

NATIONAL PREVALENCE OF A QUALITY MEDICAL HOME FOR VULNERABLE CHILDREN WITH ASTHMA AND THE RELATIONSHIP WITH SCHOOL ENGAGEMENT AND AFTER- SCHOOL ACTIVITY PARTICIPATION

Final Report

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I. Introduction

A. Nature of the research problem

Researchers have previously linked medical home attributes to better child health care utilization outcomes such as decreased emergency visits and hospitalizations. While important, these adverse events are relatively rare and there is a need to understand the effects of a medical home on the daily lives of children with special health care needs (CSHCN). Moreover, we do not yet fully understand whether a medical home equally benefits vulnerable children. A method to assess child vulnerability through the use of child *risk profiles* has been validated.¹ Risk profiles have been useful in understanding disparities in primary care,¹⁻³ and in previous work to assess the prevalence of a quality medical home.⁴ Little is known of how risk profiles affect the linkage between having a medical home and child health outcomes.

This study examined whether attributes of primary care emphasized in a medical home model impact children's daily lives, specifically how children with asthma are able to attend and perform in school and the degree to which they are able to participate in after-school activities. Using the child risk profiles methodology, this study examined whether a medical home is equally beneficial for the most vulnerable children (i.e., those at higher risk for poor health outcomes). This study further examined the extent to which policy variables such as MCHB Title V funding allocations to CSHCN and primary health care provider capacity affected these relationships.

B. Purpose, scope, and methods of the investigation

Key to improving health outcomes for CSHCN is the idea a *medical home*². Since 1989, facilitating features of the medical home has been a foundation for MCHB's Title V programs for CSHCN.⁵ The purpose of the study was to assess the effects of having a high quality medical home on school performance and after-school activity participation of children with asthma and to examine whether this varied by child vulnerability level (measured by child risk profiles). The study used nationally representative survey data on over 10,700 children with asthma from two iterations of the National Survey of Children's Health carried out in 2003 and 2007.

¹ *Risk profiles*, described in full in the "variable specification section" below, are a methodology that counts well-known child risk factors for poor health outcomes. In this study, the risk profiles include risk factors based on race/ethnicity, poverty status, parent education level, child health insurance status, and language spoken at home.

² In 2002, the American Academy of Pediatrics issued a policy statement defining a *medical home*. The definition outlines an ideal model of primary care for children where the care provided is 1) accessible, 2) continuous, 3) comprehensive, 4) family-centered, 5) compassionate, 6) culturally effective, and 7) coordinated with any needed specialized services provided outside the primary care setting.

- The study aimed to answer three specific research questions:
- **Question 1:** Did changes in medical home quality occur over time, and did the changes occur differentially for less vs. more vulnerable children?
 - **Question 2:** Did a relationship exist between medical home quality and each of its key domains with reports of school performance and after-school activity participation?
 - **Question 3:** Did state level policy variables (i.e., Title V spending and primary care provider supply) affect reports of the cardinal features of a medical home?

C. Nature of the findings

The study results suggest that medical home quality declined slightly between 2003 and 2007, and declined the most for children at the highest level of risk (defined by a child risk profile based on race, poverty status, insurance coverage, parent education and family language spoken at home). The relationship of our medical home score with child school engagement and after-school participation was prominent. Before and after adjustment for personal characteristics, health insurance status, family environment, neighborhood variables, and asthma severity, total medical home score was associated with more days exercised and a greater likelihood of having performed community service or volunteer work. Additionally, the medical home features of access, comprehensiveness, and family-centered care remained favorably associated with 3 of the 6 measures of school engagement and after-school activity participation, even after adjustment. While assuring such care for children with asthma is only one of many factors likely to influence their daily life experiences, our preliminary analysis suggests that working to strengthen these medical home features may be one place to start in improving the management of children's chronic conditions and enhancing quality of life. After exploration of many permutations, neither of the two policy-level variables, primary care provider supply and Title V Spending on CSHCN, were strongly related to reported medical home quality.

II. Review of the Literature

In 2007, over 10 million children in the U.S. (or 13.8% of all children age 0-18) had ever been diagnosed with asthma, and about seven million children (or 9.4% of all children) were reported to currently have the disease.⁶ While the health care burden of children with asthma is significant, with rates of emergency visits and hospitalizations more than triple the average,⁷ asthma has a broader impact on the lives of children beyond their health care utilization. Children with mild persistent asthma may account for up to 70% of all childhood asthma, but rarely use health services beyond primary care, even though their daily life experiences may be greatly affected by asthma.⁸

