Low Parental Literacy Associated with Worse Asthma Care Measures in Children

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Abstract

Objective—To determine if parental literacy is related to emergency department visits, hospitalizations, and days of school missed for children with asthma.

Methods—We performed a retrospective cohort study at a university pediatric clinic. We enrolled children between 3 and 12 years old with a diagnosis of asthma and a regular source of care at the site of the study and their parent or guardian. Primary asthma care measures included self-reported rates of emergency department visits, hospitalizations, and days of school missed. Secondary asthma care measures included rescue and controller medication use, classification of asthma severity and parental asthma-related knowledge.

Results—We enrolled 150 children and their parents. Twenty-four percent of the parents had low literacy. Children of parents with low literacy had greater incidence of emergency department visits (adjusted incidence rate ratio [IRR] 1.5; 95% CI 1.1, 2.1), hospitalizations (IRR 3.2; 1.4, 7.3), and days missed from school (IRR 2.5; 2.1, 3.0) even after adjusting for asthma-related knowledge, disease severity, medication use and other socio-demographic factors. Parents with low literacy had less asthma-related knowledge, and their children were more likely to have moderate or severe persistent asthma and had greater use of rescue medications.

Conclusions—Low parental literacy is associated with worse care measures for children with asthma.

Keywords

asthma; literacy; children; parents; hospitalization

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Introduction

Asthma is the most common chronic condition among children and prevalence is increasing. [1] Children with asthma miss more days of school, [2] have more unexpected emergency department (ED) visits and hospitalizations, and a higher rate of disability than children without asthma. [3] Hospitalization rates for children with asthma increased between 1998 and 2001. [4] Preventing poor outcomes requires prescribing and adhering to optimal therapies and effective self-management. [5]

As with many chronic conditions, disparities in asthma outcomes exist according to race and socioeconomic status. Black children are at greater risk for hospitalization, even after controlling for socioeconomic status. [4] Children of lower socioeconomic status have higher rates of hospitalization independent of their race[6] and report worse health status on self-report measures. [7] The reasons for these disparities are not well understood and may be related to severity of illness, environmental exposures, quality of care, and/or differing self-management strategies.

Low literacy is associated with a range of adverse health outcomes in adults including self-reported health status, diabetes control, HIV viral load, rate of all-cause hospitalization, and all-cause mortality. [8, 9] Additionally, low literacy is associated with several other markers of vulnerability including non-white race and low socioeconomic status (SES). [10] Many researchers have hypothesized that low literacy may be a contributing factor in disparities according to race or SES, although this research is just emerging. [11–13]

Adult asthma patients with low literacy have less knowledge about asthma self-management. [14] Specifically, adult asthma patients with low literacy scored lower on a knowledge test, and also performed worse on metered-dose inhaler technique. [14] Adults with low literacy also have higher rates of emergency department visits and lower asthma-related quality of life. [15] Fewer studies have examined the effect of parental or child literacy on child health outcomes and none have evaluated this relationship in children with asthma. In one study, parental literacy, but not child literacy, was related to glycemic control in children with type 1 diabetes. [16] Another study found no relationship between parental literacy and knowledge about pediatric health services. [17] Because parents are often responsible for ensuring self-management behaviors for young children, we sought to examine whether parental literacy may be related to asthma care measures in children. We hypothesized that children whose parents have low literacy would have worse asthma outcomes and processes of care independent of other important factors such as race or ethnicity , socioeconomic status, or severity of asthma.

Methods

Study Design

We conducted a retrospective cohort study in 3 outpatient pediatrics clinics (general, asthma and allergy, and pulmonary) at the North Carolina Children's Hospital, the public children's hospital of the state. Patients in these clinics receive care from attending faculty and residents from the University of North Carolina at Chapel Hill School of Medicine.

