Shared Decision-Making and Health Care Expenditures Among Children With Special Health Care Needs

AUTHORS: Alexander G. Fiks, MD, MSCE,[a,b,c,d,e] Stephanie Mayne, MHS,[a,b,c,d] A. Russell Localio, PhD,[f] Evaline A. Alessandrini, MD, MSCE,[g] and James P. Guevara, MD, MPH[a,c,d,e]

[a]*The Pediatric Research Consortium (PeRC),* [b]*Center for Biomedical Informatics (CBMI),* [c]*Center for Pediatric Clinical Effectiveness, and* [d]*PolicyLab, The Children's Hospital of Philadelphia, Philadelphia, Pennsylvania;* [e]*Department of Pediatrics, and* [f]*Department of Biostatistics and Epidemiology, University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania; and* [g]*James M. Anderson Center for Health Systems Excellence, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio*

KEY WORDS
children with special health care needs, communication, decision-making, health care expenditures

ABBREVIATIONS
AHRQ—Agency for Healthcare Research and Quality
CI—confidence interval
CSHCN—children with special health care needs
ED—emergency department
IOM—Institute of Medicine
IRB—institutional review board
MEPS—Medical Expenditure Panel Survey
NHIS—National Health Interview Survey
SDM—shared decision-making

The content is solely the responsibility of the authors and does not necessarily represent the official views of the Eunice Kennedy Shriver National Institute of Child Health & Human Development or the National Institutes of Health.

www.pediatrics.org/cgi/doi/10.1542/peds.2011-1352

doi:10.1542/peds.2011-1352

Accepted for publication Sep 7, 2011

Address correspondence to Alexander G. Fiks, MD, The Pediatric Generalist Research Group, The Children's Hospital of Philadelphia, 3535 Market Suite, Room 1546, Philadelphia, PA 19104. E-mail: fiks@email.chop.edu

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

FINANCIAL DISCLOSURE: *The authors have indicated they have no financial relationships relevant to this article to disclose.*

Funded by the National Institutes of Health (NIH).

WHAT'S KNOWN ON THIS SUBJECT: Children with special health care needs (CSHCN) account for more than one-third of pediatric health care costs. Little is known regarding the impact of shared decision-making (SDM) over time on child health care expenditures and utilization.

WHAT THIS STUDY ADDS: In a national sample, we found that increasing SDM was associated with decreased health care costs and utilization for CSHCN. Results support prospective studies to determine if pediatric interventions to foster SDM reduce the financial burden of caring for CSHCN.

abstract

BACKGROUND AND OBJECTIVES: To understand the association between shared decision-making (SDM) and health care expenditures and use among children with special health care needs (CSHCN).

METHODS: We identified CSHCN <18 years in the 2002–2006 Medical Expenditure Panel Survey by using the CSHCN Screener. Outcomes included health care expenditures (total, out-of-pocket, office-based, inpatient, emergency department [ED], and prescription) and utilization (hospitalization, ED and office visit, and prescription rates). The main exposure was the pattern of SDM over the 2 study years (increasing, decreasing, or unchanged high or low). We assessed the impact of these patterns on the change in expenditures and utilization over the 2 study years.

RESULTS: Among 2858 subjects representing 12 million CSHCN, 15.9% had increasing, 15.2% decreasing, 51.9% unchanged high, and 17.0% unchanged low SDM. At baseline, mean per child total expenditures were $2131. Over the 2 study years, increasing SDM was associated with a decrease of $339 (95% confidence interval: $21, $660) in total health care costs. Rates of hospitalization and ED visits declined by 4.0 (0.1, 7.9) and 11.3 (4.3, 18.3) per 100 CSHCN, and office visits by 1.2 (0.3, 2.0) per child with increasing SDM. Relative to decreasing SDM, increasing SDM was associated with significantly lower total and out-of-pocket costs, and fewer office visits.

CONCLUSIONS: We found that increasing SDM was associated with decreased utilization and expenditures for CSHCN. Prospective study is warranted to confirm if fostering SDM reduces the costs of caring for CSHCN for the health system and families. *Pediatrics* 2012;129:99–107

In shared decision-making (SDM), families and clinicians both participate in decisions, exchange information, express preferences, and negotiate the treatment plan.[1] Given benefits of SDM in increasing patients' knowledge, decreasing uncertainty, and limiting the overuse of treatments that patients do not value,[2] the Institute of Medicine (IOM) recently encouraged research assessing the comparative effectiveness of SDM[3] and the 2010 Patient Protection and Affordable Care Act supports the implementation of SDM in clinical settings.[4] In pediatrics, partnership between families and clinicians is one of the Maternal and Child Health Bureau's 6 core measures of the care of children with special health care needs (CSHCN)[5] and a primary attribute of the medical home.[6,7] Despite this emphasis, little is known regarding the impact of SDM on children's health care costs and utilization.

