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Shared Decision-Making in Pediatrics: A National Perspective

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Abstract

OBJECTIVES—To identify patterns of shared decision-making (SDM) among a nationally representative sample of US children with attention-deficit/hyperactivity disorder (ADHD) or asthma and determine if demographics, health status, or access to care are associated with SDM.

PATIENTS AND METHODS—We performed a cross-sectional study of the 2002–2006 Medical Expenditure Panel Survey, which represents 2 million children with ADHD and 4 million children with asthma. The outcome, high SDM, was defined by using latent class models based on 7 Medical Expenditure Panel Survey items addressing aspects of SDM. We entered factors potentially associated with SDM into logistic regression models with high SDM as the outcome. Marginal standardization then described the standardized proportion of children's households with high SDM for each factor.

RESULTS—For both ADHD and asthma, 65% of children's households had high SDM. Those who reported poor general health for their children were 13% less likely to have high SDM for ADHD (64 vs 77%) and 8% less likely for asthma (62 vs 70%) when adjusting for other factors.

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Results for behavioral impairment were similar. Respondent demographic characteristics were not associated with SDM. Those with difficulty contacting their clinician by telephone were 26% (ADHD: 55 vs 81%) and 29% (asthma: 48 vs 77%) less likely to have high SDM than those without difficulty.

CONCLUSIONS—These findings indicate that households of children who report greater impairment or difficulty contacting their clinician by telephone are less likely to fully participate in SDM. Future research should examine how strategies to foster ongoing communication between families and clinicians affect SDM.

Keywords

ADHD; asthma; communication; decision-making; telephone care

Shared decision-making (SDM) involves the active participation of both clinicians and families in treatment decisions, the exchange of information, discussion of preferences, and joint determination of treatment plans.¹ The Institute of Medicine highlighted the delivery of patient-centered care, the focus of SDM, as 1 of 6 priority areas for improvement in health care for the 21st century and recently stressed the importance of research to assess the comparative effectiveness of SDM.^{2,3} Despite this emphasis, little is known regarding the prevalence and determinants of SDM in the medical care of children in the United States.

Attention-deficit/hyperactivity disorder (ADHD) and asthma, 2 common chronic behavioral or physical health conditions experienced by children, provide a context for the study of SDM in pediatrics. For both conditions, there are multiple evidence-based treatments,^{4–6} personal and cultural values influence selection of these treatments,^{7–11} and adherence, which is often poor, mediates the effectiveness of the treatment.^{4,12–14} In addition, national guidelines for both conditions explicitly recommend the participation of patients and their families in the initial treatment choice and subsequent optimization of treatment.^{6,15}

Nevertheless, passive participation in pediatric encounters is common.¹⁶ This pattern is concerning, because improved communication may lead to better outcomes for childhood physical and behavioral conditions.^{17,18} We conducted this study to identify patterns of and factors associated with SDM among a nationally representative sample of US children with ADHD or asthma. We hypothesized that access to care would be strongly associated with SDM for children with both of these conditions. More broadly, by identifying characteristics of those who were least likely to participate in SDM and assessing the association of access to care with increased participation, we designed this study to help inform future interventions to promote SDM in pediatrics.

PATIENTS AND METHODS

Study Design and Data Source

We conducted a cross-sectional analysis of the 2002–2006 Medical Expenditure Panel Survey (MEPS), which is administered annually by the Agency for Healthcare Research and Quality and was previously used to study ADHD and asthma.^{19–21} Between 12 810 and 14 828 households²² were sampled annually from the US civilian, noninstitutionalized population drawn from the previous year's National Health Interview Survey. In the MEPS, the person from each household who is most knowledgeable about the health of its members responds to questioning and provides information on health status, health insurance, and health care utilization. Detailed interviews are supplemented by surveys from medical providers, health insurers, and employers.

Study Population

For our analysis of patterns of SDM, the study population included all children from birth through 17 years of age included in the 2002–2006 MEPS full-year consolidated data files. From this population, children with ADHD and asthma were selected if they had an event (ie, office visit or prescription) associated with *International Classification of Diseases, Ninth Revision* (ICD-9) codes 314 or 493 in the MEPS medical conditions file. 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 outcome in the MEPS data set. Although response rates for completion of all survey rounds during the years considered ranged from 58.3% to 64.7%,²² we were able to generalize results to the general population of affected children in the United States by accounting for the stratification, clustering, and unequal probabilities of selection and response in the complex survey design.

Outcome Measure

The outcome in this study is families' participation in SDM as determined by responses to 7 separate MEPS items that reflect concepts of SDM. These items are shown in Table 1 and correspond to the 4 components of SDM in the most widely accepted definition of SDM.¹ Items were drawn from the access-to-care and communication and quality-oriented CAHPS (formerly known as the Consumer Assessment of Health Plans Survey) sections of the MEPS.

