Which Components of Medical Homes Reduce the Time Burden on Families of Children with Special Health Care Needs?

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Objectives. To examine which components of medical homes affect time families spend arranging/coordinating health care for their children with special health care needs (CSHCNs) and providing health care at home.

Data Sources. 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN), a population-based survey of 40,242 CSHCNs.

Study Design. NS-CSHCN is a cross-sectional, observational study. We used generalized ordered logistic regression, testing for nonproportional odds in the associations between each of five medical home components and time burden, controlling for insurance, child health, and sociodemographics.

Data Collection/Extraction Methods. Medical home components were collected using Child and Adolescent Health Measurement Initiative definitions.

Principal Findings. Family-centered care, care coordination, and obtaining needed referrals were associated with 15–32 percent lower odds of time burdens arranging/coordinating and 16–19 percent lower odds providing health care. All five components together were associated with lower odds of time burdens, with greater reductions for higher burdens providing care.

Conclusions. Three of the five medical home components were associated with lower family time burdens arranging/coordinating and providing health care for children with chronic conditions. If the 55 percent of CSHCNs lacking medical homes had one, the share of families with time burdens arranging care could be reduced by 13 percent.

Key Words. Care coordination, children, chronic illness, medical home, family time burden

Patient-centered medical homes (PCMHs) are designed to improve quality of care and reduce costs, especially for patients with complex medical needs, by coordinating care more effectively (Medical Home Initiatives for Children with Special Needs Project Advisory Committee 2002; Barr 2008;

Rittenhouse and Shortell 2009). Four medical professional societies organized behind the concept in 2007 and have worked with the National Committee on Quality Assurance (NCQA) to build a program that guides physicians through its implementation (Cassidy 2010; Gray, Weng, and Holmboe 2012). Evaluations of the PCMH have focused on use of medical services (e.g., hospitalizations, emergency room visits), indices of quality (e.g., preventive services, blood pressure control), patient experience and satisfaction, and costs. Results are somewhat mixed, but many studies show lower costs with the same or better quality (Cassidy 2010; Gray, Weng, and Holmboe 2012; Martsof et al. 2012; Paustian et al. 2013). The time burden that arranging and providing health care imposes on patients and families is another important outcome for those with complex medical needs, but it has received less attention.

While the NCQA's definition is widely used, medical homes were first developed for children with special health care needs (CSHCNs) (The Child and Adolescent Health Measurement Initiative [CAHMI] 2009b; Cassidy 2010; Fields, Leshen, and Patel 2010; Laraque and Sia 2010). The Maternal and Child Health Bureau (MCHB) defines CSHCNs as children with chronic physical, developmental, behavioral, or emotional conditions that require medical care beyond that required by children generally (McPherson et al. 1998). The MCHB's definition of a medical home shares themes common to other definitions (e.g., care coordination) but also reflects the need to consider the whole family. Drawing on extensive research led by the Child and Adolescent Health Measurement Initiative (CAHMI), the MCHB developed and refined its definition for use in the periodic National Surveys of Children with Special Health Care Needs (NS-CSHCN), which ask about medical homes' five components: usual source of care, personal doctor or nurse, family-centered care, coordinated care, and obtaining needed referrals (CAHMI 2009b; National Center for Health Statistics [NCHS] 2007). These items effectively capture the American Academy of Pediatrics definition of medical home (Bethell, Read, and Brockwood 2004).

Researchers who study medical homes have drawn attention to variation in their form across settings, which allows medical homes to adapt to particu-

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lar patients and their needs, but also makes it more difficult to identify exactly what is, or is not, working (Cassidy 2010; Thygeson et al. 2012). Which components are successful? Can they work independently or do all need to be in place to be effective (Paustian et al. 2013)? Identifying the specific services offered, and tasks done, by medical homes might be more informative than treating the concept as an undifferentiated whole.

