

Comparison of Experiences with Care Coordination for Children with Special Healthcare Needs (CSHCN) in Illinois

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Received date: Jun 29, 2014, Accepted date: Sep 03, 2014, Published date: Sep 8, 2014

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Abstract

Background: Care coordination (CC), a central responsibility of the medical home, significantly impacts health outcomes of CSHCN. Most studies to date have focused on either provider provision of CC or patient experience with CC.

Objective: We compared how providers for, and parents of, CSHCN experience subspecialty access, communication amongst physicians, and barriers to CC, and examined associated characteristics.

Methods: Two datasets were analyzed: a survey of Illinois primary care pediatricians and the Illinois sample within the National Survey of CSHCN.

Results: 376 physicians and 793 parents were analyzed. Providers and parents were highly satisfied with obtaining subspecialty referrals and with communication amongst doctors (76-92%), however 41% of parents and 38% of physicians identified CC barriers. Doctors more frequently reported CC barriers if employed by community hospitals (OR: 2.4 [95%CI: 1.2-4.6]), without academic appointments (OR: 1.6[1-2.4]), did not participate in a medical home project (OR: 4.5[1.7-12.1]), or cared for an overrepresentation of Hispanic patients (OR: 2.1[1.2-3.8]). Parents were 60% less likely to report poor doctor communication if they had a primary caregiver and 60% less likely to report difficulty with referrals if they had a usual place for care.

Conclusions: Patients and physicians are overall highly satisfied with access to and communication with subspecialists, however over a third of parents and physicians of CSHCN, particularly non-academic community providers, report CC barriers.

Keywords: Children with special healthcare needs; Care coordination; Medical home

Abbreviations

Children with Special Healthcare Needs (CSHCN); Primary Care Physicians (PCPs); National Survey of Children with Special Health Care Needs (NS- CSHCN); Emergency Room (ER); Division of Specialized Care for Children (DSCC); Illinois Medical Home Project (IMHP)

Introduction

Children with special healthcare needs (CSHCN), those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally [1], represent a large and growing population of pediatric youth [2-3] for whom care coordination can significantly impact health outcomes. Care coordination is a process that links CSHCN and their families to services and resources in a coordinated effort to maximize the potential of the children and provide them with optimal health care [4]. Care coordination is a central responsibility of the medical home [5] and there is growing evidence that its

implementation can improve efficiency of healthcare delivery through avoidance of emergency department (ER) and office visits [6-7] and decreased duration of hospitalizations [8]. However, there are many barriers to providing and receiving coordinated care for CSHCN, time and financial constraints referenced commonly [9]. Patient experiences with and understanding of care coordination have been less well completely described than providers'. A qualitative study in 2005 by MacKean, Thurston, & Scott described, via focus group and semi-structured interviews, professional and family perspectives on family-centered care [10]. While providers emphasized training families in assuming more responsibility and advocacy skills, families described a desire to work collaboratively. Therefore, we hypothesized that providers for and parents of CSHCN experienced and conceptualized care coordination differently. Discourse in the current literature about care coordination is often focused on providers [9,11], but we hypothesized that providers and parents representing the same population would respond differently when asked about accessing subspecialists, communication between doctors and care coordination overall. In this study, we sought to explore provider and patient experiences with core medical home components including referrals to subspecialists, communication amongst doctors, and care coordination.

This study utilized two data sources, a 2008 survey of Illinois pediatricians and the Illinois subset within the 2009-2010 National Survey of Children with Special Health Care Needs, to describe and compare how providers for, and parents of, CSHCN experience access to subspecialty care, communication amongst physicians, and barriers to care coordination. We also explored patient and provider characteristics and their relationships with care coordination experiences.

Methods

Sample

Two datasets were analyzed separately: a 2008 survey of Illinois primary care pediatricians and the 2009-2010 National Survey of Children with Special Health Care Needs. The 2008 survey of Illinois Primary Care Pediatricians, the provider survey, was sent to all primary care pediatricians (PCPs) that were members of the Illinois Chapter of the American Academy of Pediatrics. It was designed to assess the PCPs' experiences and satisfaction in providing care to CSHCN [9]. The National Survey of Children with special Health Care Needs (NS-CSHCN), the parent survey, is a national telephone survey conducted via random digit dialing of a sample of US households. Additional details of the NS-CSHCN can be found elsewhere [12]. This analysis was limited to the subset of Illinois respondents (N=793).

