randomly selected call, they would be taken through the survey by the skilled interviewer taking approximately 33 minutes. If they did not identify any of their children as one with special health care needs, some sociodemographic data was 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 0-17 ("The NS-CSHCN at a glance").

The NS-CSHCN was designed to examine the physical, emotional, and behavioral health of U.S. children with special health care needs ("The NS-CSHCN at a glance"). The survey also inquires about information regarding access to quality health care, CC, access to a medical home, transition services, and the impact on the families of CMC's ("The NS-CSHCN at a glance").

## Measures:

The subsample of children used for this analysis were those that were considered the most complex medical cases who have “a need for medical care, evidenced by a positive response to the medical care question on the National 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” (Kuo et al., 2014) (Table 1). To create this variable we coded the “Medically Complex” as subjects 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 and met 4 or more of the screeners criteria for special health care needs. In addition, to satisfy the definition of medical complexity listed above, we also needed to include a qualifier based on seeing 2 or more specialty doctors within 1 year. To achieve this we created a new variable that restricted those who have seen more than 2 specialists per year when asked how many specialty doctors did the child see within the past 12 months. We then used those respondents who indicated 2 or more specialty doctor visits in a year in combination with the qualifiers listed above to create the variable for medical complexity and isolate our focus to those most medically complex children (figure 1).

In the survey, parents/guardian were asked what type of support they had for CC, with response options that included someone in a doctor’s office, someone in the family or social network, or no CC help at all. Based on the answers to those questions, we created our outcome variable as children were categorized as having CC in the form of 1) clinical support, 2) family/social network support, 3) both clinical and family/social network support, or 4) no support (table 2). In order to isolate any impact of clinical CC, we simplified this outcome for

bivariate and multivariate regression models to be binary: 1) any clinical CC support versus 2) no clinical CC support.

Covariates of interest were variables that indicated CC dynamics (i.e. hours per week spent coordinating care), impact on child (i.e. days of school missed in past month due to medical appointments), impact on family (i.e. need for mental health services for family members of the CMC), and household characteristics (i.e. family income).

#### Statistical Analysis:

All analyses were conducted in STATA v.13.1. Analyses were weighted using the “svy” command to account for complex sampling strategy and to provide more accurate estimates. First, proportions were estimated according to the four-category outcome measure of CC. Chi-square and t-tests statistical tests assessed differences in distribution across CC levels for CC dynamics, impact on child, impact on family, and household variables. Associations between clinical 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 alpha level was  $>0.05$ .



## Chapter IV: Results

Among the children with special health care needs, 6.57% were determined to be the most medically complex. Of those CMC, the majority of parents reported receiving no CC support (66.47%), while others received CC support from clinical CC support (15.17%), both Clinical support and Family/Social Networks (10.56%), and family/social networks only (7.80%).

In terms of CC, fewer than half of those with CMC reported that they usually received as much help as desired arranging or coordinating care (See Table 3). This differed significantly according to level of CC received with those not receiving CC having a lower proportion indicating that they usually received as much help as desired arranging or coordinating care (10.99%), compared to those that received CC from family/social network (30.21%), clinical (30.83%), or both (47.57%)( $p < 0.001$ ). Similarly, those with CMC that were not receiving CC were reported that they could have used extra help arranging or coordinating care at higher levels (50.86%) compared those receiving CC from family/social network only (45.64%), clinical only (40.12%), or both (37.03%)( $p < 0.020$ ). CC that involved both family/social network and clinical support to coordinate the CMC's care had higher ratings of being "very satisfied" with communication between their child's doctor and other health care providers (61.19%) compared to those with clinical only (51.46%), family/social network only (51.89%), or no CC (41.79%) ( $p = 0.004$ ). Conversely, reporting being dissatisfied with communication among the CMC's doctor and other health providers was highest among those not receiving CC. There were not significant differences in hours per week spent by family providing and/or coordinating care among the different levels and type of CC support.

In regression analyses of variables measuring CC dynamics, CMC not receiving clinical CC were more likely indicate that could have used extra help arranging or coordinating care (OR=1.62 95% CI (1.18-2.25)) compared to those receiving clinical CC (see Table 4). Among CMC that indicated that they could have used extra help arranging or coordinating care, CMC that “sometimes” or “never” got as much care as desired arranging or coordinating care were less likely to report receiving clinical CC (OR=0.48 95% CI (0.27-0.86) and OR=0.04 95% CI (0.01-0.11), respectively) compared to CMC that “usually” got as much care as desired arranging or coordinating care. Receiving clinical CC was independently associated with satisfaction with communication between the child’s doctor and other health providers; Parents of CMC that were “very dissatisfied” with communication between the child’s doctor and other health providers were 79% less likely to report receiving clinical CC (AOR 0.21 (0.07-0.66)).