CSHCN, those who have or are at increased risk of a chronic physical, developmental, behavioral, or emotional condition and require health and related services beyond those required by children generally,[8] are an ideal population to study the impact of SDM on health care costs and utilization. CSHCN have health care expenses that are 3 times higher than other children.[9] Although they represent approximately 15% of the population, CSHCN account for 33.6% or more of total health care costs attributable to children.[9–11] CSHCN also have 4 times the number of hospitalizations, twice as many physician visits, 1.5 times as many emergency department (ED) visits, and receive 5 times the number of prescriptions.[9] Reflecting the impact of higher health care utilization and costs, approximately 40% of families of CSHCN experience burdensome out-of-pocket expenses even when they are eligible for safety net programs.[12,13]

Prior literature has described health care costs and utilization for CSHCN, but has not examined the impact of SDM on these outcomes. We conducted a longitudinal analysis of a nationally representative dataset to address this knowledge gap. We hypothesized that both increases in SDM and higher absolute levels of SDM over time would lead to decreased costs and utilization of health services.

METHODS

Study Design and Data Source

We conducted a longitudinal analysis of the Medical Expenditure Panel Survey (MEPS), administered annually by the Agency for Healthcare Research and Quality (AHRQ) and previously used to study expenditures for CSHCN.[9,11] All children <18 years old were followed for 2 years. Between 12 810 and 14 828 households were sampled annually from the US civilian, noninstitutionalized population drawn from the previous year's National Health Interview Survey (NHIS).[14] The person from each household who was most knowledgeable about the health of its members provided information on health status, health insurance, and health care utilization. Household interviews were supplemented by surveys from medical providers, health insurers, pharmacies, and employers who provided additional health expenditure and utilization data.

Study Sample

The study sample included all children <18 years of age in MEPS panels 7 to 10 (2002–2006). From this sample, CSHCN were identified using the validated CSHCN Screener that identifies children based on functional limitations or health care needs.[15,16] Children were excluded if they had no usual source of care or their household did not respond to any of the items used to create the SDM measure. MEPS response rates for completion of all survey rounds for the years considered ranged from 58.3% to 64.7%.[14] We were able to generalize results to the general population of CSHCN in the United States by accounting for the stratification, clustering, and unequal probabilities of selection and response in the complex survey design.

Outcome Measures

We examined total health care expenditures as well as multiple components of cost. Total health care expenditures included direct payments to health care providers for outpatient visits, home health care, prescriptions, dental visits, hospital stays, ED visits, and other medical equipment and expenses.[11,14] We separately considered out-of-pocket (copayments and payments not reimbursed by insurance),[17] office-based, inpatient, ED, and prescription costs. To avoid bias from extreme outliers and violations of the assumptions of normality of our statistical models,[9] we calculated all expenditure results with the top 2.5% of values trimmed to the 97.5 percentile. As a sensitivity analysis that also minimized bias from outliers, we assessed the cost percentile rank for each subject for each year for these outcomes.

We also assessed the impact of SDM on health care utilization, including the rates of hospitalizations and ED visits per 100 children per year, as well as office visits and prescriptions per child per year.

Independent Variables

As we have previously reported in detail,[18] we determined families' participation in SDM using a latent class analysis of responses to 7 separate MEPS items that address the 4 components of SDM in the most widely accepted definition (Table 1).[1] Latent class models identify homogeneous groups of people according to their observed response patterns.[18–20] Items were drawn from the Access to Care and the

TABLE 1 Items Included in the Latent Class Analysis of SDM

SDM Items from the Medical Expenditure Panel Survey	Corresponding Component(s) of the Definition of SDM[a]	Unweighted Distribution of Scores, n (%)				
		1 (Never)	2 (Sometimes)	3 (Usually)	4 (Always)	Not Evaluable[b]
If there were a choice between treatments, how often would your medical provider ask you to help make the decision?	1, 4	192 (7)	323 (11)	588 (21)	1552 (54)	203 (7)
Thinking about the types of medical, traditional, and alternative treatments you are happy with, how often does your medical provider show respect for these treatments?	3	70 (2)	180 (6)	586 (21)	1715 (60)	307 (11)
In the past 12 mo, how often did your child's doctors or other health providers listen carefully to you?	2,3	16 (1)	158 (5)	519 (18)	1847 (65)	318 (11)
In the past 12 mo, how often did your child's doctors or other health providers explain things in a way that you could understand?	2, 3	25 (1)	114 (4)	497 (17)	1907 (67)	315 (11)
In the past 12 mo, how often did your child's doctors or other health providers show respect for what you had to say?	3,4	25 (1)	127 (5)	465 (16)	1926 (67)	315 (11)
In the past 12 mo, how often did your child's doctors or other health providers spend enough time with you?	2	57 (2)	184 (6)	539 (19)	1762 (62)	316 (11)
		1 (No)			4 (Yes)	Not Evaluable
Does a medical person at your usual source of care present and explain all options to you?	2	160 (6%)			2572 (90%)	126 (4%)

[a] Components of SDM:
(1) Both the doctor and the patient are involved in the treatment decision-making process;
(2) Both share information with each other;
(3) Both take steps to participate in the decision-making process by expressing treatment preferences;
(4) Both the doctor and the patient agree on the treatment to implement.
[b] "Not evaluable" category includes subjects to whom the question was inapplicable, not ascertained, or who answered "don't know."
Table partially reproduced with permission from *Pediatrics*, Vol. 126, Page(s) 306–314, Copyright © 2010 by the AAP. The distribution of scores was not in the original publication.

communication and quality-oriented Consumer Assessment of Health Plans Survey sections of the MEPS survey.