Studies of CSHCNs have found that medical homes are associated with fewer hospitalizations (Cooley et al. 2009), less delayed or foregone care, and fewer unmet needs (Benedict 2008; Strickland et al. 2009; Kuo, Bird, and Tilford 2011; Miller et al. 2013), fewer missed school days (Arauz Boudreau et al. 2012; Katz et al. 2012), and better parental coping with the stress of caring for their child (Arauz Boudreau et al. 2012; Drummond, Looman, and Phillips 2012). Research has also established associations between medical homes and lower risks of several types of family financial burden: out-of-pocket medical costs, additional income needed, and other financial problems (Kuhlthau et al. 2005; Kogan et al. 2008; Kuo, Bird, and Tilford 2011; Katz et al. 2012), family members having to cut back or quit paid employment (Kuhlthau et al. 2005; Kogan et al. 2008; Okumura et al. 2009; DeRigne and Porterfield 2010; Kuo, Bird, and Tilford 2011; Katz et al. 2012), and combinations of those burdens (Viner-Brown and Kim 2005; Kogan et al. 2008). For CSHCNs as for other population groups, however, less attention has been paid to associations between medical homes and families' time burdens arranging/coordinating or providing health care at home.

The time required to arrange and provide medical care for children with disabilities is a stressor for many families, one that could be substantially reduced by medical homes, which are intended to help with locating, arranging, and coordinating services to meet the particular needs of patients and families. Arranging and coordinating care encompasses scheduling appointments, ensuring that the child's primary provider, specialists, and others (e.g., home health aides, physical, speech, or respiratory therapists) are up to date about the child's diagnoses and treatments, and following up on services to address the child's needs (Fields, Leshen, and Patel 2010). In addition, many families provide health care themselves at home, forming what Schuster, Chung, and Vestal (2011) describe as a "shadow health care system," which includes frequent monitoring and interventions to prevent or manage complications from the child's condition (Leiter et al. 2004). The 2009–2010 NS-CSHCN showed that more than 60 percent of families of CSHCNs devoted at least 1 hour a week to arranging/coordinating or providing health care for the child, and one-sixth spent 11 hours a week or more (U.S. Department of Health and Human Services 2013).

Prior research has shown that medical homes are associated with lower odds of combined time burden (arranging and providing care) among children with autism (Kogan et al. 2008). Moreover, some individual medical home components are associated with lower time burdens. Families who reported adequate care coordination had lower odds of spending more than 4 hours per week arranging/coordinating care (Turchi et al. 2009), while family-centered care was associated with lower odds of spending 1 or more hours per week either arranging/coordinating or providing care (Kuo, Bird, and Tilford 2011). However, no association was found between medical homes, or their components, and a composite measure of both types of time among families of children with diabetes (Katz et al. 2012).

We used data from the 2009–2010 NS-CSHCN to build on prior studies in several ways. First, we separately analyzed time spent arranging/coordinating and providing health care, rather than only one or a composite of the two. Second, we used generalized ordered logistic regression to estimate the association between medical homes and ordered categories of time spent, rather than a single, binary indicator of time above some arbitrary cutoff, and allowed for nonproportionality in the odds ratios. Third, taking advantage of the fact that the NS-CSHCN asked respondents about each of the five components of medical homes, we estimated the associations between those components and time spent, to identify the specific mechanisms by which medical homes reduce time burdens. Fourth, we controlled for child's health status, insurance, and sociodemographics to estimate medical homes' effects net of those characteristics.

DATA AND METHODS

The 2009–2010 NS-CSHCN is a national, population-based survey of 40,242 CSHCNs conducted as part of the U.S. State and Local Areas Integrated Telephone Survey (MCHB 2012). The response rate was 43.7 percent for the land-line sample, 15.2 percent for the cellphone sample, and 25.5 percent overall (MCHB 2012). To be included in the sample, households had to have at least one child with a special health care need (SHCN), as defined by the CSHCN Screener (CAHMI 2009a). Respondents—parents or guardians who were the most knowledgeable in the household about the child's health and care—were asked whether the child used prescription medications; had elevated service use; had functional limitations; needed special therapies; and had emotional, developmental, or behavioral problems. Children who met one or more of

these criteria because of a medical, behavioral, or health condition that had lasted, or was expected to last, at least 12 months were classified as CSHCNs. Each child in the sample had at least one SHCN; 48 percent had more than one. Within households with more than one CSHCNs, one such child was randomly selected as the subject of the interview.