Regarding the impact on the families of those with CMC according to level and type of CC support, those receiving clinical CC support (27.52% for those receiving clinical and family/social network support and 22.29% for those receiving clinical CC only) had lower proportions of reporting a time when family members needed mental health care or counseling related to the child’s medical conditions compared to those receiving CC support from family/social network support only (34.02%) and those not receiving CC support (34.65%) (p=0.025). There was a higher proportion reporting receiving family-centered care, among those receiving CC from both family/social network and clinical support (66.93%), or clinical support only (69.14%) compared to those receiving CC support from family/social networks support only (54.11%) and those not receiving CC support (52.35%)(p=0.001). There were not significant differences across levels/type of CC support in terms of having experienced financial

burden due to their child's health, having unmet needs for family support services, having the need for respite care among family, or having a family member cut back hours/stop working.

Families were less likely to receive clinical CC support that received mental health care due to their child's health issues (OR=0.61 CI=0.44-0.85), had one or more unmet needs for family support services (OR=0.66 CI=0.45-0.97), and did not have family centered care (OR=0.51 CI=0.37-0.72). After controlling for age, income, and other variables related to care coordinating and the impact on the child, receiving family-centered care was negatively associated with receiving clinical CC (AOR=0.63 95%CI (0.42-0.94).

For the variables related to the impact on the CMC, over a third of those CMC's who had no CC support and just under half who had clinical CC support had missed 11 or more days of school ( $p=0.157$ ). Compared to those missing 0-3 school days, as the number of days that the CMC missed increased, the association with receiving clinical CC strengthened; CMC that missed 11 or more day of school were two times as likely to receive clinical CC after controlling for age and other factors (AOR=2.03 95%CI (1.27-3.24)). A higher proportion of families that had no CC support reported experiencing interruptions with the CMC's ability to go on outings, such as to the park, library, zoo, shopping, church, restaurants, or family gatherings, (58.18%) as compared to those who participate in CC with the clinical team, (38.57%)( $p=0.330$ ). When examining need for 14 specific health care services or equipment, nearly half of CMC that were not receiving CC support reported "no unmet needs" which was lower proportionately to those receiving some level of CC support; Similarly nearly a quarter of parents without CC support reported that their CMC had 2 or more unmet needs, which was higher than those with CC support ( $p=0.063$ ). CMC's who had 2 or more unmet needs for services/equipment were 45% less likely to receive clinical CC (OR=0.55 CI=0.36-0.85).

Household characteristics of families with CMC differed across level/type of CC support by income, but not by family structure or adequacy of health insurance. CMC receiving CC support from family/social network only as well as those receiving no CC support had slightly higher ages, on average, compared to those receiving clinical CC only or receiving both clinical and family/social network ( $p < 0.001$ ). The families with no CC support reported higher levels of income (57.41% at 200% or above the federal poverty level) than those who use other CC support services ( $p = 0.026$ ). The families that had family/social network CC support or clinical CC and family/social network support reported higher levels of having experienced financial burdens due to their child's health needs and had lower income (over 50% below 200% federal poverty level). The adequacy of the CMC's insurance and the family structure had no significant differences across the levels/type of CC support. Families at 100%-199% of the FPL were twice as likely to receive clinical CC support (OR=2.11 CI=1.37-3.23). Also, those families who have inadequate insurance (OR=0.77 CI=0.55-1.07) or are uninsured (OR=0.84 CI=0.27-2.57) were less likely to receive clinical CC support when compared to those families with adequate health insurance. When examining the age of the CMC, for every increase in age in years, they are 4% less likely to have clinical CC support (OR=0.96 CI=0.93-0.99). CMC in the lowest household income bracket were more likely to receive clinical CC, even after controlling for other variables; Those at 0-99% FPL were 1.94 times (95% CI 1.18-3.20) more likely to be receiving clinical CC compared to those at 400% FPL or greater.

## Chapter V: Discussion

Type of CC among the most medically complex cases was most markedly different for parent/guardian's reported need for CC help, getting the needed CC support, having family-centered care, and satisfaction with the communication between the CMC's doctors. In multivariate models, parent/guardians that were dissatisfied with communication among the child's doctor and other health care providers, and those receiving family-centered care were less likely to be receiving clinical CC. Those more likely to report currently receiving clinical CC were below the federal poverty level, and CMC that missed seven or more school days. In terms of age, clinical CC support is currently being used by younger CMC. These factors may assist clinical teams in identifying ways in which they can improve their CC efforts to impact the family positively.