Dependent variables

The dependent variables of interest were three similar items compared between the provider and parent surveys. The 'difficulty with subspecialty referral' theme was captured by "How satisfied are you with your general ability to obtain subspecialty consultation about a child's health condition when needed" from the provider survey and "Was getting referrals a big problem, a small problem, or not a problem?" from the parent survey. To analyze respondents' level of 'dissatisfaction with communication amongst doctors', responses from the questions: "How satisfied are you generally with the communication you receive from subspecialists?" (provider survey) and "Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among [Child's name]'s doctors and other health care providers?" (parent survey) were compared. Experiencing care coordination barriers were defined as responding affirmatively to "Care coordination is a possible barrier preventing pediatric providers from providing effective primary care to CSHCN" on the provider survey, and "How often did you get as much help as you wanted with arranging or coordinating [Child's Name]'s care" on the parent survey.

Demographics

Provider survey: Respondents answered questions about their gender, residency training, and estimated patient population

characteristics. For the univariate analysis, individual providers were characterized as being from practices serving an over representation of minority patients if at least 1/3 of patients in their practice were from that racial/ethnic group, indicating at least twice the percentage in the general population. Similarly, providers were considered to care for a majority publicly or privately insured population if they reported greater than 50% of their population with public or private insurance. Providers were asked if they were a Division of Specialized Care for Children (DSCC) (State of Illinois Title V CSHCN program) certified medical home provider or if their practice participated in the Illinois Medical Home Project (IMHP), a program implemented between 2004-2009 which provided training and technical assistance to practices and public health clinics implementing the medical home model [13].

Parent survey: Parents provided information about their CSHCN as well as family and healthcare characteristics. Head of household education was dichotomized into more than high school education vs. less. Parents responded with the number of ER visits and missed school days for illness in the last 12 months. In the NS-CSHCN dataset, all respondents who reported 14 or more ER visits were grouped at 14 visits and frequent missed school days grouped as 11-15, 16-20, and 21+ to protect respondent anonymity. For the sake of this analysis, ER visits was dichotomized into those who had none or one versus at least two ER visits. Missed school days were dichotomized into three or fewer missed school days versus more (with 3 days being the median value). Caregivers were asked if they had a usual place for care when their child is sick and if they have a person they think of as their child's personal doctor or nurse, which was interpreted as "has PCP."

Statistical analysis

Chi-square statistics were used to compare binary survey responses. Univariate analyses were conducted using logistic regression. Statistical analyses were completed with Stata 11.2 (Stata Corp, College Station, TX).

Results

Responses from 376 physicians and 793 parents from Illinois were eligible for analysis. Twenty-six percent of physicians completed the survey. Respondents were 58% female and on average had 18 years of practice experience. 59% were trained at a university-centered residency and 51% did not have current academic appointments (Table 1). There were a wide range of patient group composition, with 15% of practices serving an overrepresentation of non-Hispanic black patients and 15% of practices serving an overrepresentation of Hispanic patients. 64% served majority privately insured and 23% served majority publically insured patients.

Physician Characteristics	N	%	Mean (Range)
Years in practice	370		17.9 (1-52)
Female Sex	376	58	-
Type of Residency	374		

University		59	-
Community and Other		41	
Practice Characteristics			
Participation in Illinois Medical Home Project	362	11	
Division of Specialized Care for Children (DSCC) certified	372	14	
Type of Practice	375		-
Hospital-based		14	
Office-based		75	
Other		11	
No academic appointment	375	51	
Population Characteristics			
Percent CSHCNa			9.1 (0-100)
Overrepresented NHBb	358	15	-
Overrepresented Hispanicb	358	15	
Majority private insurancec	354	64	
Majority public insurancec	355	23	

Table 1: Characteristics of Illinois Provider and Practices included in Barriers to Care Questionnaire((a) Physicians respondents estimated % of CSHCN practice; (b) overrepresented Non-Hispanic Black (NHB) or Hispanic defined as >1/3 of practice; (c) Majority private/public insurance defined as estimated >50% of practice)

Parent respondents, described in Table 2, were 78% mothers, 16% fathers and 6% other relative or guardian. The children with special healthcare needs were 38% female and had mean (range) age of 10.1 (0-17) years. 63% of the children were white, 16% non-Hispanic black, 15% Hispanic, and 6% other. The majority of households had an adult with more than high school education (84%); 5% had less than high school education. 59% of CSHCN were insured by private insurance, 30% by public. On average, CSHCN had 1 ER visit a year (range 0-14) and 5 missed school days for illness (range 0-21).