For each study year, each child's household was initially categorized to have low, intermediate, or high participation in SDM. Because the low SDM group represented <1% of the population, results were unchanged when the low and intermediate groups were combined. Then, to demonstrate the impact of both the level of and change in SDM over the 2 study years, we classified households into 4 patterns: increasing, decreasing, unchanged low (combines intermediate and low), or unchanged high SDM. Increasing and decreasing SDM were defined based on movement between the initial 3 SDM categories between the 2 study years. For example, a change from low to intermediate, low to high, or intermediate to high SDM was categorized as an increasing pattern. We determined that these subgroups had similar effects on study outcomes before combining them.

Covariates

We considered additional variables that might confound the relationship between SDM, expenditures, and utilization. These covariates consisted of demographic characteristics including the child's age (0–4 vs 5–12 vs 13–17 years), gender, race (white, black, other) and Hispanic ethnicity, region of residence (Northeast, Midwest, South, West), parental education (no high school diploma, high school diploma, bachelor's degree, graduate-level degree, or other degree), and household income (poor, <100% of the applicable poverty line; near poor, 100% to <125%; low, 125% to <200%; middle, 200% to <400%; high, ≥400%), as well as any private health insurance (versus others). To ensure that findings were not confounded by child health, we adjusted for general health status based on the overall score (low, <15; medium, 15 to <20; and high, ≥20) from 5 Likert-scaled items derived from the Child Health Questionnaire, General Health Subscale.[18,21] Specifically, we considered 5 patterns of health status: unchanged low, medium, or high, increasing, and decreasing.

Statistical Analysis

Characteristics of the Study Sample

We initially described the weighted proportion of CSHCN in MEPS included versus excluded from the study and compared the characteristics of CSHCN with each pattern of SDM using χ^2 tests. Following guidance from AHRQ, all statistical analyses were conducted using a statistical package (Stata) designed specifically for the analysis of longitudinal data from the weighted, clustered, and stratified MEPS survey.[22] This approach provides conservative estimates accounting for repeated measures over time.[22] *P* values of <.05 were considered significant.

Assessing the Impact of SDM on Expenditure and Utilization Outcomes

To assess the impact of SDM on all expenditure outcomes in the presence of skewed cost data, we used 2 approaches that would be resistant to high-cost outliers. First, we calculated the mean cost for each child during each of the 2 study years, with the top 2.5% of values trimmed to the 97.5 percentile. Second, without trimming, we estimated the mean expenditure percentile rank for CSHCN with each of the observed patterns of SDM for each study year. We next calculated the change in expenditures as well as expenditure percentile rank with 95% confidence intervals (CIs) for those with increasing, decreasing, or unchanged high or low SDM.

We used the same approach for all utilization measures, first describing the mean rate of hospitalizations, ED visits, office visits, or prescriptions for each child in each study year by SDM pattern and then calculating the change in rates with 95% CIs for each of these patterns.

Linear regression was then used to estimate the impact of SDM on expenditures and utilization while adjusting for differences in children's characteristics across the distinct SDM patterns. For all expenditure and utilization outcomes, linear regression models with robust variance estimates that reflect the complex survey design were used with the change in expenditures or utilization between study years as the outcome and pattern of SDM as the independent variable. Expenditure results were confirmed by models using cost percentile rank as the outcome.

We then constructed models with and without covariates. Since the inclusion of covariates did not change the association of SDM with expenditures or utilization, unadjusted results are presented for all analyses. Models were implemented in Stata 10 and 11 (StataCorp, College Station, TX). The Children's Hospital of Philadelphia Institutional Review Board (IRB) determined this study to be IRB exempt.

RESULTS

Study Sample

The study sample, which included 2858 CSHCN, was representative of 12 million US children. This sample, composed of those with a pattern of SDM assigned and a usual source of care, included 90% of the weighted US population of CSHCN (Table 2). Those excluded were significantly more likely to be of black or other non-white race ($P < .001$), to be Hispanic ($P = .03$), to have lower levels of parental education ($P = .02$) and higher levels of poverty ($P < .001$), and to have no private health insurance ($P < .001$).

In the weighted study population, 15.9% had increasing, 51.9% unchanged high, 17.0% unchanged low, and 15.2% decreasing SDM (Table 2). Overall, these groups had similar demographic characteristics; however, children whose families reported increasing or unchanged high SDM were less likely to be 0 to 4 years of age ($P = .009$). Additionally, children whose families reported decreasing or unchanged high SDM were more likely to have private insurance ($P = .04$), and those whose families reported unchanged high SDM were more likely to have persistently high overall health ($P = .0005$).

Association of SDM With Health Care Expenditures

At baseline, there were no significant differences between those with distinct SDM patterns for any cost or utilization outcome. CSHCN had mean total, out-of-pocket, office-based, inpatient, ED, and prescription expenditures of $2832, $454, $645, $617, $82, and $624, respectively. With the top 2.5% of expenses trimmed, values were $2131, $389, $557, $127, $64, and $478 (Table 3). We present trimmed values for all subsequent results.