Those families who work with their clinical team to CC have the highest satisfaction rating of the level of communication between the doctor of the CMC and other health professionals compared to those families with no CC support. Thus, rationale for expanding and strengthening clinical CC would be an improved experience from the patient/family perspective as a result of clinical CC.

Though not significant in our final model, families who either leaned on the clinical team for CC services entirely or worked collaboratively with them had significantly lower needs for mental health care services or counseling due to the CMC's medical conditions, as compared to those who either take the CC burden upon themselves or have no CC support at all. This may indicate that those families that don't utilize the clinical teams 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.

Interestingly, this study found that those CMC receiving clinical CC miss more school days than those not receiving clinical CC. Efforts in clinics that coordinate care to reduce absenteeism in schools should be considered. However, though not independently associated with clinical 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 to those who have no CC support.

In terms of CC dynamics between families and clinics, the families that received clinical CC support were more likely to not need extra help coordinating care, spend less time coordinating care, get the help they needed coordinating care, and report more satisfaction with the communication between their doctors. This illustrates the burden that can be removed from families of CMC when CC is utilized.

It is also 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 CC support level they chose; clinical, family/social network, both, or neither, with more than half of these CMC families having a family member cut back or stop working due to the needs of their CMC. Those in the lowest income bracket (below the federal poverty level), were more likely to receive clinical CC. More research is needed to determine what reasons may impact the financial reasons for receiving clinical CC. Other suggestions for future research should investigate the CMC family and clinical team CC dynamic to identify the ideal contributions from either group

in an attempt to identify a framework or model that can be utilized for CC efforts across the CMC's continuum of care.

Our data analysis as limitations and strengths that should be noted. Our analysis uses the latest available NS-CSHCN dataset from 2009/2010 and we acknowledge the CC efforts nationwide likely have grown and changed with a changing 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 does not allow us to consider the duration of CC received, or timelines including trajectories for impact on the child, family, or CC. 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.

In addition to improving care, there is a need to reduce the number of CMC's that do not have CC support to improve their quality of life, lessen the burden on families. While research on the impact of CC on health outcomes grows, 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.

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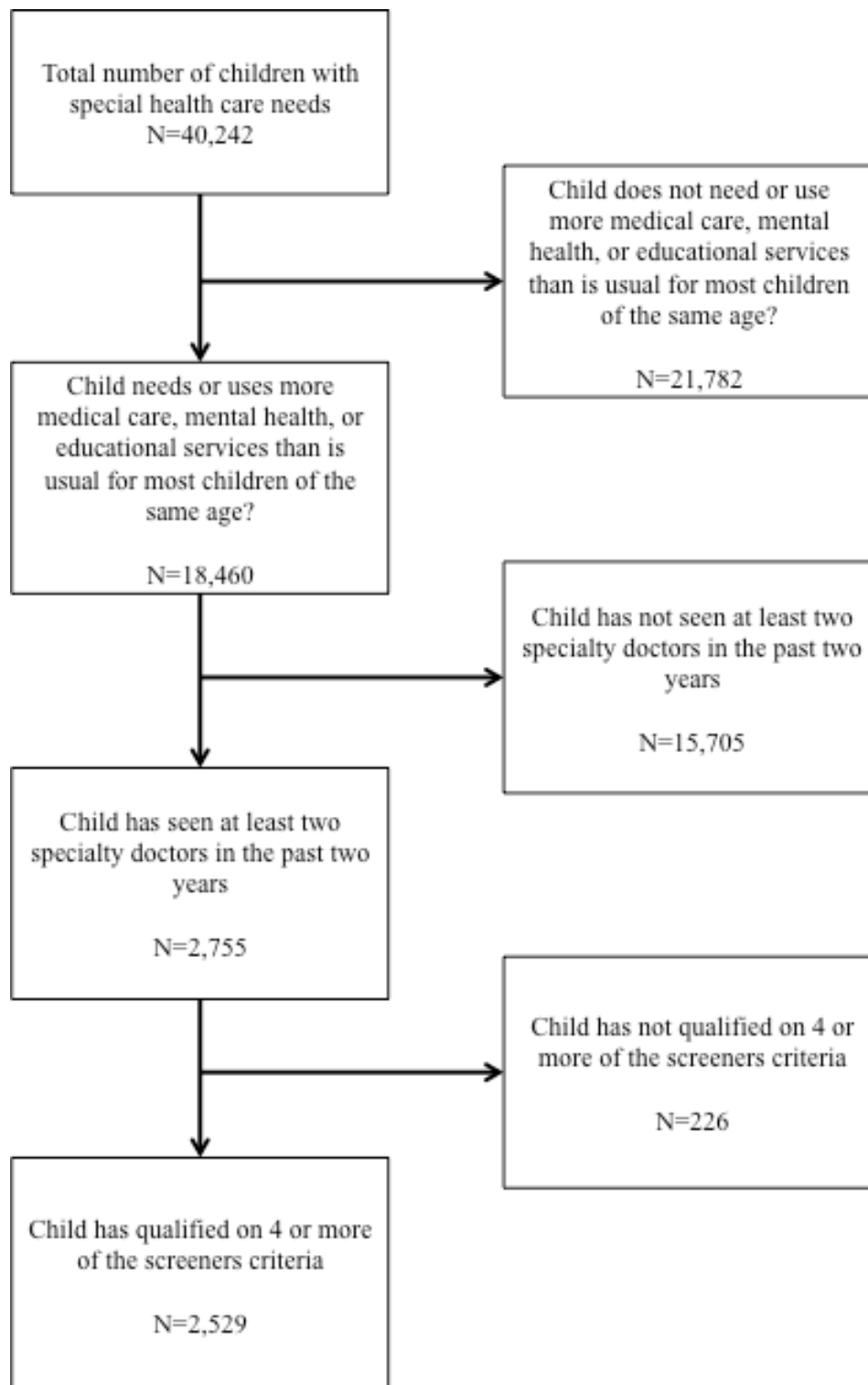
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## Appendix A: Medically Complex Pediatrics Population Isolation