Independent Variables

Independent variables included child and family sociodemographic characteristics and items that address health status and access to care. Demographic characteristics considered were patient gender, patient race (white, black, or other), household income (poor [$<100\%$ of the applicable poverty line], near poor [100% to $<125\%$], low [125% to $<200\%$], middle [200% to $<400\%$], or high [$\geq 400\%$]), parental education (no high school diploma, high school diploma, bachelor's degree, graduate level degree, or other degree), and insurance status (any private, public, or none). General health status was based on the overall score (low [<15], medium [15 to <20], or high [≥ 20]) 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).²³ In the analysis, items were recoded so that a score of 5 indicated the best and of 1 indicated the worst health for each item. The presence of psychological impairment was determined by using standard scoring for the validated 13-item Columbia Impairment Likert Scale, which assesses interpersonal relationships, broad domains of psychopathology, functioning at school, and use of leisure time.^{24–26}

Statistical Analysis

Latent Class Analysis of Patterns of SDM—Latent class models distinguished patterns of SDM.²⁷ These models, an application of random-effects models, identify a relatively small number of underlying and unobserved classes in which to group individuals according to a larger number of observed variables. The resulting classes can then be tested and described by their ability to separate individuals by their covariates and outcomes. In the present case, the observed variables used to determine the latent classes (patterns of SDM) were the categorical responses to the 7 questions from the MEPS.²⁸ The statistical model produces homogeneous groups of people according to their response patterns.²⁹

We implemented the latent class analysis in Stata 10 (Stata Corp, College Station, TX) using the “gllamm” program (generalized linear latent and mixed models). We derived patterns of

SDM by using data from all children so that patterns were defined on the broadest group possible. We then compared solutions with 2, 3, or 4 latent classes (patterns of SDM) by using likelihood ratio tests. The 3-class solution was retained because it better discriminated individuals on the basis of their patterns of SDM compared with the 2-class solution and because the 4-class model did not converge. The latent class analysis identified 152 distinct response patterns with high SDM, 1445 with intermediate SDM, and 460 with low SDM. Those in the high-SDM group generally scored 4 of 4 for most items, those in the intermediate group commonly scored 3's with some 1's, 2's, or 4's, and those in the lowest group had many 1's and 2's. No single item was responsible for the class distinction.

To characterize the outcome of the latent class analysis, we calculated mean responses to the 7 SDM items for those in each of the SDM groups. Next, demographic characteristics of the study population of children with ADHD and asthma, those with a class assigned and a usual source of care, were each compared with those of other children in the MEPS with ADHD and asthma, respectively, by using both unadjusted and logistic regression analyses.

Identifying Factors Associated With SDM—Because the low-SDM group represented <4% of the study population, we combined the low- and intermediate-SDM groups and compared the combined group to the high-SDM group for our main analyses. With this approach and separately for those with ADHD and asthma, we described the proportion of respondents with each pattern of SDM for each independent variable. If 2 variables were co-linear or if results of bivariate analyses indicated an inadequate sample size for comparison, the most clinically meaningful variable was retained. As a result, although the assignment of latent class was the same for individuals with either condition, factors included in subsequent analyses differed between ADHD and asthma. The survey year was considered a marker for changes in SDM over time, lacked association with SDM, and was dropped from our final models. The remaining independent variables were then entered into logistic regression models with pattern of SDM (high SDM versus others) as the dependent variable. Marginal standardization based on these models described the proportion of children's households with high SDM if they were standardized to the characteristics of the entire sample.³⁰

In the process of developing our final analyses, ordinal logistic regression models including the 3 SDM groups were tried but discarded because of violations of the proportional odds assumption. As a sensitivity analysis, multinomial regression, a technique that accommodates the 3 patterns of SDM as the dependent variable but does not account for the order of these groups, was also explored. These models were implemented in Stata 10 and 11.

This study was determined to be exempt from review by The Children's Hospital of Philadelphia institutional review board.

RESULTS

Study Population

The study sample of 1397 children with ADHD and 2738 children with asthma represented a population of 2 264 866 US children with ADHD and 4 032 411 children with asthma. This population, which comprised those with a pattern of SDM assigned and a usual source of care, included 93% of the weighted population of children with ADHD in the MEPS (Table 2) and 94% of those with asthma (Table 3).

We found several differences between those included and those excluded from the study population. For both ADHD and asthma, included children were more likely to have health

insurance ($P = .01$ based on logistic regression models). Among those with ADHD, children included were more likely to be between 5 and 12 years of age ($P < .001$), whereas for those with asthma, higher parental educational attainment was associated with inclusion ($P < .001$). Significant differences were not observed for other demographic characteristics.