Study Participants

Potential subjects were identified at the beginning of each clinic session. A research assistant (RA) screened daily appointment lists for patients aged 3 to 12 years and reviewed their electronic medical records to determine potential eligibility. Patients were eligible if they had a clinical diagnosis of asthma for at least 3 months, as determined by the patient's physician, and a history of recurrent episodes of wheezing or coughing. Participants must have had a previous visit with a physician in the clinic no more than 12 months prior to the index visit.

They had to be undergoing treatment for asthma with one or more of the following: inhaled bronchodilators, inhaled corticosteroids or oral leukotriene inhibitors. The RA assessed medication use in the interview by asking about each type of medication supplemented by pictures. We excluded patients with a diagnosis of severe developmental delay, cystic fibrosis, severe neurological impairment, or those not accompanied by their primary caregiver on the day of the study.

The primary caregiver was defined as the person responsible for coordinating the medical care of the child and helping the child adhere to the asthma therapy, based on self-report. This could have been a sibling, parent, grandparent, aunt, uncle or guardian. In most cases, this was a parent. When more than one person accompanied the child to the visit, we asked which person considered themselves the primary caregiver, specifically in regard to the child's medical care. For the purposes of this paper, we will refer to all caregivers as parents. Parents had to be aged 18 years or older and use English as their primary language. The RA also reviewed the inclusion and exclusion criteria with each eligible patient and their parent to ensure that both did in fact meet eligibility criteria.

This study was approved by the University of North Carolina at Chapel Hill Biomedical Institutional Review Board. Written consent was obtained from parents before enrollment, and written assent was obtained from children aged 7 years or older. Because we were likely to encounter parents and patients who could not read well, we designed the consent form with plain language, and it was read aloud for those who had trouble understanding the form.

Procedures

Participants were recruited between January 2004 and March 2005. If the patient and parent met eligibility criteria and consented to participate, the RA administered a questionnaire to the parent; to mitigate literacy-related barriers to questionnaire responses, all questions were read aloud in a private area within the clinic (office or exam room). All data were collected during one clinic session. The RA did not assess literacy level in the parent until all other data were collected.

Measures

Primary variables measured were classification of asthma severity, self-reported frequency of albuterol use, controller medication use (i.e. inhaled corticosteroids and/or oral leukotriene inhibitors), parental asthma-related knowledge, and self-reported number of school absences, ED visits, and hospitalizations. Parents and children together were asked to recall number of school days missed, ED visits, and hospitalizations. The questions were asked with an open-ended response format (Table 1). Severity and frequency of medication use were based on recall over the previous 2 week period. School absences, ED visits, and hospitalizations were based on recall over the past 12 months.

The RA classified severity of illness based on self-reported symptoms (cough, wheeze and difficulty breathing) using questions based on the NHLBI asthma severity guidelines from 2002. [18] To measure asthma-related knowledge, we orally administered a previously used 20-item true/false questionnaire. [14] Although this knowledge questionnaire is not validated by comparison to health outcomes, it contains high face validity with regard to asthma education standards. We used parental self-report for child's date of birth, gender, name of child's physician, household income, parental age, gender, marital status, years of education, employment, insurance status, tobacco use, race, and the presence of co-morbidities.

We measured parental literacy using the Rapid Estimate of Adult Literacy in Medicine (REALM), a reliable and validated instrument used to assess literacy and shown to predict

many health outcomes in adults. [8, 19] The REALM is a word recognition test that uses 66 health-related words. It has a high correlation with standardized, non-health-related reading tests in validation studies. [19] Its score is a count of correctly pronounced words. We defined low literacy as less than a ninth grade reading level. In the published literature regarding literacy and health outcomes, the relationship between literacy and the outcome appears stable regardless of the cut-point chosen. [8] In some cases, literacy may have a threshold effect, meaning that people with literacy above a certain level can function well and distinguishing between good readers and very good readers is not important. However, within a relatively broad range (e.g. 3rd grade to 9th grade) of limited ability, the effect of choosing a specific cut-point is unclear. In this study, where the participants (parents) were younger than many populations in which literacy has been measured, we anticipated needing to use a higher cut-point to have adequate numbers in the low literacy group. As such, for this study, we used a cut-point of ≤8th grade for the low literacy category.