*Figure 1. Pediatric Medical Complexity Classification*



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

Medical Complexity Classification	Frequency	Percent	Cumulative
Not Medically Complex	35,977	93.43	93.43
Medically Complex	2,529	6.57	100
Total	38,506	100	

*Table 2. Care Coordination Classification among all participants, NS-CSHCN 2009-2010*

Care Coordination Classification	Frequency	Percent	Cumulative
Clinical CC help	4,517	11.39	11.39
Family/ Social Network CC help	2,111	5.32	16.71
No CC help	31,380	79.09	95.8
Clinical and Family CC help	1,668	4.2	100
Total	39,677	100	

## Appendix B: Data tables

*Table 3. Comparison of CC characteristics, impact on families and individuals, among medically complex children according to level of CC support in the United States, NS-CSHCN 2009-2010*

	CC support from both Clinical & Family/Social Network  n=258  n (weighted %)	Clinical CC Support  n=386  n (weighted %)	Family/Social Network CC Support  n=214  n (weighted %)	No CC Support  n=1,668  n (weighted %)	Chi square P-value
<b>CC</b>					
How many hours per week do you spend providing and/or coordinating child's care?					0.524
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%)	
Have you felt that you could have used extra help arranging or coordinating care? (Yes)	91 (37.03%)	145 (40.12%)	82 (45.64%)	785 (50.86%)	0.020
How often did you get as much help as you wanted with arranging or coordinating care?					<0.001
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?					0.004
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%)	
<b>Impact on family</b>					
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%)	0.863

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%)	0.025
One or more unmet needs for family support services? (Yes)	53 (21.73%)	91 (23.12%)	59 (34.19%)	485 (30.47%)	0.093
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%)	0.242
Family member cut back hours or stopped working or both (Yes)	165 (62.02%)	245 (70.55%)	128 (63.84%)	1106 (67.47%)	0.528
Child has family centered care (Yes)	179 (66.93%)	256 (69.14%)	135 (54.11%)	915 (52.35%)	0.001
<b>Impact on child</b>					
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%)	0.330
Missed school days by child					0.157
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					0.063
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%)	
<b>Household characteristics</b>					
Family Structure					0.567
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?					0.026

0%-99% FPL	71 (22.96%)	68 (19.80%)	41 (31.61%)	267 (22.54%)	
100%-199% FPL	65 (31.68%)	91 (27.38%)	45 (24.32%)	343 (20.05%)	
200%-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					0.563
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)	<0.001

*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*

Variables	OR (95% CI)	AOR (95% CI)
<b>CC dynamics</b>		
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)	-
Have you felt that you could have used extra help arranging or coordinating care? (ref=Yes)	1.62 (1.18-2.25)	-
How often did you get as much help as you wanted with arranging or coordinating care? (ref=Usually)	-	-
Never	0.04 (.014-0.11)	-
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 (0.091-1.37)	0.21 (0.07-0.66)
<b>Impact on family</b>		
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)
<b>Impact on child</b>		
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)	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)	-
<b>Household characteristics</b>		
Family Structure (Ref=Two 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%-99% FPL	1.36 (0.86-2.15)	1.94 (1.18-3.20)
100%-199% FPL	2.11 (1.37-3.23)	1.44 (0.88-2.37)
200%-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)