Dependent Variables—Time Burden

We used three dependent variables: time spent per week (1) *arranging or coordinating health care for the child*; (2) *providing health care for the child at home*; and (3) a *combined measure* of the two. Time spent arranging/coordinating care was collected using the question “How many hours per week do you or other family members spend arranging or coordinating [the sampled CSHCN]’s care? By this I mean making appointments, making sure that care providers are exchanging information, and following up on their care needs” (NCHS 2011). Time spent providing care was collected using the question: “Many families provide health care at home such as changing bandages, care of feeding or breathing equipment, and giving medication and therapies. Do you or other family members provide health care at home for [the sampled CSHCN]?” If the respondent said “yes,” he or she was asked how many hours were spent per week.

The responses to these open-ended questions were reported in the public use data as continuous hours per week up to 10, and categories of 11–20 and 21 or more (MCHB 2012). For arranging/coordinating care, 0 and <1 hour/week were a combined category. We created four categories of hours/week to categorize time arranging/coordinating and time providing care separately: none/<1, 1–5, 6–10, 11+. The combined time measure was categorized as “minimal” (none/<1 hour/week for *both* arranging and providing care), “low” (1–5 or 6–10 hours/week on one, with none/<1 on the other, or 1–5 hours/week on each), “moderate” (all other combinations except “high”), and “high” (21+ hours/week on either, or 11–20 hours on both); cases missing one time burden variable were classified based on the other.

Medical Home

The PCMH is defined by the American Academy of Pediatrics and other primary care professional organizations as “accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care” (Chen, Schrager, and Mangione-Smith 2012). The NS-CSHCN used the defi-

nition developed and refined by the MCHB in collaboration with national groups coordinated by CAHMI, and asked about a usual source of care, personal doctor or nurse, family-centered care, coordinated care, and obtaining needed referrals (NCHS 2007; CAHMI 2009b). We defined five dummy variables, each indicating the presence of one component; the reference category was lacking that component. In constructing the overall medical home indicator, children whose parents reported that they did not need referrals, care coordination, or family-centered care were classified as having those components. Children for whom all five components were present were classified as having a medical home, those with four or fewer as lacking a medical home. Cases missing information on one or more components were included in a separate “missing” category in regressions.

Control Variables

The regressions included controls for type of insurance at the time of interview and an indicator of whether those covered at the time of interview experienced insurance gaps in the preceding 12 months (Table 1). Because time burden can vary substantially depending on the child’s condition, we controlled for three summary measures of child’s health shown in Table 1 and defined in Appendix SA2. We also included indicators of whether the child currently had any of 20 specific diagnoses, listed in the figure notes; their prevalence is shown in Table SA3-1. Health status and health conditions were from parental reports. Finally, we controlled for sociodemographic covariates as coded in Table 1. Our analyses include CSHCNs with complete information on the covariates and providing care ($N = 37,700$), arranging/coordinating care ($N = 37,340$), and combined time burden ($N = 38,029$). See Appendix SA2 for information on how missing values were handled.

To investigate multicollinearity among covariates, we calculated variance inflation factors (VIFs). Except for “obtained needed referrals” ($VIF = 4.05$) and “income below 133 percent of the FPL” ($VIF = 2.64$), all VIFs were less than 2.0, below the cutoff of 2.5 used to identify problematic levels of collinearity (Allison 1999).

Statistical Methods

To maximize use of available information about time families spent arranging/coordinating or providing care, we used Stata’s *gologit3* procedure with

Table 1: Descriptive Statistics on Time Burden and Covariates, 2009–2010 National Survey of Children with Special Health Care Needs