Characteristic	N	%	Mean (Range)
Age (years)	793		10.1 (0-17)
Female sex	793	38	-
Race/ethnicity of child	785		
White		63	
Non-Hispanic Black (NHB)	-	16	-
Hispanic		15	
Other		6	
Respondent	789		-
Mother		78	-
Father		16	
Other		6	

Highest household education	779		
Less than high school		5	
High school		12	
More than high school		84	-
Insurance	792		
Private only	-	59	
Public only		30	
Both public and private		6	-
Other comprehensive insurance		3	
Uninsured		2	
Family Characteristics			
Primary language not English			
Cash Assistance Program	288	10	-
SSI supported	778	8	
Healthcare Characteristics			
Has primary care provider	793	93	-
Has medical home	791	92	

ER visits in last year	791		0.9 (0-14)
Average missed school days	666	-	5.1 (0-21)

Providers for, and parents of, CSHCN were overall similarly satisfied with their ability to obtain a subspecialty referral (84 and 76%, respectively) Table 3.80% of physicians and 92% of parents were satisfied with communication amongst doctors and subspecialists, Table 4.41% of parents and 38% of physicians experienced care coordination barriers, Table 5.

Table 2: Characteristics of Illinois Participants in National Survey-Children with Special Healthcare Needs

	Physicians		Parents	
Difficulty with Subspecialty Referral	16%		24%	
Predictors	OR*	p	OR*	p
Physician Characteristics				
Gender	0.75	NS		
Years in Practice	0.99	NS	-	
University based Residency	1.12	NS		
Practice Characteristics				
Hospital-based practice	1.09	NS	-	
Community Hospital	2.36a	0.04		
No academic appointment	0.62	0.08		
DSCC Certified Medical Home	1.17	NS		
IMHP Participant	0.76	NS		
Patient Population Characteristics				
Percent CSHCN (OR per 10% CSHCN)	1.22a	0.02	-	
Overrepresented NHBC	1.16	NS		
Overrepresented Hispanic	2.08a	0.03		
Majority private insured	0.55a	0.03		
Majority public insured	1.65	NS		
CSHCN Characteristics				
Age of child			0.99	NS
Gender of child			1.23	NS
Race/Ethnicity	-			NS
NHW			1	
NHB			1.45	NS
Hispanic			1.94	0.07
Other			1	NS
Family Characteristics				
Household education beyond high school			0.62	NS
Primary language in home not English			1.58	NS
Cash Assistance Program			1.45	NS
SSI supported			1.97	NS
Healthcare Characteristics	-			

Has primary care provider		0.6	NS
Has medical home		0.40a	<0.05
Type of insurance			
Private insurance		1	NS
Public Insurance/No insurance	-	1.85b	0.06
Combined public/private insurance		1.45	NS
Other insurance		1.64	NS
>1 ER visits in last year		1.1	NS
>3 missed school days in last year		0.68	NS

Table 3: Predictors of Difficulty with Subspecialty Referral ((a) Statistically significant, p<0.05; (b) Trend toward significance, p<0.10; (c) Physician respondents estimated % of each race/ethnicity in practice; overrepresented Non-Hispanic Black (NHB) or Hispanic defined as >1/3 of practice. (d) Majority private/public insurance defined as estimated >50% of practice; Parents reported race/ethnicity of child. DSCC=Division of Specialized Care for Children; IMHP= Illinois Medical Home Project)

	Physicians		Parents	
Dissatisfaction with communication among doctors	20%		8%	
Predictors	OR*	p	OR*	P
Physician Characteristics				
Gender	0.76	NS	-	
Years in Practice	0.98	NS		
University based Residency	1.13	NS		
Practice Characteristics				
Hospital-based practice	1.53	NS	-	
Community Hospital	2.87a	0.01		
No academic appointment	0.88	NS		
DSCC Certified Medical Home	0.59	NS		
IMHP Participant	0.88	NS		
Patient Population Characteristics				
Percent CSHCN (OR per 10% CSHCN)	1	NS	-	
Overrepresented NHBc	1.36	NS		
Overrepresented Hispanicc	1.05	NS		
Majority private insureded	0.7	NS		
Majority public insureded	1.5	NS		
CSHCN Characteristics				
Age of child			1	NS
Gender of child	-		0.97	NS