In a review, van Gent et al. summarized the impact of asthma on children's daily life experiences, including school engagement, social functioning, and participation in sports and recreation.⁹ For example, children with uncontrolled asthma missed about two more school days annually than children with controlled asthma¹⁰⁻¹³ and were more likely to have comorbid behavior problems affecting school functioning.¹⁴⁻¹⁶ It also restricted family social activities, parents' employment, contacts with friends and relatives and attendance at social events—all factors that contribute to a full life.¹⁷⁻²⁰ Lastly, children

with asthma were about two to three times less likely to participate in vigorous physical activity and sports.²¹⁻²³

Studies have shown deficits in the prescription and appropriate use of preventive asthma medications, adoption of patient self-management tools, and coordination of care with specialists and schools.²⁴⁻²⁶ These and other elements of asthma care may be more effectively delivered in a practice that adopts the features of a medical home.²⁷ While poorer quality medical homes (e.g., practices that do not provide the features of a medical home as well, or provide fewer medical home features altogether) may contribute to poorer asthma control, there has been very little empirical work examining this.

III. Study Design and Methods

A. Study design

This study used nationally representative data from the 2003 and 2007 iterations of the NSCH conducted by the National Center for Health Statistics and the Federal Maternal and Child Health Bureau.²⁸ Depending on the analysis, we either compared data across years (from 2003 to 2007), conducted analysis in a single year only (2007), or combined the data from both years to yield larger sample sizes. For analyses of policy-level variables, we obtained annual Title V spending data on CSHCN as reported by states, primary care provider state-level counts from the Area Resource Files (2002-2008) and census data on the child population for each state to create per capita rates.

B. Population studied and sample selection

NSCH data were obtained via the State and Local Area Integrated Telephone Survey, which used the random-digit dial sampling frame of the National Immunization Survey to identify households with children <18 years in 50 U.S. states and District of Columbia.²⁹ One child in each home was randomly selected to be the focus of the survey. The respondent was an adult identified as "the parent or guardian living in the household knowing the most about the health and health care of the child." This was a parent in 96% of cases in 2003 and 94% of cases in 2007.

C. Sample selection

In our study, children were included only if they were at least 2 years old, because asthma is difficult to diagnose among children younger than two, and reported their child currently has asthma:

- The **2003 NSCH** was carried out from January 2003 to July 2004. It contains 102,353 interviews with a final response rate of 55.3%. In the sample, 8,360 children ages 2 years and older (9.4%) reported currently having asthma.
- The **2007 NSCH** was carried out from April 2007 to July 2008. It contains 91,642 interviews with a final response rate of 46.7%. In the sample, 7,673 children ages 2 years and older (9.4%) reported currently having asthma.
- For analyses of school-performance: only school-age children (6 years and older) from the 2007 NSCH were included in our analysis. In that sample, 6,357 of children ages 6 years and older (9.9%) reported currently having asthma.

D. Instruments used

Child Risk Profiles: This study examined five child risk factors for poor health care access and quality. They are based on child race/ethnicity, family poverty status,

parent education level, child health insurance coverage, and family language spoken at home. The categories considered to be “risk” include: 1) non-white race/ethnicity, 2) income <200% of the Federal Poverty Level (FPL) as calculated from reported family income and size by NSCH staff, 3) highest household education level < high school, 4) child uninsured status, and 5) not speaking English at home.

Medical Home Measures: Using previous studies as a guide,³⁰⁻³² we created indices for five of the seven AAP medical home features: 1) *access*, 2) *continuity*, 3) *comprehensiveness*, 4) *family-centered care*, and 5) *coordination of care*. For our analyses, we required two versions of the medical home measure, one for a comparison of medical home scores across years (using a core set of variables that were asked in both iterations of the NSCH), and one more robust measure to study the full relationship of medical home quality with school performance using the 2007 NSCH.

For the core medical home set, we used five variables with one variable reflecting each of the domains above (see bolded items in Appendix A). For the robust measure, the five features were each measured using one to five survey questions (see Appendix A, all items). The responses to each question were assigned a score from 0 to 12 to handle ordinal variables with two, three or four response categories using integers, with the scores equally numerically distributed across the spectrum and with 12 being the best score. A summary value for each feature was computed as the average of all non-missing questions. A total medical home score was the average of all non-missing values of the four features (i.e., an average of the averages). We decided a priori that 65% of the questions for each feature must have been answered in order to compute a feature score. About 25% of children with asthma did not use multiple medical services and so did not answer questions on coordination of care.

School Engagement and After-School Activity Participation: Three measures of school engagement were assessed: 1) the number of missed school days due to illness or injury (measured continuously), whether the child had repeated a grade since Kindergarten (yes/no), and the number of times the school contacted the parent about problems the child is having with school (measured continuously). Three measures of after-school activity participation were assessed. Physical activity was assessed by asking, “On how many days in the past week did your child exercise, play a sport, or participate in physical activity for 20+ minutes that made him/her sweat and breathe hard?” Participation in the past year in sports and performance of community service or volunteer work were assessed dichotomously (yes/no).