Between years 1 and 2 of the study, increasing SDM was associated with a significant decrease in total health care expenditures (−$339 (95% CI: −$660, −$21) (Table 2). Total costs did not change significantly over time for those with any other SDM pattern. During the study period, prescription expenditures increased for all groups.

When we assessed the relative differences in the change in costs from year 1 to 2 between those with each SDM pattern (Table 4), we found that those with increasing SDM had significantly lower total and out-of-pocket health care expenditures compared with those with decreasing SDM with relative differences of −$584 (−$1131, −$38) and −$142 (−$265, −$19). No significant contrasts were observed between the unchanged high and low SDM groups for any outcome. These expenditure results were confirmed in secondary analyses with the cost percentile rank as the outcome.

Association of SDM With Health Care Utilization

At baseline, CSHCN had rates of 6.5 hospitalizations and 27.0 ED visits per 100 children per year and 6.1 office visits and 7.8 prescriptions per child per year.

We found that increasing SDM was associated with significant decreases in hospitalizations, ED visits, and office visits over time (Table 3). Rates of hospitalizations and ED visits for CSHCN with increasing SDM declined by 4.0 (0.1, 7.9) and 11.3 (4.3, 18.3) per 100 children per year, respectively. Results showed a mean drop of 1.2 (0.3, 2.0) outpatient visits per child per year with increasing SDM. When we examined relative differences over time between those with each SDM pattern, we found that those with increasing SDM had 1.7 (0.3, 3.2) fewer office visits per child per year

TABLE 2 Characteristics of Children with Special Health Care Needs (CSHCN), Age 0–17 Years, by SDM Category

Variable	Included				Excluded[a]	*P* Value[b] Comparing SDM Patterns	*P* Value[b] Comparing Included Versus Excluded
	Increasing	Unchanged High	Unchanged Low	Decreasing			
N	483	1443	484	448	393		
No. children represented in population	1.9 million	6.3 million	2.0 million	1.8 million	1.4 million		
Percent represented	15.9%	51.9%	17.0%	15.2%			
Demographic characteristics	%	%	%	%	%		
Age, y						.009	.6
0–4	13.3	11.8	20.5	17.1	16.3		
5–12	50.8	50.3	45.3	47.5	49.5		
13–17	35.9	37.9	34.2	35.4	34.2		
Female	44.1	43.8	40.8	43.7	46.0	.8	.4
Race						.4	<.001
White	80.2	79.0	75.7	77.2	68.2		
Black	15.0	16.5	17.2	16.1	19.4		
Other	4.8	4.5	7.1	6.7	12.4		
Hispanic	16.4	12.7	12.0	14.9	18.2	.2	.03
Region						.9	.2
Northeast	19.6	19.7	17.9	15.7	12.7		
Midwest	21.6	22.8	22.9	21.0	24.9		
South	37.2	39.0	38.5	40.6	40.6		
West	21.6	18.5	20.7	22.7	21.9		
Parental education						.8	.02
No degree	11.9	9.2	11.3	11.9	17.1		
High school complete	45.4	45.7	48.4	44.3	48.7		
Bachelor's degree	19.0	16.5	15.0	19.7	11.3		
Graduate-level degree	10.1	13.3	12.6	11.7	11.5		
Other degree	13.6	15.3	12.7	12.4	11.4		
Poverty						.1	<.001
Poor	23.0	17.7	21.9	19.5	28.3		
Near poor	4.2	4.1	5.9	4.1	5.8		
Low income	15.7	15.6	16.4	12.9	15.3		
Middle income	32.9	29.1	31.1	31.7	33.6		
High income	24.2	33.5	24.7	31.8	16.0		
Insurance coverage						.04	<.001
Any private	60.1	67.7	60.7	65.1	50.3		
Other	39.9	32.3	39.3	34.9	49.7		
General health status pattern[c]						.0005	.06
Increasing	23.3	19.7	20.0	18.1	16.0		
Unchanged high	31.4	39.0	24.5	30.2	28.8		
Unchanged intermediate	14.3	12.7	18.0	14.7	18.0		
Unchanged low	11.4	8.4	12.0	11.5	7.4		
Decreasing	18.6	20.2	25.5	25.5	29.8		

[a] Children were excluded if they had no usual source of care or their household did not respond to any of the items used to create the SDM measure.

[b] *P* values calculated by χ^2 tests with robust variance estimates accounting for the weighted, clustered, and stratified MEPS survey design.

[c] General Health Status determined using the overall score from 5 Likert-scaled items derived from the Child Health Questionnaire, General Health Subscale (child seems less healthy than other children, child has never been seriously ill, child usually catches whatever is going around, expect child will have a healthy life, respondent worries more than is usual about child's health). For each year, the overall score was categorized as (low, <15; medium, 15 to <20; or high, ≥20). Patterns over the 2 study years are presented.

compared with those with decreasing SDM, 1.3 (0.3, 2.3) fewer visits compared with those with unchanged high SDM, and 2.2 (0.2, 4.2) fewer visits compared with those with unchanged low SDM (Table 5). Over time, those with increasing SDM had 4.4 (0.1, 8.7) fewer hospital visits and 10.3 (1.9, 18.6) fewer ED visits per 100 CSHCN per year than those with unchanged high SDM. We observed no differences over time in prescription rates. As with expenditure outcomes, we found no relative differences in utilization over time when comparing those with unchanged high versus low SDM.