Race/Ethnicityb			NS
NHW		1	
NHB		0.69	NS
Hispanic		1	NS
Other	-	1.16	NS
Family Characteristics			
Household education beyond high school	-	0.93	NS
Primary language in home not English		0.82	NS
Cash assistance program		1.62	NS
SSI supported		1.2	NS
Healthcare Characteristics			
Has primary care provider		0.40a	0.03
Has usual place for care		0.62	NS
Type of insurance			
Private insurance	-	1	NS
Public Insurance/No insurance		1.46	NS
Combined public/private insurance		1.1	NS
Other insurance		2.15	NS
>1 ER visits in last year		2.17a	<0.01

>3 missed school days in last year		2.16a	0.02
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Table 4: Predictors of Dissatisfaction with communication among doctors ((a)Statistically significant, p<0.05; (b)Trend toward significance, p<0.10; (c)Physician respondents estimated % of each race/ethnicity in practice; overrepresented NHB or Hispanic defined as >1/3 of practice. (D)Majority private/public insurance defined as estimated >50% of practice; Parents reported race/ethnicity of child. DSCC=Division of Specialized Care for Children; IMHP= Illinois Medical Home Project)

	Physicians		Parents	
Experienced Care Coordination Barriers	38%		41%	
Predictors	OR*	p	OR*	P
Physician Characteristics				
Gender	0.98	NS	-	
Years in Practice	1.01	NS		
University based Residency	0.76	NS		
Practice Characteristics				
Hospital-based practice	0.38a	<0.01	-	
Community Hospital	2.37a	<0.01		
No Academic appointment	1.6a	0.04		
DSCC Certified Medical Home	0.52b	0.06		
Not a IMHP Participant	4.5a	<0.01		
Patient Population Characteristics				
Percent CSHCN (OR per 10% CSHCN)	1	NS	-	
Overrepresented NHBc	1.08	NS		
Overrepresented Hispanicc	2.11a	0.01		
Majority private insured	0.69	NS		
Majority public insured	1.1	NS		
CSHCN Characteristics				
Age of child	-		1.03	NS
Gender of child			0.52	NS
Race/Ethnicityb			NS	
NHW			1	
NHB			0.54	NS
Hispanic			0.27b	0.06

Other		0.54	NS
Family Characteristics			
Household education beyond high school	-	1.13	NS
Primary language in home not English		0.61	NS
Cash assistance program		0.45	NS
SSI supported		1.5	NS
Healthcare Characteristics			
Has primary care provider	-	0.78	NS
Has usual place for care		0.68	NS
Type of insurance			
Private insurance	-	1	NS
Public Insurance/No insurance		0.86	NS
Combined public/private insurance		0.2	NS
Other insurance		0.73	NS
>1 ER visits in last year		0.84	NS
>3 missed school days in last year		1.93	NS

Table 5: Predictors of Barriers to Care Coordination ((a) Statistically significant, p<0.05; (b)Trend toward significance, p<0.10; (c) Physician respondents estimated % of each race/ethnicity in practice; overrepresented NHB or Hispanic defined as >1/3 of practice. (d) Majority private/public insurance defined as estimated >50% of practice; Parents reported race/ethnicity of child. DSCC=Division of Specialized Care for Children; IMHP= Illinois Medical Home Project

Doctors were more likely to report that care coordination is a barrier if they worked at community hospitals (OR: 2.4 [95%CI: 1.2-4.6]), did not have academic appointments (OR: 1.6 [95%CI 1-2.4]), did not participate in a medical home project (OR: 4.5 [95%1.7-12.1]) or cared for an overrepresentation of Hispanic patients, defined as greater than 1/3 of their total patient population (OR: 2.1 [95%CI 1.2-3.8]). Providers from community hospitals were nearly three times more likely to report dissatisfaction with doctor communication (p=0.01), and 2.4 times as likely to report difficulty with subspecialty referral (p=0.04).

Parents whose children had more ER visits and missed school days were twice as likely to report dissatisfaction with doctor communication (p<0.01 and 0.02, respectively). Those caregivers who identified PCP (N=739) were half as likely to be dissatisfied with doctor communication (OR=0.40, p=0.03). Those with a usual place for care were less than half as likely to report difficulty obtaining a subspecialty referral (OR=0.4, p<0.05).