Patterns of SDM

We found that patterns of SDM were similar for ADHD and asthma. Among those with ADHD, 65% of children had high, 33% had intermediate, and 2% had low levels of SDM, whereas for asthma the proportions were 65%, 32%, and 3%, respectively. These proportions also closely matched those in the overall population of children in which 66% of households had high, 31% had intermediate, and 3% had low participation in SDM. For children with either ADHD or asthma, mean responses to the 7 SDM items were 3.9, 3.2, and 2.0 of 4.0 for those with high, intermediate, and low participation in SDM, respectively. Results for the overall population were similar.

Factors Associated With SDM For ADHD and Asthma

We next examined factors associated with SDM with ADHD and asthma and found that households of children with greater impairment were less likely to participate in SDM. Specifically, those who reported poor general health for their children were 12.9% less likely to have high SDM for ADHD (63.7 vs 76.6%) (Table 4) and 8.4% less likely to have high SDM for asthma (61.5 vs 69.9%) (Table 5) when adjusting for other factors ($P = .003$). Similarly, children with behavioral impairment on the Columbia Impairment Scale were 12.9% less likely to have high SDM for ADHD (62.2 vs 75.1%, $P = .003$) and 6.6% less likely to have high SDM for asthma (63.6 vs 70.2%; $P = .03$). With the exception of a smaller proportion of households of children with asthma with high SDM if they were of neither white nor black race (versus white), demographic characteristics were not associated with SDM for ADHD or asthma.

Of all the characteristics considered, telephone access to the usual source of care was most strongly associated with high SDM, and differences in SDM were nearly twice as large as those based on impairment. Those with difficulty contacting their clinician by telephone were 25.8% (ADHD: 54.8 vs 80.6%) and 28.7% (asthma: 48.1 vs 76.8%) less likely to have high SDM than those without difficulty ($P < .001$). These differences are in contrast to much smaller, nonsignificant associations between high SDM and difficulties in getting to the usual source of care.

Multinomial regression models that included the low-, middle-, and high-SDM groups confirmed our results for both ADHD and asthma. In addition, results were unchanged in sensitivity analyses that included only those households (1) that responded to all 7 SDM items, (2) with at least 1 of the access-to-care items complete, or (3) with at least 1 of the Consumer Assessment of Health Plans Survey items completed.

DISCUSSION

To our knowledge, this is the first study to examine levels of participation in SDM for children with ADHD and asthma by using a national sample. We found that 66% of households of children overall and 65% of those with a child with ADHD or asthma reported high participation in SDM. The closest parallel to this analysis is work done with the National Survey of Children With Special Health Care Needs (NS-CSHCN). Findings from that survey have indicated that 57% of families of children with special health care needs partner in decision-making and are satisfied with the health care they receive³¹ and that half of children with autism receive all aspects of family-centered care, a construct that

partially overlaps SDM.³² Results from the direct observation of pediatric visits are similar. Discussion of alternatives, risks, and benefits at pediatric acute visits occurred at 58%, 54%, and 69%, respectively, of visits with pediatricians or family practitioners.³³ Variability in results between these studies likely reflects differences in the outcomes assessed, their measurement, and the specific study population. Because previous work in pediatrics has revealed that parents want to be involved in treatment decisions, and this involvement may affect both parent satisfaction and the outcomes of care,^{17,18,34,35} additional work is needed nationally to maximize the involvement of families in decision-making.

This work may be best targeted toward families of the most impaired children. For both ADHD and asthma, we found that significantly fewer families of children with impaired general health or behavioral health had high SDM, and gaps as great as 12.9% were found. Differences of this magnitude were also observed in the National Survey of Children With Special Health Care Needs.³¹ These gaps may have arisen because families of more severely affected children need increased support with decision-making. Although the American Academy of Pediatrics has emphasized the importance of family-centered care and information-sharing as part of care coordination for children with special health care needs, financial and other barriers to meeting these needs persist and may be reflected in our results.^{36,37} Our findings underscore the importance of developing feasible approaches to support SDM within the medical home.

Our most striking result is the dramatic impact of open telephone communication on reported SDM. We hypothesized that access to care would be strongly associated with SDM. However, we did not expect to find that telephone communication was much more strongly linked to SDM than the level of difficulty in getting to the usual source of care. For both ADHD and asthma and adjusting for all factors considered, including challenges in reaching the office, families with difficulties contacting their usual source of care by telephone were at least 25.8% less likely to have high SDM than those without difficulty. Because most studies of communication have centered on the clinical encounter, the importance of contact outside of office visits specifically to ongoing SDM has not been reported previously in pediatrics.