DISCUSSION

In a US sample representing 12 million CSHCN, we found that increasing SDM was associated with decreases in health care expenditures and utilization. For those with increasing SDM, total costs declined by $339. Relative to those with decreasing SDM, CSHCN with increasing SDM had $584 lower total costs over the study period, and costs trended lower for those with increasing SDM in all expense categories studied except for prescriptions. Overall, savings were substantial compared with the mean baseline costs of $2131 across all CSHCN.

TABLE 3 Health Expenditures and Utilization Among CSHCN by SDM Group

	All CSHCN	SDM Increasing	SDM Unchanged High	SDM Unchanged Low	SDM Decreasing
Sample *N*	2858	483	1443	484	448
No. children represented in population	12.0 million	1.9 million	6.3 million	2.0 million	1.8 million
Percent represented	100.0%	15.9%	51.9%	17.0%	15.2%
Mean total health expenditures[a]:					
in year 1[b]	2131	2050	2111	2222	2178
in year 2	2071	1711	2033	2204	2423
change (95% CI)[c]	−60 (−202, 82)	−339 (−660, −21)	−78 (−260, 104)	−18 (−459, 422)	245 (−181, 672)
Mean out-of-pocket expenditures[a]:					
in year 1[b]	389	398	396	392	351
in year 2	374	333	384	334	428
change (95% CI)[c]	−15 (−46, 17)	−65 (−150, 21)	−12 (−58, 34)	−58 (−133, 17)	77 (−12, 166)
Mean office-based expenditures[a]:					
in year 1[b]	557	521	544	645	538
in year 2	537	452	541	566	576
change (95% CI)[c]	−20 (−60, 20)	−69 (−146, 8)	−3 (−53, 47)	−79 (−193, 34)	38 (−80, 157)
Mean inpatient expenditures[a]:					
in year 1[b]	127	133	107	140	173
in year 2	130	85	120	204	126
change (95% CI)[c]	3 (−35, 38)	−48 (−130, 34)	13 (−34, 60)	64 (−41, 169)	−47 (−135, 42)
Mean ED expenditures[a]:					
in year 1[b]	64	63	66	60	59
in year 2	54	32	62	45	58
change (95% CI)[c]	−10 (−19, 1)	−31 (−51, 12)	−4 (−17, 10)	−15 (−39, 8)	−1 (−29, 28)
Mean prescription expenditures[a]:					
in year 1[b]	478	430	505	422	498
in year 2	547	508	571	511	548
change (95% CI)[c]	69 (38, 101)	78 (9, 148)	66 (23, 108)	89 (19, 159)	50 (−30, 131)
Mean rate of hospitalizations[d]:					
in year 1[b]	6.5	7.5	5.0	6.8	10.2
in year 2	5.9	3.5	5.4	7.9	7.4
change (95% CI)[c]	−0.6 (−2.4, 1.2)	−4.0 (−7.9, −0.1)	0.4 (−1.8, 2.7)	1.1 (−3.4, 5.6)	−2.8 (−9.0, 3.3)
Mean rate of ED visits[d]:					
in year 1[b]	27.0	26.1	24.6	32.3	30.3
in year 2	22.5	14.8	23.5	23.9	25.5
change (95% CI)[c]	−4.5 (−7.9, -1.1)	−11.3 (−18.3, −4.3)	−1.1 (−5.2, 3.1)	−8.4 (−18.3, 1.4)	−4.8 (−15.0, 5.4)
Mean rate of office visits[e]:					
in year 1[b]	6.1	6.3	6.0	6.4	5.6
in year 2	6.2	5.1	6.2	7.4	6.2
change (95% CI)[c]	0.1 (−0.3, 0.6)	−1.2 (−2.0, −0.3)	0.2 (-0.4, 0.7)	1.0 (−0.8, 2.9)	0.6 (−0.6, 1.7)
Mean rate of prescriptions[e]:					
in year 1[b]	7.8	7.7	8.0	7.3	8.0
in year 2	8.0	7.3	8.4	7.7	8.1
change (95% CI)[c]	0.2 (−0.1, 0.6)	−0.4 (−1.1, 0.3)	0.4 (−0.2, 1.0)	0.4 (−0.4, 1.2)	0.1 (−0.9, 1.0)

[a] The highest 2.5% of expenditure values were trimmed at the 97.5 percentile to avoid bias and ensure that assumptions of normality of the statistical models were not violated. All amounts are in US dollars ($).

[b] There were no significant baseline differences between groups with different SDM patterns for any of the outcomes (all $P > .05$ based on linear regression accounting for the survey design).

[c] 95% confidence intervals calculated from linear regression with robust variance estimates accounting for the weighted, clustered, and stratified MEPS survey design.