	<i>N</i> *	% [‡]
Time burden		
Arranging and coordinating care for the child		
None or <1 hour/week	19,310	47.8
1–5 hours/week	15,489	43.7
6–10 hours/week	1,259	4.2
11+ hours/week	1,282	4.3
Providing health care for the child at home		
None or <1 hour/week	25,898	66.0
1–5 hours/week	7,611	20.7
6–10 hours/week	1,589	5.0
11+ hours/week	2,602	8.3
Combined time burden: Providing, arranging/coordinating [‡]		
Minimal	16,762	40.0
Low	16,591	45.4
Moderate	2,332	7.0
High	2,344	7.5
Health system factors		
Medical home—overall		
Has medical home	17,728	42.5
Lacks medical home	19,583	54.8
Missing	1,034	2.7
Medical home subcomponents (more than one can apply for each respondent)		
Has personal doctor or nurse	35,103	93.4
Has usual source of care	33,957	89.6
Receives family-centered care	25,724	65.4 [§]
Receives care coordination	16,465	57.0 [¶]
Able to obtain needed referrals	9,870	77.6**
Insurance type		
Private and other comprehensive	23,921	54.7
Public	10,606	34.1
Private and public	2,746	7.9
Uninsured	1,072	3.4
Insurance continuity		
Currently uninsured or insured continuously	36,533	94.3
Currently insured, with gaps over year	1,812	5.7
Child's health status		
Screeners subgroup		
Functional limitations (alone or w/other SHCNs)	8,374	23.0
Prescription meds and elevated services	8,349	21.4
Elevated services only	5,470	15.4
Prescription meds only	16,152	40.3

Continued

Table 1. *Continued*

	<i>N</i> *	% [†]
Activity limitations		
Consistently, often a great deal	9,026	26.3
Moderately, some of the time	14,886	38.5
Never	14,433	35.2
Stability of child's health care needs		
Change all the time	2,100	6.9
Change once in a while	10,047	27.5
Usually stable	26,154	65.5
None of the above	44	0.1
Sociodemographic factors		
Family income, imputed		
133% or less of federal poverty level (FPL)	8,761	28.9
>133–200% of FPL	4,921	14.3
>200–300% of FPL	6,478	16.2
>300–400% of FPL	5,584	12.6
Above 400% of FPL or higher	12,601	27.9
Education, imputed		
High school or less	7,639	30.5
At least some college	30,706	69.5
Number of adults in the household, imputed		
One	5,213	18.2
Two	25,320	62.1
Three or more	7,812	19.7
Language spoken at home, imputed		
English	36,982	93.6
Non-English	1,363	6.4
Number of CSHCN in household		
1 [index CSHCN only]	30,682	64.9
1 or more other CSHCN	7,663	35.1
Number of non-CSHCNs in household		
No non-CSHCNs	16,581	47.5
1 non-CSHCN	13,732	33.0
2+ non-CSHCNs	8,032	19.5
Race/ethnicity, imputed		
Non-Hispanic white	26,792	59.5
Non-Hispanic black	3,819	16.2
Hispanic	4,206	16.5
Other	3,528	7.8
Child's age (years)		
5 or younger	6,942	20.8
6–11	15,069	38.6
12–17	16,334	40.6

Continued

Table 1. *Continued*

	<i>N</i> [*]	% [†]
Child's sex		
Male	23,010	59.4
Female	15,335	40.6
Residence		
Rural	5,733	15.3
Urban	20,655	74.6
Missing	11,957	10.1

*Unweighted *N*.

†Weighted to the population level using weights provided with the NS-CSHCN (MCHB 2012).

‡The combined measure was calculated from the measures of (1) arranging/coordinating and (2) providing care and categorized as “minimal” (none/<1 hour/week for *both* providing and arranging care), “low” (1–5 or 6–10 hours/week on one variable with 0 or <1 on the other, or 1–5 hours/week on each), “moderate” (all other combinations of time burden except high), and “high” (21+ hours/week on either variable, or 11–20 hours on both); cases who were missing values of one time burden variable were classified based on the other time burden measure.

§Of the 37,238 cases who reported a need for family-centered care.

¶Of the 27,882 cases who reported a need for care coordination.

**Of the 12,206 cases who reported a need for referrals.

the autofit option to estimate generalized ordered logistic regressions with controls for health insurance, child's health, and sociodemographic characteristics. The autofit option tests each covariate for *nonproportionality* using a Wald statistic (Williams 2006). If proportionality is confirmed, one adjusted odds ratio (AOR) is estimated. If proportionality is violated, the procedure estimates separate AORs for each contrast (Fu 1998): <1 versus 1+, <6 versus 6+, and <11 versus 11+ hours/week. For parsimony, our final models specified proportional AORs for all covariates except those for which the procedure showed nonproportionality at $p < .01$, a *partial proportional odds* specification (Williams 2006). See Appendix SA2 for more detail.