These findings, if replicated elsewhere, would lend support for more widespread and simplified reimbursement for telephone care for children with chronic illness, which is a priority of the American Academy of Pediatrics that should improve access to clinicians.³⁸ In addition, although our study addressed telephone communication, the results also may support a broader evaluation of tools to enhance communication. For example, e-mail is an increasingly popular, effective, efficient, and well-accepted approach to information exchange in pediatrics; however, its impact on the decision-making process for children with chronic illness remains poorly understood.^{39–41} The same holds true for patient portals tied to electronic health records, which are tools that have attracted increased attention and are capable of supporting decision-making.

We found no association between demographic characteristics and participation in SDM. Although racial discordance between clinicians and patients has been associated with physician-patient interaction in the adult setting,⁴² race, as in our study, was not found to be an important factor in a study specifically focused on children's primary health care.^{42,43} The impact of socioeconomic status, including parental education and the child's insurance coverage, on participation in SDM was likely blunted by the requirement that everyone in our study population had a usual source of care. Less than 3% of the study population with asthma or ADHD had no health insurance. Corresponding with our results, the results of previous research across adult health settings have also suggested that the clinical context

may be more important than the educational attainment of parents in determining who actively participates in health care.⁴⁴

Because previous studies have been limited to examining SDM in the context of office visits and in specific practice settings, this study was designed to characterize patterns of SDM and factors associated with SDM in a nationally representative sample of children with ADHD or asthma. Additional strengths of this study included multiple items within the MEPS that correspond to the most widely accepted conceptualization of SDM.¹ To address the absence of a validated measure of SDM in the MEPS, we implemented latent class analysis to rigorously identify and match children to distinct patterns of SDM on the basis of responses to available items. Although these items correspond to the 4 components of SDM, additional items exploring whether providers elicited families' preferences, concerns, and information needs may have allowed us to better characterize patterns of SDM. In our analysis, we considered responses along a spectrum of low to high SDM. However, we were unable to formally distinguish whether the clinician, patient/family, or both ultimately made decisions. In addition, although data on clinician characteristics would have been helpful in studying SDM,⁴⁵ we were unable to include these factors because most households did not identify a single clinician as the medical provider for the child. Although results were consistent with those from the direct observation of pediatric visits, we considered reported as opposed to observed SDM. As a result, although parents reported on whether clinicians presented all options, we could not verify how many treatment options were presented. Finally, because we conducted a cross-sectional study, we were able to show associations but not causality.

CONCLUSIONS

Our findings indicate that households of children who report greater impairment and have difficulty reaching their clinicians by telephone are less likely to have high SDM. Our results suggest that additional work should be directed at developing strategies to better engage families of the most impaired children in SDM. For children with chronic illness, further research is needed to examine how strategies to foster regular communication outside of the context of office visits affect SDM, treatment acceptability, adherence, and health outcomes over time. Existing and emerging technologies may ultimately facilitate this process.