[d] Rates are per 100 patients per year.

[e] Rates are per patient per year.

These results, confirmed in sensitivity analyses and unchanged in analyses that considered multiple covariates, including trends in general health status, are consistent with our hypothesis that increases in SDM over time would result in overall savings.

Although increasing SDM was associated with lower costs, our results did not show that higher absolute levels of SDM resulted in savings. No significant absolute or relative change in total costs was observed over time among those with unchanged high or low SDM. In the context of decreases in total expenditures with increasing SDM, these results might reflect an initial savings when moving to a higher level of SDM, but a lack of a continued reduction in costs when high levels of SDM versus lower levels are maintained. With stable levels of SDM, disease severity may be the primary determinant of costs and the impact of SDM may be minimized.[23] Prospective studies will be needed to confirm and explain these results in more detail.

In contrast to total health care expenditures, out-of-pocket costs reflect the financial burden for affected families. We found that out-of-pocket costs dropped

TABLE 4 Relative Difference in Change Over Time in Health Expenditures Between SDM Groups[a]

	Total Health Expenditures[b] (95% CI)	*P* Value[c]	Out-of-Pocket Expenditures[b] (95% CI)	*P* Value[c]	Office-based Expenditures[b] (95% CI)	*P* Value[c]	Inpatient Expenditures[b] (95% CI)	*P* Value[c]	Emergency Department Expenditures[b] (95% CI)	*P* Value[c]	Prescription Expenditures[b] (95% CI)	*P* Value[c]
SDM increasing vs unchanged high	−260 (−620, 99)	.2	−53 (−149, 44)	.3	−67 (−157, 24)	.1	−61 (−152, 30)	.2	−28 (−52, −3)	.03	12 (−68, 93)	.8
vs unchanged low	−320 (−850, 210)	.2	−6 (−123, 110)	.9	10 (−129, 150)	.9	−112 (−243, 19)	.09	−16 (−46, 14)	.3	−11 (−107, 85)	.8
vs decreasing	−584 (−1131, −38)	.04	−142 (−265, −19)	.02	−107 (−245, 30)	.1	−1 (−128, 126)	.9	−31 (−65, 3)	.07	28 (−69, 125)	.6
SDM unchanged high vs unchanged low	60 (−427, 546)	.8	−46 (−137, 44)	.3	−77 (−196, 42)	.2	51 (−64, 166)	.1	−12 (−37, 2)	.4	23 (−58, 105)	.6
vs decreasing	−324 (−790, 142)	.2	−89 (−195, 16)	.1	−41 (−171, 89)	.5	60 (−44, 164)	.3	−3 (−36, 30)	.8	15 (−75, 106)	.7
SDM unchanged low vs decreasing	−264 (−890, 362)	.4	−135 (−248, −23)	.02	−118 (−286, 50)	.2	110 (−27, 248)	.1	−15 (−52, 22)	.4	39 (−63, 140)	.4

[a] Because the inclusion of covariates did not change the association of SDM with expenditures, unadjusted results are shown.

[b] The highest 2.5% of expenditure values were trimmed at the 97.5 percentile to avoid bias and ensure that assumptions of normality of the statistical models were not violated. All amounts are in US dollars ($).

[c] *P* values calculated from linear regression with robust variance estimation accounting for the complex survey design.

by $142 over time for those with increasing versus decreasing SDM. In SDM, treatment decisions explicitly account for families' values and preferences,[1] including those related to out-of-pocket cost. In fact, some have advocated for SDM as a way to help clinicians acknowledge and address families' financial concerns.[24] Our findings suggest that when SDM increases as opposed to declines, families and clinicians may reach decisions that are less financially burdensome. Given that prior work has demonstrated that more than half of CSHCN have high out-of-pocket expenses,[12,13] SDM may prove to be an important approach to help many families manage the costs of caring for medically complex children.

Little work has examined the impact of SDM on child health care costs and utilization. Decreases in cost were observed in a quality improvement initiative that used telephone-based case management to foster doctor-patient communication, patient self-management skills, and SDM for high-risk adults and children.[25] In that study, preferences for more conservative treatments among adults participating in SDM were largely responsible for cost reductions. Prior research on health costs and utilization for CSHCN has primarily focused on the benefits of care coordination and the medical home.[26–28] The introduction of care coordination through ambulatory subspecialty clinics for children with chronic conditions was found to reduce hospital costs,[29] and expanded community-based care coordination also resulted in savings.[30] In addition, findings from the 2005–2006 National Survey of CSHCN indicate that those with access to the medical home and adequate care coordination have approximately half the odds of having more than $500 in out-of-pocket costs[31] and report fewer financial problems.[32] Our findings extend these results by showing that including

TABLE 5 Relative Difference in Change Over Time in Health Utilization Between SDM Groups[a]