For each dependent variable, we estimated three multivariable regressions, each with a different approach, explained more fully in the results section, to specifying medical home components: (1) *overall* medical home; (2) separate dummy variables for presence of each of the five medical home *components*; (3) indicators of “all except __” for each medical home component. To assess the potential impact of increasing the availability of medical home components, we calculated attributable risk, a statistic that estimates the importance of a risk factor (e.g., *lack* of a medical home component) by combining information on the AOR and prevalence of that risk factor (see Appendix SA2 for details on the calculations).

The NS-CSHCN used a complex sample design that drew a representative sample from each of the 50 U.S. states and the District of Columbia. Except as noted, all statistics were weighted to the national population of CSHCNs using the child interview weights (MCHB 2012) and the *svy* commands with *subpop* option in *Stata* 12.1 (StataCorp 2011), adjusting for the complex sample design.

RESULTS

In our analytic sample, more than half of families with CSHCNs (52.2 percent) spent at least an hour per week arranging/coordinating care (Table 1). The mode was 1–5 hours (43.7 percent of all families), but 4.2 percent spent 6–10, and 4.3 percent spent 11 or more. More than a third of families spent at least an hour each week providing health care for the child at home: about one-fifth spent 1–5, 5.0 percent spent 6–10, and 8.3 percent spent 11 or more hours.

Multivariable Analysis of Overall Medical Home

Figure 1 shows the adjusted odds ratios (AORs) for each time burden outcome (arranging/coordinating care; providing care; combined) by presence of a medical home. After controlling for child's health status and health conditions, insurance, and sociodemographic characteristics, families whose CSHCNs had a medical home had reduced odds of each time burden. Proportional odds were confirmed for arranging/coordinating care and the combined time measure. The AOR for arranging/coordinating was 0.64 (shown for all three contrasts in Figure 1), showing 36 percent lower odds for those with medical homes. The AOR for the combined measure was 0.73, a reduction of 27 percent.

Having a medical home was associated with nonproportional odds of providing health care for the child at home, with increasing protection against being in the highest time categories (Figure 1). The AOR for <1 versus 1+ hours/week was 0.92 and not statistically significant; the AORs for <6 versus 6+ and <11 versus 11+ hours/week were 0.80 and 0.75, respectively, both $p < .01$. Thus, medical homes were associated with 20 percent lower odds of spending more than 6 hours/week providing care at home. Neither a binary nor a standard ordered logistic model (which assumes proportionality) revealed the larger effect at higher time burdens.

Figure 1: Adjusted Odds Ratios and 95 percent Confidence Intervals for Association between Presence of Medical Home and Time Burden for Families of Children with Special Health Care Needs, by Type of Time Burden, Allowing for Nonproportional Odds, 2009–2010 NS-CSHCN

Note. Based on generalized ordered logistic regressions of each time burden, controlling for all variables shown in Table 1 as well as indicators of whether the child has ADHD, allergies, anxiety, arthritis, asthma, autism, behavior problems, blood problems, cerebral palsy, cystic fibrosis, depression, developmental delays, diabetes, Down syndrome, epilepsy, heart problems, intellectual disability, migraines, muscular dystrophy, and traumatic brain injury. The AORs are from separate models of each time burden outcome. Weighted to the population level using weights provided with the NS-CSHCN (MCHB 2012).