Discussion

To our knowledge, physician and parent experiences with care coordination have not been directly compared in the literature. Our study of two representative populations within the state of Illinois over a similar time period clarifies experiences with care coordination and factors that impede improved care. Physicians and parents of CSHCN report a high level of satisfaction with access to subspecialists and communication between doctors, yet more than a third of parents and physicians report barriers to care coordination. Therefore, other components of care coordination beyond access and interaction with subspecialists may explain this discrepancy. In these surveys, and many like it, "care coordination" is not defined explicitly, and physicians and families may conceptualize care coordination differently. For example, patients may desire improved care coordination efforts between PCPs and services outside of the medical profession, such as with educational and therapy centers. In a survey of parents of children in a physical disabilities clinic, 50% described that health care providers never communicated with schools and only 22% had been informed about community programs including respite care [14]. In a 2000 survey by Gupta, O'Connor, & Quezada-Gomez (2004) to members of the AAP, 71% of physicians reported dedicated care coordination in their practice, yet only 24% reported always contacting the school and 41% discussed family needs for financial services, respite care, equipment, or transportation [15]. As we continue to promote care coordination activities as a central component of the medical home, meeting the distinct objectives of families and providers will be indelibly linked to system-level improvement. Additionally, these surveys were completed before the enactment of the Affordable Care Act. The increased autonomy of families to choose healthcare plans, and therefore variable coverage for therapy and subspecialty services, has the potential to increase the complexity of families' care coordination needs.

Since these surveys' distributions, the definition and components of care coordination have been more explicitly defined. In a framework developed with input from multidisciplinary experts in a 2009 publication by Antonelli, et al., specific functions of care coordination were outlined: "to promote communication with families and among professional partners, and define minimal intervals between communications; arrange for and coordinate referrals; support and facilitate all care transitions from practice to practice, etc." This report also included recommendations for assessing outcomes of coordinated care [16]. Though incredibly important to define, our study confirms that providers are not equally positioned to provide such services. Overall, providers and parents in these surveys were highly satisfied with their ability to access subspecialists and with the communication amongst doctors. Other investigators have described increased satisfaction by pediatric PCPs when the specialist provided written and telephone feedback [11], and it is optimistic that this subset of PCPs in the state of Illinois were overall satisfied. However, those located in practices associated with community hospitals were nearly three times more likely to describe dissatisfaction, and therefore communication must be improved with providers located outside of academic and tertiary care settings.

We also acknowledge that our study focused on the primary care perspective. Specialists must be sufficiently informed to care for patients referred to them, however the initial communication only occurs an estimated 50% of the time [17], and parents are variably comfortable with filling the communication gap between doctors [18].

It is well established that CSHCN are disproportionately poor and disadvantaged [19], and therefore may have even more difficulty accessing coordinated care. In our analysis, however, insurance status, ethnicity, nor other markers of economic status (household education, cash assistance participation) emerged as significantly predicting dissatisfaction with subspecialty access and communication amongst neither physicians nor poor experience with care coordination. However, parents who reported greater frequency of illnesses in their child via more emergency room visits or missed school days were twice as likely to report dissatisfaction with communication between physicians. Perhaps improved doctor-to-doctor communication (or patient perception thereof) may minimize ER visits and missed school days for illness by establishing improved care plans and parental self-efficacy for CSHCN, though the cross-sectional nature of this study did not allow for such exploration.

There are several important limiting factors of this study. First, although each study targeted a representative sample of parents and providers within the state of Illinois (the NS-CSHCN is a nationally representative sample and ICAAP membership is estimated to be 80% of the population of Illinois providers), the providers and parents were not necessarily tied to the same patient population and this study is limited by representing a system of healthcare from one state in the US. Second, only 26% of ICAAP members responded to the survey. Although low, this response rate for physician groups is consistent with other multi-paged mailed surveys without financial incentive [20].

Third, the compared survey items were not identically worded, however the authors feel they essentially captured a similar construct indicating that care coordination challenges hindered receipt of healthcare services.

Conclusion

Illinois providers for and parents of CSHCN report high levels of satisfaction with access to subspecialists and communication amongst doctors, however more than a third of both groups report care coordination barriers. Care coordination is a complex concept which encompasses cooperation with non-health organizations such as schools and other service providers in the community. Future initiatives should focus on access and communication barriers experienced by non-academic community physicians and on those taking care of a greater proportion of underserved populations in order to improve overall care coordination with, and therefore overall health of, the vulnerable population of CSHCN.

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