Analysis

We first created tables of descriptive statistics and examined distribution patterns. We then performed bivariate analyses of the relationship between parental literacy and pediatric asthma outcomes, using chi-squared tests for categorical data, and t-tests for normally distributed continuous data when normally distributed. We used non-parametric tests (Wilcoxon rank sum) when the continuous data was not normally distributed. We performed Poisson regression for count data (number of school absences, number of ED visits, and number of hospitalizations.) Relationships are expressed as incidence rate ratios (IRR) with 95% confidence intervals.

To obtain the best estimate of the relationship between parental literacy and asthma outcomes and utilization, we performed multivariate Poisson regression. To identify the most important variables to include in the model, we identified demographic and clinical characteristics known to contribute to pediatric asthma outcomes in previous studies, including child age, [20, 21] household income, [21] parental race, [22, 23] parental asthma knowledge, [24] parental tobacco use, [25] asthma severity classification,[26] and controller medication use. [21] Additionally, the site of care may affect the estimate of the relationship between parental literacy and asthma measures either because of the care provided or because of a different case mix, so we examined this variable as well. Because we were most interested in isolating a potential etiologic role for literacy in the outcomes, we sought to include all potential confounders in the model. We excluded variables from the model which we thought were in the causal pathway between literacy and the outcome (e.g., years of education completed). [27] To identify specific variables that should be excluded from the model, we performed analyses for collinearity using the STATA program COLLIN. We considered collinearity important if the variance inflation factor was greater than 10. In this study, the variance inflation factor was never greater than 1.5 and we do not present the results of these analyses in the results section.

Although examination of the relationship between parental literacy and asthma care measures was the primary goal of this study, we also examined the relationship of other common markers of vulnerability with asthma care measures: parental years of education completed, household income, and race. Of particular interest, we wondered if the relationship between these other markers of vulnerability and asthma outcomes was as strong as the relationship between literacy and the outcomes.

All analyses were performed using STATA 8.0 (College Station, TX).

Results

Between January 2004 and March 2005, 150 children with asthma and their parents were enrolled in the study (Figure 1). The characteristics of study participants are shown in Table

2, stratified by parental literacy status. Among the 150 participating parents, 36 (or 24%) were considered to have low literacy, defined as less than a ninth grade reading level on REALM. Those in the low parental literacy group were more likely to be African American and to have an annual household income below $15,000. On average, parents with low literacy reported fewer years of education. The children of parents with low literacy were more likely to have Medicaid insurance; no children were uninsured.

Asthma Severity

Children of parents with low literacy were more likely to have moderate persistent or severe persistent asthma, as opposed to mild persistent or mild intermittent asthma: 56% of children of parents with low literacy had moderate or severe persistent asthma, compared to 35% of children of parents with higher literacy (p = 0.03)

Medication Use

Children of parents with low literacy reported more frequent use of albuterol (mean days per week: 2.7 vs. 1.5, p = 0.01) and greater total weekly use (mean: 6 vs. 3 doses per week, p = 0.03). Appropriate controller use (if child had persistent asthma) was also less common in the low literacy group: 68% vs. 82%, but the difference was not statistically significant (p = 0.15).

Parental Asthma Related Knowledge

Low literacy was associated with less parental asthma-related knowledge. Parents in the low literacy group scored a mean of 14 out of 20 vs. 16 out of 20 in the higher literacy group (p <0.001).