E. Statistical techniques employed

Analyses were computed using Stata10. Survey procedures were invoked for all analyses to account for the complex survey design. Descriptive statistics are provided for the national population of children with asthma, including independent and dependent variables (Table 1) but most analyses involved multivariable linear or logistic regressions with accompanying Beta coefficients (B) or odds ratios (OR), and their respective 95% confidence intervals (CI).

IV. Detailed Findings

A. Question 1: Before and after adjustment for personal characteristics, medical home quality appears to have declined slightly between 2003 and 2007 using a sub-set of core medical home measures that were present in both datasets. In unadjusted analyses,

the mean total core medical home score value declined from 10.82 to 10.59 for the population of children with asthma in 2003 and the population of children with asthma in 2007 ($p < .001$). Examined using a cut-off score at 11 (out of 12, i.e., the 50th percentile), the percent of children with asthma obtaining that total score or higher declined from 64.6% to 55.9% ($p < .0001$). After adjustment for the study covariates, the odds of having a total medical home score above the 50th percentile in 2007 vs. 2003 was $OR = 0.70$ [95% Confidence Interval (CI) = 0.61-0.80].

In examining whether the changes in medical home were different depending on whether a child is considered more or less vulnerable, we examined the relationship between the variable for year and the total core medical home score for each level of risk based on the child risk profile. To assure sufficient sample size for children at higher levels of risk, we grouped children with 3 risk factors and above into a single category. The odds ratio reflecting the medical home score in 2007 vs. 2003 for children with 0 risk factors was 1.11 (95% CI: 0.90-1.37), which was not statistically significant. For those with higher risk factor counts, the odds ratio was 0.68 (95% CI: 0.53-0.86), 0.48 (0.37-0.64), and 0.23 (95% CI: 0.12-0.46), respectively. The results indicate that the medical home appeared to decline more from 2003 to 2007 for higher risk children.

B. Question 2: Cross-sectional examination of children with asthma suggests that the reported quality of their primary care medical home is related to daily life experiences, measured by school engagement and after-school activity participation. In particular, total medical home score was significantly associated with all measures of after-school participation and all but one measure of school engagement—repeating a grade—after adjustment for personal characteristics and health insurance status. After further adjustment for family environment, neighborhood variables, and child asthma severity, total medical home score remained significantly associated with the number of days exercised in the past week and volunteering in the past year.

The three medical home features of access, comprehensiveness and family-centered care were most consistently associated with measures of school engagement and after-school participation and may be key features of a quality medical home for children with asthma. These findings held in all models. For instance, after adjustment for other factors, a one-point increase in access was correlated with 6% greater odds of playing sports and 9% greater odds of volunteering. A one-point increase in comprehensiveness was associated with a 1.29-day decrease in school days missed and 11% lower odds of repeating a grade. Finally, a one-point increase in family-centered care was associated with a 0.10-day increase in the number of days exercised in the past week and 9% higher odds of playing sports or taking sports lessons.

C. Question 3: In addition to the many personal level variables, we included two higher-level policy variables that we anticipated may be related to medical home quality. After much analysis, neither primary care provider to child population ratios, nor state Title V spending on CSHCN were related to our measures of medical home. Entered in logistic regression models as second order variables (level 2), the odds ratio for having a core total medical home score greater than 11, associated with the state per child capita spending on CSHCN (the 50th percentile) was nearly identical to 1 ($OR = 0.99$, 95% CI: 0.98-1.00). The odds ratio for primary care provider per 10,000 children in a state was in the expected direction ($OR = 1.08$, 95% CI: 0.97-1.19) but not statistically significant.

V. Discussion and Interpretation of Findings

A. Conclusions to be drawn from findings

This study adds to the knowledge about the value of a medical home for child health outcomes, and also highlights the ongoing barriers that many vulnerable children face in accessing a medical home. While it is difficult to explain the observed decline in the experience of medical home quality, the findings suggest that those who are most at risk for poor health outcomes (i.e., high risk profile children) were also the most likely to experience declines in medical home, as a population, over time. This highlights a need to continue to focus attention and resources on vulnerable children. The absence of a direct effect of primary care provider supply and Title V spending on CSHCN should not rule out the value of these essential structural features, but may reflect an absence of technical knowledge of how to enhance medical home practice. Only recently has the first demonstration of a medical home transformation initiative been published.

B. Explanation of study limitations

First, the data are cross-sectional and so only demonstrate an association, not causality, between medical home quality and a child's daily life experiences. Second, the NSCH did not allow us to account for all of the potential confounders. These include personal factors (child genetics and preferences for school achievement, getting exercise and playing sports), neighborhood factors (quality of schools, opportunities for after-school activity participation, and environmental asthma triggers), and health care factors (prescription and use of appropriate asthma medications), all of which may confound the relationship between medical home and school performance and participation. Third, the NSCH had a relatively low response rate, although survey weights are designed to account for non-response. Fourth, there is some potential endogeneity—that is, parents of healthier, more active and more school-engaged children might be more content overall and thus more likely to report better medical home experiences. Many of the questions asked of the parents, however, were reporting-type questions rather than subjective ratings, and so may be less prone to this bias.