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ABBREVIATIONS

SDM	shared decision-making
ADHD	attention-deficit/hyperactivity disorder

MEPS Medical Expenditure Panel Survey

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. [PubMed: 9032835]
2. Institute of Medicine, Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press; 2001.
3. Institute of Medicine, Committee on Comparative Effectiveness Research Prioritization. *Initial National Priorities for Comparative Effectiveness Research*. Washington, DC: National Academy Press; 2009.
4. MTA Cooperative Group. National Institute of Mental Health Multimodal Treatment Study of ADHD follow-up: 24-month outcomes of treatment strategies for attention-deficit/hyperactivity disorder. *Pediatrics*. 2004; 113(4):754–761. [PubMed: 15060224]
5. Jensen PS, Arnold LE, Swanson JM, et al. 3-Year follow-up of the NIMH MTA study. *J Am Acad Child Adolesc Psychiatry*. 2007; 46(8):989–1002. [PubMed: 17667478]
6. Loe IM, Feldman HM. Academic and educational outcomes of children with ADHD. *Ambul Pediatr*. 2007; 7(1 suppl 1):82–90. [PubMed: 17261487]
7. dosReis S, Zito JM, Safer DJ, Soeken KL, Mitchell JW Jr, Ellwood LC. Parental perceptions and satisfaction with stimulant medication for attention-deficit hyperactivity disorder. *J Dev Behav Pediatr*. 2003; 24(3):155–162. [PubMed: 12806227]
8. dosReis S, Butz A, Lipkin P, Anixt J, Weiner C, Chernoff R. Attitudes about stimulant medication for attention-deficit/hyperactivity disorder among African American families in an inner city community. *J Behav Health Serv Res*. 2006; 33(4):423–430. [PubMed: 17078011]
9. Olaniyan O, dosReis S, Garriett V, et al. Community perspectives of childhood behavioral problems and ADHD among African American parents. *Ambul Pediatr*. 2007; 7(3):226–231. [PubMed: 17512883]
10. Rand CS. Adherence to asthma therapy in the preschool child. *Allergy*. 2002; 57 (suppl 74):48–57. [PubMed: 12371913]
11. Conn KM, Halterman JS, Fisher SG, Yoos HL, Chin NP, Szilagyi PG. Parental beliefs about medications and medication adherence among urban children with asthma. *Ambul Pediatr*. 2005; 5(5):306–310. [PubMed: 16167856]
12. McMaster University Evidence-Based Practice Center. *Treatment of Attention-Deficit Hyperactivity Disorder*. Rockville, MD: Agency for Health Care Policy and Research; 1999.
13. Moderators and mediators of treatment response for children with attention-deficit/hyperactivity disorder: the Multimodal Treatment Study of Children With Attention-Deficit/Hyperactivity Disorder. *Arch Gen Psychiatry*. 1999; 56(12):1088–1096. [PubMed: 10591284]
14. Bauman LJ, Wright E, Leickly FE, et al. Relationship of adherence to pediatric asthma morbidity among inner-city children. *Pediatrics*. 2002; 110(1 pt 1) Available at: www.pediatrics.org/cgi/content/full/110/1/e6.
15. American Academy of Pediatrics, Subcommittee on Attention-Deficit/Hyperactivity Disorder and Committee on Quality Improvement. Clinical practice guideline: treatment of the school-aged child with attention-deficit/hyperactivity disorder. *Pediatrics*. 2001; 108(4):1033–1044. [PubMed: 11581465]
16. Cox ED, Smith MA, Brown RL. Evaluating deliberation in pediatric primary care. *Pediatrics*. 2007; 120(1) Available at: www.pediatrics.org/cgi/content/full/120/1/e68.
17. Wissow LS, Gadowski A, Roter D, et al. Improving child and parent mental health in primary care: a cluster-randomized trial of communication skills training. *Pediatrics*. 2008; 121(2):266–275. [PubMed: 18245417]
18. McWilliams DB, Jacobson RM, Van Houten HK, Naessens JM, Ytterberg KL. A program of anticipatory guidance for the prevention of emergency department visits for ear pain. *Arch Pediatr Adolesc Med*. 2008; 162(2):151–156. [PubMed: 18250240]

19. Hudson JL, Miller GEP, Kirby JB. Explaining racial and ethnic differences in children's use of stimulant medications. *Med Care*. 2007; 45(11):1068–1075. [PubMed: 18049347]
20. Stevens J, Harman JS, Kelleher KJ. Race/ethnicity and insurance status as factors associated with ADHD treatment patterns. *J Child Adolesc Psychopharmacol*. 2005; 15(1):88–96. [PubMed: 15741790]
21. Chen AY, Escarce JJ. Family structure and the treatment of childhood asthma. *Med Care*. 2008; 46(2):174–184. [PubMed: 18219246]
22. Agency for Healthcare Research and Quality. [Accessed April 15, 2010] Medical Expenditure Panel Survey. Available at: www.meps.ahrq.gov/mepsweb/survey_comp/household.jsp
23. Landgraf, J.; Abaetz, L. The CHQ User's Manual. Boston, MA: Health Institute, New England Medical Center; 1996.
24. Bird HR, Shaffer D, Fisher P, et al. The Columbia Impairment Scale (CIS): pilot findings on a measure of global impairment for children and adolescents. *Int J Methods Psychiatr Res*. 1993; 3:167–176.
25. Bird HR, Andrews H, Schwab-Stone M, et al. Global measures of impairment for epidemiologic and clinical use with children and adolescents. *Int J Methods Psychiatr Res*. 1996; 6:295–307.
26. Harris ES, Canning RD, Kelleher KJ. A comparison of measures of adjustment, symptoms, and impairment among children with chronic medical conditions. *J Am Acad Child Adolesc Psychiatry*. 1996; 35(8):1025–1032. [PubMed: 8755799]
27. McCulloch CE, Lin H, Slate EH, Turnbull BW. Discovering subpopulation structure with latent class mixed models. *Stat Med*. 2002; 21(3):417–429. [PubMed: 11813228]
28. Bartholomew, DJ. The Analysis and Interpretation of Multivariate Data for Social Scientists. Boca Raton, FL: Chapman & Hall/CRC; 2002.
29. Goodman L. On the assignment of individuals to latent classes. *Sociol Methodol*. 2007; 37:1–22.
30. Graubard BI, Korn EL. Predictive margins with survey data. *Biometrics*. 1999; 55(2):652–659. [PubMed: 11318229]
31. US Department of Health and Human Services, Health Resources and Service Administration, Maternal and Child Health Bureau. The National Survey of Children With Special Health Care Needs: Chart book 2005–2006. Rockville, MD: US Department of Health and Human Services; 2008.
32. Kogan MD, Strickland BB, Blumberg SJ, Singh GK, Perrin JM, van Dyck PC. A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics*. 2008; 122(6) Available at: www.pediatrics.org/cgi/content/full/122/6/e1149.
33. Cox ED, Raaum SE. Discussion of alternatives, risks and benefits in pediatric acute care. *Patient Educ Couns*. 2008; 72(1):122–129. [PubMed: 18343624]
34. Lewis CC, Pantell RH, Sharp L. Increasing patient knowledge, satisfaction, and involvement: randomized trial of a communication intervention. *Pediatrics*. 1991; 88(2):351–358. [PubMed: 1861939]
35. Merenstein D, Diener-West M, Krist A, Pinneger M, Cooper LA. An assessment of the shared-decision model in parents of children with acute otitis media. *Pediatrics*. 2005; 116(6):1267–1275. [PubMed: 16322146]
36. 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. [PubMed: 10506246]
37. 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):1522–1528. [PubMed: 15121921]
38. American Academy of Pediatrics, Section on Telephone Care and Committee on Child Health Financing. Payment for telephone care. *Pediatrics*. 2006; 118(4):1768–1773. [PubMed: 17015574]
39. Kleiner KD, Akers R, Burke BL, Werner EJ. Parent and physician attitudes regarding electronic communication in pediatric practices. *Pediatrics*. 2002; 109(5):740–744. [PubMed: 11986430]