	Hospitalizations[b] (95% CI)	*P* Value[c]	ED Visits[b] (95% CI)	*P* Value[c]	Office-based Visits[d] (95% CI)	*P* Value[c]	Prescriptions[d] (95% CI)	*P* Value[c]
SDM increasing vs unchanged high	−4.4 (−8.7, −0.1)	.04	−10.3 (−18.6, −1.9)	.02	−1.3 (−2.3, −0.3)	.01	−0.8 (−1.8, 0.2)	.1
vs unchanged low	−5.1 (−10.8, 0.7)	.08	−2.9 (−14.5, 8.6)	.6	−2.2 (−4.2, −0.2)	.03	−0.8 (−1.8, 0.3)	.1
vs decreasing	−1.1 (−8.6, 6.3)	.8	−6.5 (−18.6, 5.6)	.3	−1.7 (−3.2, −0.3)	.02	−0.4 (−1.6, 0.8)	.5
SDM unchanged high vs unchanged low	0.6 (−4.4, 5.7)	.8	−7.3 (−17.8, 3.1)	.2	0.9 (−1.7, 2.8)	.4	−0.1 (−1.0, 1.0)	.9
vs decreasing	3.3 (−3.4, 10.0)	.3	3.7 (−7.5, 15.0)	.5	−0.4 (−1.7, 0.9)	.5	0.4 (−0.8, 1.5)	.5
SDM unchanged low vs decreasing	3.9 (−3.6, 11.5)	.3	−3.6 (−17.4, 10.2)	.6	0.5 (−1.7, 2.7)	.7	0.3 (−0.9, 1.5)	.6

[a] Since the inclusion of covariates did not change the association of SDM with utilization, unadjusted results are shown.
[b] Rates are per 100 patients per year.
[c] *P* values calculated from linear regression with robust variance estimation accounting for the MEPS complex survey design.
[d] Rates are per patient per year.

families in SDM may reduce both total and out-of- pocket costs.

In terms of health care utilization, we found that increasing SDM was associated with decreased rates of hospitalizations, ED visits, and office visits. Children with increasing SDM had 1.7 fewer office visits per child per year compared with those with decreasing SDM. Those with increasing SDM also had relatively lower rates of office visits compared with those with unchanged high or low SDM. Reducing office visits matters in this context because, at least for children with asthma, half of costs result from nonurgent outpatient visits.[33] Our results may also be reassuring to outpatient pediatricians concerned about the time investment required to engage families of CSHCN in SDM.[34] However, further study is needed to understand whether the decrease in office visits was offset by an increase in telephone care.

This study had several limitations. Although we implemented a latent class analysis to group children into distinct patterns of SDM based on their responses to 7 items corresponding to the definition of SDM,[1] additional items might have allowed us to more fully characterize SDM. SDM exists between the extremes of paternalistic decision-making by the doctor alone and informed decision-making by the patient or family alone.[1] Our study measure limited us to assessing only the extent of family involvement in decision-making, however, not who ultimately made decisions. In addition, we relied on household report as opposed to the direct observation of SDM. As a result, we could not verify how options were presented. Finally, although our data set provided a national perspective and detailed measures of cost and utilization, trials are needed to definitively assess how SDM affects costs and utilization in specific clinical contexts. Given the known high costs to pediatric practices of providing care coordination for CSHCN,[35] studies should evaluate in more detail both the total reduction in expenditures as well as the costs to pediatric offices associated with implementing SDM.

CONCLUSIONS

We found that increasing SDM is associated with decreased health care costs and utilization for CSHCN. Results support prospective studies to determine if pediatric interventions to foster SDM reduce the financial burden of caring for these children.

ACKNOWLEDGMENTS

This research was supported by an Academic Pediatric Association Young Investigator Award. In addition, the project described was supported by Award Number K23HD059919 from the Eunice Kennedy Shriver National Institute of Child Health & Human Development.

We thank Cyndi Ritz Wallin and Gary Moore of Social & Scientific Systems, Inc, and Dingwei Dai of The Children's Hospital of Philadelphia Research Institute, Healthcare Analytics Unit, for their help with data preparation.

REFERENCES

1. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med*. 1997;44 (5):681–692
2. O'Connor AM, Bennett CL, Stacey D, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2009; (3):CD001431
3. Institute of Medicine (US). *Committee on Comparative Effectiveness Research Prioritization. Initial National Priorities for Comparative Effectiveness Research*. Washington, DC: National Academy Press; 2009
4. The Patient Protection and Affordable Care Act. Public Law No: 111-148, 124 Stat 1025 (2010).
5. McPherson M, Weissman G, Strickland BB, van Dyck PC, Blumberg SJ, Newacheck PW. Implementing community-based systems of services for children and youths with

special health care needs: how well are we doing? *Pediatrics*. 2004;113(5 Suppl):1538–1544