Multivariable Analysis of Medical Home Components

Multivariable regressions in which the medical home dummy was replaced with five dummies, one for each medical home component, showed reduced odds of time burden for three of the components: family-centered care, care coordination, and no problems obtaining needed referrals (Figure 2). For example, care coordination was associated with 32 percent lower odds of a time burden arranging/coordinating care (AOR = 0.68), while obtaining needed referrals reduced the adjusted odds by 26 percent (AOR = 0.74). Associations with providing care at home were more modest (AORs = 0.81 and 0.84 for care coordination and referrals, respectively). Family-centered care was associated with lower odds of a time burden only for arranging care

Figure 2: Adjusted Odds Ratios and 95 percent Confidence Intervals for Associations between Individual Medical Home Components and Time Burden for Families of Children with Special Health Care Needs, by Type of Time Burden, 2009–2010 NS-CSHCN

Note. Based on generalized ordered logistic regressions of each type of time burden, controlling for all variables shown in Table 1 as well as indicators of whether the child has ADHD, allergies, anxiety, arthritis, asthma, autism, behavior problems, blood problems, cerebral palsy, cystic fibrosis, depression, developmental delays, diabetes, Down syndrome, epilepsy, heart problems, intellectual disability, migraines, muscular dystrophy, and traumatic brain injury. For each type of time burden, adjusted odds ratios (AORs) for the five subcomponents were all estimated within the same model. Weighted to the population level using weights provided with the NS-CSHCN (MCHB 2012).

(AOR = 0.85). Neither having a usual source of care nor personal doctor/nurse was statistically significantly associated with any of the three time burdens. AORs were proportional for all medical home components in all the time burden models; see Tables SA3-2, SA3-3, and SA3-4, which also include AORs for all covariates.

Multivariable Analysis of Lacking Only One Medical Home Component

As a more rigorous test of whether all five medical home components need to be in place before they affect time burden, we defined dummy variables for “all except ___” each component. For example, “all except care coordination”

applies to cases that have the other four components and lack only care coordination. These “all except__” variables isolate cases that have a specifically identifiable combination of medical home components, in contrast to indicators of presence of each component, which include all cases that have the named component regardless of how many or which other components they have. Results of these analyses confirm the importance of the medical home components identified above and show that complete medical homes provide something above and beyond the individual components. As shown in Figure 3, family-centered care, care coordination, and obtaining needed referrals are again the components most strongly associated with time burdens, especially time spent arranging/coordinating care. For instance, families of CSHCN who lacked only care coordination but had the other four medical

Figure 3: Adjusted Odds Ratios and 95 percent Confidence Intervals for Associations between *Lacking* Individual Medical Home Components and Time Burden for Families of Children with Special Health Care Needs, by Type of Time Burden, 2009–2010 NS-CSHCN

* Denotes non-proportional odds; see text.

Note. Compared to children with a complete medical home. Based on generalized ordered logistic regressions of each type of time burden, controlling for all variables shown in Table 1 as well as indicators of whether the child has ADHD, allergies, anxiety, arthritis, asthma, autism, behavior problems, blood problems, cerebral palsy, cystic fibrosis, depression, developmental delays, diabetes, Down syndrome, epilepsy, heart problems, intellectual disability, migraines, muscular dystrophy, and traumatic brain injury. Weighted to the population level using weights provided with the NS-CSHCN (MCHB 2012).

home components had 1.64 times the adjusted odds of a time burden for arranging care compared to CSHCNs with all five components, while those who lacked only referrals or lacked only family centered care had adjusted odds ratios of 1.60 and 1.23, respectively. The results were similar for providing care, although the differences associated with each medical home component were smaller.

In addition, the generalized ordered regressions of “all except __” revealed that a fourth medical home component also predicted time burden and had nonproportional odds: families of CSHCN who lacked only a personal doctor/nurse exhibited increasing adjusted odds of arranging/coordinating care for longer amounts of time: AOR = 1.23 ($p = .12$), 2.27, and 3.47 for time cutoffs of 1, 6, and 11 hours/week, respectively (Table SA3-5).

AORs of time burden decreased with increasing number of medical home components (Figure 3). Compared to CSHCNs who had all five medical home components, those with only two (any two) of the components had an AOR = 2.06 of arranging/coordinating care, while those with any three had an AOR of 1.78. Adjusted odds of a time burden providing care was also elevated for those with only two components.

To assess whether particular combinations of family-centered care, care coordination, and referrals were associated with greater reductions in time burden, we tested all possible two-way interactions between those components. The interaction terms were not statistically significant individually, nor did they improve the overall fit of the models for any of the time burdens compared to models with main effects terms only (data not shown).