40. Gerstle RS. American Academy of Pediatrics, Task Force on Medical Informatics. E-mail communication between pediatricians and their patients. *Pediatrics*. 2004; 114(1):317–321. [PubMed: 15231952]
41. Rosen P, Kwok CK. Patient-physician e-mail: an opportunity to transform pediatric health care delivery. *Pediatrics*. 2007; 120(4):701–706. [PubMed: 17908755]
42. Cooper-Patrick L, Gallo JJ, Gonzales JJ, et al. Race, gender, and partnership in the patient-physician relationship. *JAMA*. 1999; 282(6):583–589. [PubMed: 10450723]
43. Stevens GD, Shi L, Cooper LA. Patient-provider racial and ethnic concordance and parent reports of the primary care experiences of children. *Ann Fam Med*. 2003; 1(2):105–112. [PubMed: 15040440]
44. Street RL, Gordon H, Ward M, Krupat E, Kravitz RL. Patient participation in medical consultations: why some patients are more involved than others. *Med Care*. 2005; 43(10):960–969. [PubMed: 16166865]
45. Kaplan SH, Greenfield S, Gandek B, Rogers WH, Ware JE Jr. Characteristics of physicians with participatory decision-making styles. *Ann Intern Med*. 1996; 124(5):497–504. [PubMed: 8602709]

WHAT'S KNOWN ON THIS SUBJECT

The Institute of Medicine has prioritized SDM in health care, yet little is known regarding factors associated with SDM. Using a national sample, the authors explored this process among children with ADHD and asthma, which are prototypes for SDM in pediatrics.

WHAT THIS STUDY ADDS

The authors found that families with the most impaired children or difficulty contacting their clinician by telephone were least likely to have high SDM. Results suggest that researchers should examine how strategies to improve communication affect SDM.

TABLE 1

Items Included in the Latent Class Analysis of SDM

SDM Items From the MEPS	Corresponding Component(s) of the Definition of SDM ^a	Scoring
If there were a choice between treatments, how often would your medical provider ask you to help make the decision?	1, 4	1 (never), 2 (sometimes), 3 (usually), 4 (always)
Does a medical person at your usual source of care present and explain all options to you?	2	1 (no), 4 (yes)
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	1 (never), 2 (sometimes), 3 (usually), 4 (always)
In the last 12 months, how often did your child's doctors or other health providers listen carefully to you?	2, 3	1 (never), 2 (sometimes), 3 (usually), 4 (always)
In the last 12 months, how often did your child's doctors or other health providers explain things in a way that you could understand?	2, 3	1 (never), 2 (sometimes), 3 (usually), 4 (always)
In the last 12 months, how often did your child's doctors or other health providers show respect for what you had to say?	3, 4	1 (never), 2 (sometimes), 3 (usually), 4 (always)
In the last 12 months, how often did your child's doctors or other health providers spend enough time with you?	2	1 (never), 2 (sometimes), 3 (usually), 4 (always)

^aComponents 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; and (4) both the doctor and the patient agree on the treatment to implement.