6. American Academy of Pediatrics Medical Home Initiatives for Children With Special Needs Project Advisory Committee. Policy statement: organizational principles to guide and define the child health care system and/or improve the health of all children. *Pediatrics*. 2004;113(5 Suppl):1545–1547
7. Sia C, Tonniges TF, Osterhus E, Taba S. History of the medical home concept. *Pediatrics*. 2004;113(5 Suppl):1473–1478
8. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1 Pt 1):137–140
9. Newacheck PW, Kim SE. A national profile of health care utilization and expenditures for children with special health care needs. *Arch Pediatr Adolesc Med*. 2005;159(1):10–17
10. Neff JM, Sharp VL, Muldoon J, Graham J, Myers K. Profile of medical charges for children by health status group and severity level in a Washington State Health Plan. *Health Serv Res*. 2004;39(1):73–89
11. Chan E, Zhan C, Homer CJ. Health care use and costs for children with attention-deficit/hyperactivity disorder: national estimates from the medical expenditure panel survey. *Arch Pediatr Adolesc Med*. 2002;156(5):504–511
12. Kuhlthau K, Hill KS, Yucel R, Perrin JM. Financial burden for families of children with special health care needs. *Matern Child Health J*. 2005;9(2):207–218
13. Parish SL, Shattuck PT, Rose RA. Financial burden of raising CSHCN: association with state policy choices. *Pediatrics*. 2009;124(Suppl 4):S435–S442
14. Agency for Health Care Research and Quality. Medical Expenditures Panel Survey. Available at: www.meps.ahrq.gov/mepsweb/survey_comp/household.jsp. Accessed April 15, 2010
15. Bethell CD, Read D, Stein RE, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambul Pediatr*. 2002;2(1):38–48
16. Carle AC, Blumberg SJ, Poblenz C. Internal psychometric properties of the children with special health care needs screener. *Acad Pediatr*. 2011;11(2):128–135
17. Agency of Health Care Research and Quality. Medical Expenditures Panel Survey: MEPS Topics: Health Care Costs/Expenditures. Available at: www.meps.ahrq.gov/mepsweb/data_stats/MEPS_topics.jsp?topicid=5Z-1. Accessed March 23, 2011
18. Fiks AG, Localio AR, Alessandrini EA, Asch DA, Guevara JP. Shared decision-making in pediatrics: a national perspective. *Pediatrics*. 2010;126(2):306–314
19. Goodman L. On the assignment of individuals to latent classes. *Sociol Methodol*. 2007;37:1–22
20. McCulloch CE, Lin H, Slate EH, Turnbull BW. Discovering subpopulation structure with latent class mixed models. *Stat Med*. 2002;21(3):417–429
21. Landgraf J, Abaetz L. *The CHQ User's Manual*. 1st ed. Boston, MA: The Health Institute, New England Medical Center; 1996
22. Machlin S, Yu W, Zodet M. Computing Standard Errors for MEPS Estimates. Agency for Healthcare Research and Quality. Rockville, MD; 2005. Available at: www.meps.ahrq.gov/survey_comp/standard_errors.jsp. Accessed March 30, 2011
23. Horn SD, Torres A, Jr,Willson D, Dean JM, Gassaway J, Smout R. Development of a pediatric age- and disease-specific severity measure. *J Pediatr*. 2002;141(4):496–503
24. Hardee JT, Platt FW, Kasper IK. Discussing health care costs with patients: an opportunity for empathic communication. *J Gen Intern Med*. 2005;20(7):666–669
25. Wennberg DE, Marr A, Lang L, O'Malley S, Bennett G. A randomized trial of a telephone care-management strategy. *N Engl J Med*. 2010;363(13):1245–1255
26. Ziring PR, Brazdziunas D, Cooley WC, et al; American Academy of Pediatrics, Committee on Children with Disabilities. Care coordination: integrating health and related systems of care for children with special health care needs. *Pediatrics*. 1999;104(4 Pt 1):978–981
27. American Academy of Pediatrics Ad Hoc Task Force on Definition of the Medical Home. The medical home. *Pediatrics*. 1992;90(5):774
28. Homer CJ, Klatka K, Romm D, et al. A review of the evidence for the medical home for children with special health care needs. *Pediatrics*. 2008;122(4):e922–e937
29. Liptak GS, Burns CM, Davidson PW, McAnarney ER. Effects of providing comprehensive ambulatory services to children with chronic conditions. *Arch Pediatr Adolesc Med*. 1998;152(10):1003–1008
30. Smith K, Layne M, Garell D. The impact of care coordination on children with special health care needs. *Child Health Care*. 1994;23(4):251–266
31. Turchi RM, Berhane Z, Bethell C, Pomponio A, Antonelli R, Minkovitz CS. Care coordination for CSHCN: associations with family-provider relations and family/child outcomes. *Pediatrics*. 2009;124(Suppl 4):S428–S434
32. Ghandour RM, Perry DF, Kogan MD, Strickland BB. The medical home as a mediator of the relation between mental health symptoms and family burden among children with special health care needs. *Acad Pediatr*. 2011;11(2):161–169
33. Lozano P, Fishman P, VonKorff M, Hecht J. Health care utilization and cost among children with asthma who were enrolled in a health maintenance organization. *Pediatrics*. 1997;99(6):757–764
34. Fiks AG, Hughes CC, Gafen A, Guevara JP, Barg FK. Contrasting parents' and pediatricians' perspectives on shared decision-making in ADHD. *Pediatrics*. 2011;127(1):e188–e196
35. Antonelli RC, Antonelli DM. Providing a medical home: the cost of care coordination services in a community-based, general pediatric practice. *Pediatrics*. 2004;113(5 Suppl):1522–1528