DISCUSSION

Our analyses demonstrate that for families of CSHCNs, medical homes were associated with substantially lower odds of spending time arranging/coordinating care or providing health care for the child at home, even when insurance, child's health, and sociodemographic characteristics were controlled. The association was particularly large, 36 percent lower odds, for arranging/coordinating care, a primary objective of medical homes (Medical Home Initiatives for Children with Special Needs Project Advisory Committee 2002; Rittenhouse and Shortell 2009). The association with time spent providing care for the child at home was not uniform across the range of time spent, with virtually no association of medical homes when contrasting <1 to 1+ hours/week, but 20–25 percent lower odds for <6/6+ and <11/11+ hours/week. This

reduction may be particularly beneficial for the nearly 6 percent of families who average 3 or more hours per *day* providing health care. Overall, medical homes were associated with 27 percent lower odds of a combined time burden—arranging/coordinating plus providing care at home.

Our results contribute to an important next step in the evaluation of medical homes, identifying the effects of their specific components. Only three of the five components of medical homes were associated with lower time burden. Family-centered care, care coordination, and needed referrals had 15–32 percent lower odds of time burden arranging/coordinating care, and 16–19 percent lower odds of time burden providing care for the child at home, suggesting that these components are doing the most to help families. Yet having just four components together is not as effective as having all five—even missing one of the five was associated with increased odds of time burden.

These components are logically related to the types of time burden measured in this study. Having family-centered and coordinated care within a medical home that facilitates referrals can ease the time burden on families by transferring some tasks to medical office staff. Trained staff can assume responsibility for contacting specialists to find one who can treat the child and can assist families in identifying providers who will accept the child's insurance and making appointments. They have access to the child's medical records and can make them available to other providers, enhancing the chances that information about the child's health status, needs, and care will be coordinated across providers, and saving the family the time of acquiring copies to send to other providers.

By reducing the demands on parents who have employment, commuting, routine parenting, and other daytime responsibilities, such assistance can reduce chances that CSHCNs will receive suboptimal care or go without needed care (Miller et al. 2013) because their parents have difficulty fitting these tasks into already busy schedules. Our findings agree with studies using the 2005–2006 NS-CSHCN that found that adequate care coordination reduced the odds of spending more than 4 hours per week arranging/coordinating care (Turchi et al. 2009), and family-centered care reduced the odds of spending 1 or more hours per week (Kuo, Bird, and Tilford 2011).

The finding that medical homes, and specifically care coordination and referrals, also reduce time spent providing health care for the child at home has not been reported before, but it too is logically related to the components of medical homes associated with lower odds. It seems likely, for example, that medical homes refer families to professionals who can provide the necessary care, thus reducing parents' need to do so. Better coordinated care

would also be expected to improve the child's health and function, thus reducing the amount of care left to the family to provide.

Our results help explain others' findings about the effects of medical homes on parental employment. Using the 2005–2006 NS-CSHCN, Okumura et al. (2009) identified the same components—family-centered care, care coordination, and obtaining needed referrals—as associated with lowered odds of a parent having reduced or quit paid employment to care for the CSHCN. DeRigne and Porterfield (2010), Kuhlthau et al. (2005), and Kogan et al. (2008) found that medical homes were associated with lowered odds of cutting back or quitting paid employment, but they did not examine the separate medical home components.

This study has several strengths. First, our analyses revealed the importance of exploring specifications that take advantage of detailed ordinal measures of time burden rather than simplifying them to dichotomies, for example, <1 hour/week versus 1+, as previous studies have done. By using generalized ordered logistic regression and allowing for nonproportional AORs, we found protective effects of overall medical home on time spent providing health care at home for 6+ hours/week. We also found that having a complete medical home *except* for a personal doctor/nurse was associated with two to three times higher adjusted odds of arranging/coordinating care for more than 6 hours/week. When we estimated either binary or standard ordered logistic models, which assume proportionality of adjusted odds across all time categories, these associations with the highest time burdens were obscured in the average adjusted odds ratio. These findings are consistent with statistical evaluations comparing binary with ordered logistic regression, which have demonstrated that creating dichotomous measures of outcomes for which more detailed data are available can obscure important information about their associations with the covariates (MacCallum et al. 2002) and reduce statistical power (O'Connell and Amico 2010).