Literacy and School Absences because of Asthma

Children of parents with low literacy were more likely to report missing school because of asthma in the prior 12 months. In the low parental literacy group, a total of 241 school days were reported missed among 36 children; an average of 6.7 school absences per child. In the higher parental literacy group, there were 362 reported school absences among 114 children; a mean of 3.2 school absences per child. The unadjusted incidence rate ratio (IRR) was 2.1 (95% CI 1.8, 2.5). After adjusting for covariates (child age, household income, parental race, parental asthma knowledge, parental tobacco use, asthma severity classification and controller medication use) the relationship became even stronger (IRR = 2.8; CI 2.3, 3.4; p<0.001; Table 3).

Literacy and Health Care Utilization

Children of parents with low literacy were also more likely to have ED visits. Children in the low parental literacy group had a total of 55 ED visits, averaging to 1.53 ED visits per child. Children in the higher parental literacy group visited the ED a total of 123 times, averaging to 1.08 ED visits per child. The crude IRR for ED visits IRR was 1.4 (95% CI 1.0, 2.0). Adjusting for covariates did not change the relationship between low parental literacy and increased frequency of ED visits (IRR = 1.4, 95% CI 0.97, 2.0). Hospitalizations due to asthma were also more common among children of parents with low literacy (incidence 0.39 per child per year vs. 0.12 for children of parents with higher literacy, IRR 3.2 (95% CI 1.5, 6.6). Adjusting for baseline differences yielded an IRR of 4.6 (95% CI 1.8, 12). For all of the adjusted models, pseudo R^2 ranged from 0.14 to 0.22.

Education and Asthma Care Measures

47% of the parents completed 12 grades or less of school and were classified as low educational attainment. Children of parents with low education had higher incidence rates of hospitalization

(IRR = 4.2, 95% CI 1.7, 10.3), ED visits (IRR = 2.1, 95% CI 1.5, 2.8), and days of school missed (IRR = 1.7, 95% CI 1.4, 2.0). These relationships persisted after adjusting for potential cofounders (Table 3).

Income and Asthma Care Measures

Self-reported family income less than $15,000/year was also associated with a higher incidence rate of hospitalization than those with a higher income (IRR 2.4; 95% CI 1.1, 5.0), and a higher incidence rate of ED visits (IRR 1.5; 95% CI 1.1, 2.0) (Table 3.). The relationships were attenuated after adjusting for potential confounders (Table 3).

Race/Ethnicity and Asthma Care Measures

45% of the sample self-identified as white and 47% as African American. As seen in Table 3, African American race was not associated with adverse asthma outcomes.

Health Insurance and Asthma Care Measures

All participants in this sample had Medicaid or private insurance. Although insurance type was associated with literacy, we did not find a relationship between insurance type and the outcomes of school days missed, hospitalization, or ED visits (IRR=1 in each case, data not shown).

Discussion

We found that children of parents with low literacy reported more severe asthma symptoms and were more likely to report missing school and require ED visits or hospitalization than children of parents with higher literacy. Parents with low literacy had lower mean scores on asthma knowledge questions and reported more frequent use of albuterol but the differences were small. We find it particularly disconcerting that children whose parents have lower literacy are more prone to miss days of school, putting them at risk for poorer educational outcomes that could perpetuate literacy-related disparities.

The nature of the association between low parental literacy and adverse asthma outcomes and care processes remains unclear. Control for parental asthma-related knowledge does not remove the negative association for literacy, suggesting that literacy may exert its effects on outcomes in ways that are not knowledge mediated, or that at least are not well reflected in our current asthma knowledge measures. Low literacy, like education, may be a marker for other characteristics that have a more direct effect on adverse health outcomes. For example, low literacy may be related to facility acquiring self-management behaviors, such as correct use of a metered dose inhaler [14], or with health behaviors that are not consistent with optimal asthma control. Further study is required to better understand the pathway that leads from low literacy to worse outcomes.

Low literacy has been associated with adverse health outcomes in adults for a number of conditions, including diabetes, depression, HIV viral load, and prostate cancer. [8] For adults with asthma, Williams and colleagues found that patients with lower literacy had less asthma knowledge and were less likely to be able to demonstrate proper inhaler use, even after adjustment for potential confounders, including education. [14] Mancuso and Rincon found that adults with low literacy had more emergency department visits and worse asthma related quality of life than adults with higher literacy. [15] No previous published studies have examined the role of parental literacy in pediatric asthma outcomes.