TABLE 2

Comparison of Children With ADHD, a Pattern of SDM Determined, and a Usual Source of Care to All Other Children With ADHD

Variable	SDM Pattern Assigned and Have a Usual Source of Care, <i>n</i> (%)	Others, <i>n</i> (%)	<i>P</i> , Unadjusted	<i>P</i> , Adjusted ^a
Total population of children with ADHD ^{b,c}	2 264 866 (92.6)	180 994 (7.4)		
Child age, <i>y</i> ^d			.01	<.001
4	0.4	0.0		
5–12	62.0	53.7		
13–17	37.6	45.6		
Gender, female	27.7	34.1	.32	.24
Race			.85	.62
White	82.8	81.5		
Black	11.6	11.4		
Other	5.6	7.1		
Hispanic	11.1	6.9	.09	.07
Parental education			.25	.17
No degree	9.8	8.6		
High school complete	50.0	61.4		
Bachelor's degree	16.4	8.9		
Graduate-level degree	7.1	9.0		
Other degree ^e	16.6	11.6		
Poverty			.46	.30
Poor	19.3	18.9		
Near poor	5.2	2.0		
Low income	15.4	16.8		
Middle income	34.4	42.0		
High income	25.7	20.3		
Insurance coverage			.002	.001
Any private	65.2	53.8		
Public only	32.8	35.6		
Uninsured	2.0	10.6		
Region ^f			<.001	0.92
Northeast	18.2	18.9		
Midwest	21.4	22.1		
South	45.3	44.4		
West	15.1	10.6		

^a*P* values were determined by using the Wald test. *P* values for each factor were adjusted for all other variables listed.

^bBased on the average number of children with ADHD per year across all study years.

^cThere was no difference in the proportion of children with a class assigned according to year (*P* = .73).

^dAge was unavailable for 0.7% of the children in this group.

^eThe remainder of children in this group did not have their parental education designated or had a parent younger than 16 years.

^fFour percent of the children in this group did not have an assigned region.

TABLE 3

Comparison of Those Children With Asthma, a Pattern of SDM Determined, and a Usual Source of Care to All Other Children With Asthma

Variable	SDM Pattern Assigned and Have a Usual Source of Care, <i>n</i> (%)	Others, <i>n</i> (%)	<i>P</i> , Unadjusted	<i>P</i> , Adjusted ^a
Total population of children with asthma in MEPS ^{b,c}	4 032 411 (94.3)	243 741 (5.7)		
Child age, y ^d			<.001	.41
4	24.7	27.1		
5–12	51.7	43.1		
13–17	23.6	24.6		
Female	41.0	37.8	.49	.59
Race			.07	.49
White	70.9	60.8		
Black	22.3	28.4		
Other	6.8	10.8		
Hispanic	17.9	24.5	.06	.51
Parental education			.04	<.001
No degree	13.2	16.9		
High school complete	45.2	57.1		
Bachelor's degree	17.6	10.0		
Graduate-level degree	9.9	4.2		
Other degree	14.1	11.8		
Poverty			.002	.35
Poor	21.2	25.5		
Near poor	5.5	8.6		
Low income	15.9	27.4		
Middle income	30.4	24.9		
High income	27.0	13.6		
Insurance coverage			<.001	.01
Any private	61.6	45.8		
Public only	35.7	44.7		
Uninsured	2.7	9.5		
Region ^e			.006	.28
Northeast	20.1	17.2		
Midwest	20.9	14.1		
South	38.6	41.3		
West	20.4	26.0		

^aAdjusted *P* values were calculated by using the Wald test. Estimates were adjusted for all other variables listed in this table.

^bBased on the average number of children with asthma per year across all study years.

^cThere was no difference in the proportion of children with a class assigned according to year (*P* = .91).

^d Age was unavailable for 5.2% of the children in this group.

^e Of the children in this group, 1.4% did not have an assigned region.