C. Comparison with findings of other studies

Relatively few prior studies have examined the medical home quality for children, but the study results are consistent with those that have. For example, prior work has shown that having a regular source of primary care has been associated with the greater receipt of preventive care^{33, 34} fewer hospitalizations and emergency visits.^{35, 36} Also, several studies have examined similar disparities in discrete characteristics of primary care for children, such as the accessibility of care and continuity of the patient-provider relationship.³⁷⁻³⁹ Two studies have examined disparities in the prevalence of a medical home in a nationally representative sample of CSHCN. These studies found that only 50% received care that met established criteria for the medical home characteristics that were studied. The studies also showed that the likelihood of having a quality medical home was lower for racial/ethnic minorities and those with lower socioeconomic status.^{40, 41} Such findings have also been replicated in two states.^{42, 43}

D. Application of findings to MCH health care delivery situations

The results of this study provide some support for the movement to advance high quality medical homes. Practices serving children with asthma (and perhaps other chronic conditions) might consider efforts to improve access, comprehensiveness, and family-centered care and take steps to help assure that families do not face delays in

seeking needed care (e.g., adjusting clinic hours, retooling scheduling). For example, practices might enhance their medical interpreting services, which can encourage non-English speaking families to seek care and which can facilitate family-centered care.⁴⁴⁻⁴⁶

Why the medical home features of access, comprehensiveness and family-centered care may be particularly important to children with asthma is worth considering. Children with asthma require first and foremost access to health care services in order to begin to have their health needs attended to. Even when asthmatic children have access to health services, the symptoms of asthma are still often subtle and may occur only sporadically, making it difficult to diagnose, particularly in children. Often physicians must rely on reports of signs and symptoms from the children themselves and from their parents. Such ongoing, two-way communication requires that families receive all needed services (our measure of comprehensiveness) and that open lines of communication are encouraged and nurtured. For example, physicians need to be able to spend enough time with families and listen carefully as parents and children describe symptoms they experience and acknowledge the family context to help reduce asthma triggers and support management of asthma at home (our measures of family-centered care).^{47, 48}

An unexpected finding was that better coordination of care was associated with a higher likelihood of repeating a grade and a lower likelihood of playing sports. Though the results may reflect the difficulty of coordinating care, they may also be a reflection of the severity of illness among children who require specialty care, and thus, care coordination. Coordination questions as a whole were limited just to children who required specialty care, and specific questions were further limited to just those that said they needed care coordination. As a result, children whose parents report better coordination scores are more likely to have severe asthma and poorer health status.

E. Policy implications

Shifts towards strengthening the prevalence and capacity of primary care medical homes are beginning to be rewarded at a system level. Federal health care reform has a specific goal of establishing medical home practices as the foundation of good quality primary care, the Medicare program is piloting enhanced reimbursement for medical home practices, and the National Committee for Quality Assurance provides medical home certification (accepted as a standard by Medicare). In addition, many state level organizations working to accelerate the growth of medical home practices.⁴⁹ These investments in medical home quality in turn may contribute to improving the daily life experiences of asthmatic children. But our research also cautions that children who are considered particularly vulnerable are the least likely to experience a medical home and thus may require special investments to make sure they benefit equally.

F. Suggestions for further research

All of our study results are based on cross-sectional relationships. While the theory is well understood for the value of a medical home, and cross-sectional work such as ours is demonstrating empirical associations between a positive medical home experience and improved utilization and outcomes, there is a great need for longitudinal and prospective study designs to evaluate the actual impact of a medical home. A next step for our research is to explore these study results over a multi-year period for those children who would most benefit from ongoing primary care, e.g., those with chronic diseases (such as asthma) or children who experience barriers (such as those defined as

more vulnerable according to our risk profiles) to accessing and establishing a basic primary care medical home relationship.

VI. List of Products

The following two articles from this study have been either accepted to peer-reviewed journals or are undergoing revision for re-submission.

- Stevens GD, Pickering TA, Laqui SA. Relationship of medical home quality with school engagement and after-school participation among children with asthma. *Journal of Asthma*. 2010 Nov;47(9):1001-10.

Note: Nominated as one of the “Top 10 Must Read Papers for School Health Physicians” by the Physician Section of the American School Health Association and the American Academy of Pediatrics Council on School Health.

- Stevens GD, Tsai KY, Vane CD. Changes in the national prevalence of a quality medical home for children: the experiences of vulnerable children. (Submitted to three journals without acceptance and so currently undergoing major revision).

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