One previous study examined the effect of parental literacy on child health outcomes. [16] Ross and colleagues found that low parental literacy (measured on the National Adult Reading Test) was correlated with worse glycemic control in children with Type I diabetes (r = 0.28, p =0.01).

[16] Barriers to learning effective self-management strategies may mediate the relationship between socioeconomic status or race and clinical outcomes. Our findings add to the growing literature that seeks to understand the nature of disparities in outcomes for chronic health conditions like childhood asthma, including the role of parental factors such as literacy. [28–31]

We found similar effect sizes using literacy or education as the independent variables. In this study, it is hard to know if measuring literacy added more information than we could have obtained by simply asking for years of education completed. We have suggested previously that literacy and education are causally linked to one another and should not be included in the same regression model. [27] From this data, we cannot assert that literacy was a superior measure. However, previous studies have found that years of education are not as strongly related to outcomes as literacy. [32–35]

Our study has several limitations. It was performed at one institution's pediatrics clinics in the Southeast, and hence may not be generalizable to other populations or health settings. 20% of those approached declined to participate in the study. Although this is a reasonable response rate, the results could include bias if the relationship between literacy and outcomes was different in those who declined. Outcomes and utilization variables were generally self-reported, and we did not confirm self-report through chart review or school records. However, previous studies have also used self-report to collect data on hospitalizations, ED visits and days missed from school. [36, 37] Because the number of hospitalizations and ED visits were relatively low, we have confidence that the parent can provide an accurate report. Recall of school days missed over the previous year is more difficult, but we were reassured by the fact that the relationships observed were similar to those for hospitalization and ED visits. Research is needed to determine the validity of self-report. We did not measure child literacy; the previous study by Ross and colleagues did not find a relationship between child literacy and glycemic control [16], but whether such a relationship would be found in children with asthma, particularly older children, remains unclear.

We also did not measure length of time the child had the diagnosis of asthma nor the number of clinic visits during the past year. Longer exposure to the condition may have been related to increased knowledge about the disease and to some medication use rates. However, we do not believe these variables would have an important effect on the overall outcomes of hospitalization, ED visits or days missed from school. We do not know the significance of a 2 point difference on the asthma knowledge measure even though it was statistically significant. Lastly, some children take most of the responsibility for their health care prior to age 12 and their self-management success may be less dependent on their parent's literacy level. However, these same children had modeling by the parent at early ages to set the stage for their current interest and success in self-management, and hence, we believe that parental characteristics are still important.

Despite these limitations, we believe that our study has several important implications. First, it suggests that childhood asthma care measures are affected by parental characteristics; as such, interventions to improve asthma outcomes in children may be more successful if they are developed and implemented in the context of the family. Second, it suggests that the relationships between parental education or literacy and adverse asthma care measures are not mediated by parental asthma-related knowledge, and are not explained by adjustment for race or income, factors that have been associated with adverse outcomes in previous studies. As such, simply providing knowledge, the thrust of many interventions, may not improve literacy related disparities. Finally, our findings suggest that additional research should seek to understand the pathways by which parental education or literacy affect health outcomes, so that better interventions can be developed to reduce asthma health disparities.