TABLE 4

Characteristics Associated With High SDM Among Children With ADHD

Variable	High SDM (Unadjusted), %	High SDM (Standardized ^a), % (95% CI)	P
Demographic characteristic			
Gender			
Male	65.2	73.6 (69.2–77.9)	Baseline
Female	65.7	73.0 (67.9–78.1)	.85
Race			
White	65.6	72.9 (68.9–77.0)	Baseline
Black	63.3	73.7 (66.1–81.4)	.83
Other	66.1	76.5 (65.5–87.5)	.56
Parental education			
No degree	62.5	74.0 (65.7–82.3)	Baseline
High school complete	64.7	73.8 (68.9–78.8)	.97
Bachelor's degree	62.2	70.8 (62.5–79.1)	.60
Graduate-level degree	61.5	66.8 (53.8–79.9)	.38
Other degree	73.7	78.8 (72.1–85.4)	.33
Insurance coverage			
Any private	68.0	75.0 (70.3–79.6)	Baseline
Public	60.2	70.2 (64.5–75.9)	.21
None	60.2	70.0 (44.6–94.8)	.67
Health status			
General health: score on Child Health Questionnaire items			
Low (worst health)	51.0	63.7 (54.4–72.9)	Baseline
Medium	58.8	67.2 (61.2–73.3)	.37
High (best health)	73.2	76.6 (72.6–80.5)	.003
Behavioral impairment: Columbia Impairment Scale (only includes children 5 y old)			
Unimpaired	75.4	75.1 (70.9–79.2)	Baseline
Impaired	57.0	62.2 (57.1–67.3)	<.001
Access to care			
Difficulty in getting to usual source of care			
Very difficult	44.8	64.8 (45.3–84.4)	Baseline
Somewhat difficult	69.1	73.9 (63.9–83.9)	.43
Not too difficult	60.9	72.8 (66.6–79.0)	.38
Not at all difficult	67.5	73.5 (69.3–77.7)	.35
Difficulty in contacting usual source of care by telephone			
Very difficult	43.2	54.8 (38.6–70.9)	Baseline
Somewhat difficult	45.5	57.7 (47.2–68.1)	.74
Not too difficult	56.7	66.2 (59.5–72.9)	.18
Not at all difficult	75.6	80.6 (76.7–84.6)	<.001

^aMarginal standardization was used for comparisons and can be interpreted as the fraction of subjects who would engage in full participation if standardized to the characteristics of the entire sample.

TABLE 5

Characteristics Associated With High SDM Among Children With Asthma

Variable	High SDM (Unadjusted), %	High SDM (Standardized ^a), % (95% CI)	P
Demographic characteristic			
Gender			
Male	66.4	68.6 (65.3–71.8)	Baseline
Female	63.9	66.9 (62.9–70.9)	.47
Race			
White	67.0	69.0 (65.7–72.2)	Baseline
Black	61.8	65.1 (59.9–70.3)	.14
Other	59.8	60.7 (53.3–68.0)	.04
Parental education			
No degree	63.6	69.8 (64.4–75.3)	Baseline
High school complete	64.7	67.7 (63.7–71.8)	.46
Bachelor's degree	66.1	65.8 (60.0–71.5)	.29
Graduate-level degree	72.9	70.1 (61.8–78.4)	.96
Other degree	63.2	66.7 (60.5–72.9)	.45
Income			
Poor	61.0	63.5 (56.9–70.0)	Baseline
Near poor	55.7	61.2 (51.5–70.8)	.69
Low income	64.5	67.0 (62.1–71.9)	.28
Middle income	66.1	69.4 (64.8–74.0)	.17
High income	70.6	70.0 (64.0–76.0)	.2
Insurance coverage			
Any private	67.2	67.1 (63.9–70.3)	Baseline
Public	63.1	70.5 (65.0–75.9)	.32
None	54.7	59.8 (44.9–74.6)	.32
Region			
Northeast	69.0	71.2 (64.7–77.7)	Baseline
Midwest	69.9	69.8 (66.2–73.4)	.69
South	63.3	66.2 (61.5–70.9)	.2
West	60.9	65.6 (60.8–70.4)	.16
Health status			
General health: score on Child Health Questionnaire items			
Low (worst health)	58.7	61.5 (56.8–66.2)	Baseline
Medium	62.5	63.6 (60.0–67.2)	.42
High (best health)	71.9	69.9 (66.2–73.7)	.002
Behavioral Impairment: Columbia Impairment Scale (only includes children < 5 y old)			
Unimpaired	69.1	70.2 (66.9–73.4)	Baseline
Impaired	56.1	63.6 (58.1–69.0)	.03
Access to care			
Difficulty in getting to usual source of care			

Variable	High SDM (Unadjusted), %	High SDM (Standardized ^a), % (95% CI)	P
Very difficult	42.3	56.2 (39.4–73.0)	Baseline
Somewhat difficult	45.6	59.5 (48.5–70.6)	.73
Not too difficult	51.1	60.0 (53.7–66.2)	.68
Not at all difficult	70.7	70.3 (67.2–73.4)	.08
Difficulty in contacting usual source of care by telephone			
Very difficult	38.6	48.1 (36.3–59.9)	Baseline
Somewhat difficult	41.7	46.9 (39.7–54.2)	.86
Not too difficult	54.2	59.5 (53.8–65.2)	.07
Not at all difficult	76.1	76.8 (73.6–80.1)	<.001

^aMarginal standardization was used for comparisons and can be interpreted as the fraction of subjects who would engage in full participation if standardized to the characteristics of the entire sample.