Another strength is that the NS-CSHCN is a large, national sample of CSHCNs, the population for which medical homes were originally developed (Laraque and Sia 2010). The survey contains a thoroughly tested measure of medical home, created and refined by a group of professional organizations including the MCHB and led by CAHMI (NCHS 2007; CAHMI 2009b). That measure has the advantage that patients are not asked directly whether they are in a medical home, but rather whether their child received specific types of assistance. Their answers are used to define the components of a medical home and ascertain whether the CSHCN has one, helping to overcome the problem identified by Cassidy (2010) that patients are often una-

ware that they are in a medical home and remain unclear what the term means. The NS-CSHCN also includes measures of child health status that allowed us to control for the child's medical needs. Finally, the 2009–2010 NS-CSHCN improved upon representativeness compared to previous rounds of the survey by including both landlines and cellphones (Centers for Disease Control and Prevention 2011).

This study also has limitations. First, respondents were asked to report time they or other family members spent arranging or providing care, so some were giving proxy reports, which may be less accurate than responses about time they themselves spent. Time burden estimates might also be affected by recall bias. In addition, the survey understates the total time parents spent on health care for their CSHCNs because it does not ask about time taking the child to appointments. Studies of adults have shown that these activities require a substantial amount of time, including travel and waiting time (Russell, Ibuka, and Carr 2008). These tasks are in addition to the constant supervision and therapeutic activities required by some conditions (McCann, Bull, and Winzenberg 2012), and the routine daily care that parents provide, including feeding, bathing, and supervising homework and bedtime.

Another limitation is that the measure of medical home used here is based on parental report of received services, which may differ from the services offered by practices as assessed against national standards such as the NCQA (2011). There is growing agreement, however, that deciding whether a patient has a medical home should be based on both provider and patient reports (Gray, Weng, and Holmboe 2012). Information on health status and service needs is also based on parental reports, which may overstate or understate their prevalence (Miller, Gaboda, and Davis 2001). Finally, the NS-CSHCN is a cross-sectional study, which makes it difficult to disentangle the relative timing of medical home components, parents' time on paid employment, and time caring for their child.

Our findings extend those of previous studies that focused on the effects of medical homes on the quality and costs of care (Fields, Leshen, and Patel 2010; Gray, Weng, and Holmboe 2012; Martsolf et al. 2012) by addressing another important outcome: time spent by family members arranging/coordinating health care, or providing health care for the CSHCN at home. Collectively, these results suggest that medical homes have substantial benefits for patients and their families, both in traditional health care settings and in patients' homes. Of particular importance, our findings add to the growing evidence base identifying the medical home components that are most instrumental in producing these benefits.

Attributable risk calculations suggest that if the 55 percent of CSHCNs who lack medical homes had one, the share of families with time burden arranging/coordinating care for the child could be reduced by as much as 13 percent. Offering care coordination to those who currently lack it would reduce the odds of a time burden arranging/coordinating care by 8 percent, while removing problems obtaining referrals would reduce the odds of a combined time burden (coordinating and providing health care at home) by 9 percent. These estimates provide upper bounds on potential reductions in time burden and could be achieved only if the entire association between medical homes and time burden were causal.

These benefits will not, however, be fully realized until all children with chronic illnesses have access to medical homes. In our 2009–2010 sample, only about half of CSHCNs had medical homes, based on parents' reports of services received, a finding consistent with the 2007–2008 National Ambulatory Medical Care Survey estimate that nearly half of all U.S. medical practices failed to meet NCQA standards for medical home recognition (Hollingsworth et al. 2012). Much remains to be done to make medical homes available to all CSHCNs and to other populations with complex medical needs who may benefit from them.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article:

Appendix SA1: Author Matrix.

Appendix SA2: Supplementary Data and Methods Material.

Appendix SA3: Supplementary Tables—Medical Home and Time Burden.