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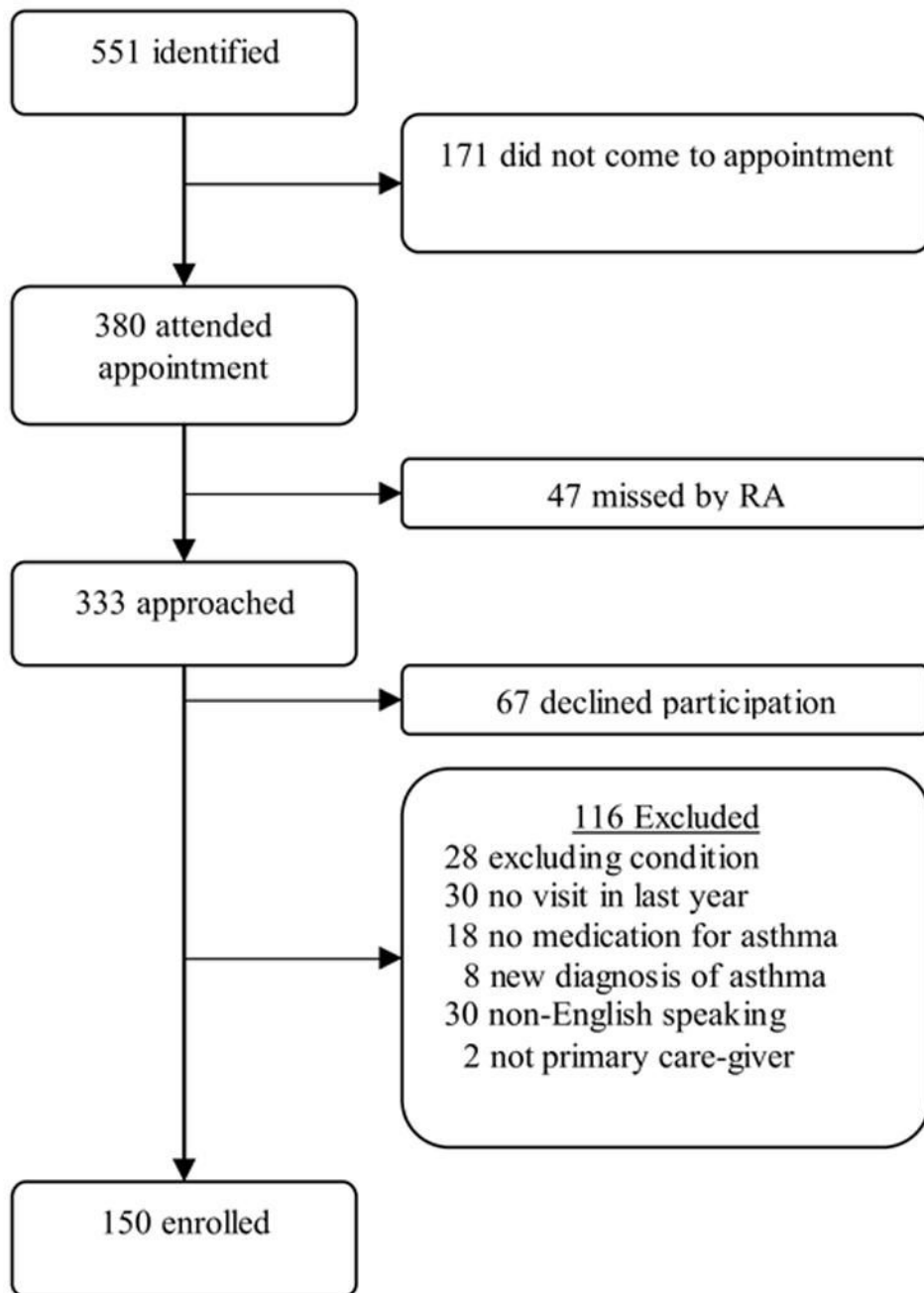
Figure 1.
Recruitment of the cohort.

Table 1

Measures use in the analysis.

Measure	Type	Use of Measure in Analysis	Question or Categories
Controller Medication Use	Dichotomous	Dependent variable Potential confounder	Yes if using salmeterol, montelukast, or any steroid inhaler
Albuterol use	Continuous	Dependent variable	How many days in the last week did your child use his/her albuterol inhaler? On the days your child used their albuterol inhaler, how many times a day did he/she use it?
Hospitalization	Continuous	Dependent variable	Has your child ever had to stay overnight in the hospital because of his/her asthma? If yes, how many times in the last year?
Emergency Department	Continuous	Dependent variable	Has your child ever had to go to the emergency room for his/her asthma? If yes, how many times in the last year?
School days missed	Continuous	Dependent variable	Has your child ever had to miss school because of his/her asthma? If yes, how many days in the last year?
Household income	Dichotomous	Independent variable	<$15,000 vs. >$15,000
Years of education	Dichotomous	Independent variable	What is the last grade you completed in school? (note: GED counted as 12) 12 years or less vs. >12 years
Smoking	Dichotomous	Independent variable	Do you smoke?
Asthma-related knowledge	Continuous	Dependent variable Potential mediator/ confounder	Previously developed questionnaire. [14]

Table 2

Participant characteristics

	Entire Sample (n=150)	Higher Parental Literacy ≥ 9th grade (n=114)	Low Parental Literacy < 9th grade (n=36)	p value
Mean age, yrs Child Parent	7.7 (SD=2.8) 35 (SD=8.7)	7.7 (SD=2.8) 35 (SD=7.5)	7.7 (SD=2.8) 35 (SD=12)	0.98 0.89
Parental Race African-American Caucasian	47% 45%	39% 52%	69% 25%	0.05
Household income of < $15,000/yr	27%	21%	44%	<0.01
Parent Education, mean yrs % >12 yrs % 12 yrs	13.5 54 39 8	13.5 63 39 4	12.2 22 58 19	<0.01
Child's Insurance Medicaid Private	57% 43%	43% 57%	86% 14%	<0.01
Parental smoking	28%	26%	33%	0.41
Controller medication use if persistent asthma	(n=97) 80%	68%	82%	0.15

Table 3

Poisson regression analysis of the roles of education, income and race.

Variable	N	Hospitalization		Emergency Department Visits		Days Missed from School	
		Unadjusted IRR (95% CI)	Adjusted* IRR (95% CI)	Unadjusted IRR (95% CI)	Adjusted* IRR (95% CI)	Unadjusted IRR (95% CI)	Adjusted* IRR (95% CI)
Literacy	≥9th grade=114, <9th grade=36	3.2† (1.5, 6.6)	4.6† (1.8, 12)	1.4† (1.0, 2.0)	1.4 (0.97, 2.0)	2.1† (1.8, 2.5)	2.8† (2.3, 3.4)
Education	≤12th grade=70, >12th grade = 80	4.2† (1.7, 10.3)	3.4† (1.3, 8.9)	2.1† (1.5, 2.8)	1.6† (1.2, 2.3)	1.7† (1.4, 2.0)	2.0† (1.6, 2.4)
Income	<$15,000/yr =40, ≥$15,000/yr=110	2.4† (1.1, 5.0)	2.0 (0.8, 5.2)	1.5† (1.1, 2.0)	1.2 (0.8, 1.8)	1.0 (0.9, 1.2)	1.3† (1.0, 1.6)
Race	African American =68, White = 70	0.81 (0.4, 1.8)	0.93 (0.3, 2.6)	0.81 (0.6, 1.1)	1.1 (0.7, 1.6)	1.2† (1.0, 1.5)	1.0 (0.83, 1.3)

*
Potential confounders included in the analysis:

Literacy Model: child age, household income, parental race, parental asthma knowledge, parental smoking, asthma severity classification, controller medication use, and site of care.

Education Model: child age, household income, parental race, parental asthma knowledge, parental smoking, asthma severity classification, controller medication use, and site of care.

Income Model: parental literacy, child age, parental race, parental asthma knowledge, parental smoking, asthma severity classification, controller medication use, and site of care.

Race Model: parental literacy, child age, household income, parental race, parental asthma knowledge, parental smoking, asthma severity classification, controller medication use, and site of care.

†
Denotes p<0.05 on Poisson regression.