

# The Impact of Parent's Health Literacy on Pediatric Asthma Outcomes

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**Background:** Health literacy has been associated with health disparities in many disease outcomes, including children's asthma. Parents are responsible for most of children's healthcare. Therefore, parents' health literacy may impact children's health outcomes, including asthma control. This study sought to determine the association between parent health literacy and children's asthma control among a cohort of predominately minority urban children aged between 6 and 12 years.

**Methods:** This cross-sectional study assessed children with asthma and their parents at a single outpatient visit. English-speaking parents and their children, aged between 6 and 12 years with physician-diagnosed asthma, were eligible for this study. Healthcare providers assessed asthma control and severity, and parents completed demographic, health literacy, asthma control, and asthma knowledge measures. Children completed a pulmonary function test as part of the Asthma Control Questionnaire (ACQ) scoring.

**Results:** A total of 281 parent-child dyads provided data, with the majority of parents being mothers and African American, with a high school level education or less. Lower parent health literacy was associated with worse asthma control as rated both by the provider ( $p=0.007$ ) and the ACQ ( $p=0.013$ ), despite only moderate concordance between ratings ( $\rho=0.408$ ,  $p<0.0001$ ). Lower parent health literacy also was associated with less asthma knowledge, which was associated with worse asthma control.

**Conclusions:** Higher parent health literacy was associated with more parent asthma knowledge and better child asthma control. Pediatric providers should consider tailoring education or treatment plans or utilizing universal precautions for low health literacy.

## Introduction

JUST UNDER 10% of U.S. children under the age of 18 years have asthma,<sup>1</sup> with increasing disease prevalence and morbidity disproportionately affecting minority children in urban areas and children in lower socioeconomic groups.<sup>1-7</sup> Minority children have greater asthma symptom severity, sleep disturbances, and activity limitations than white children.<sup>2</sup> Furthermore, black and Hispanic children miss more school and have more emergency department (ED) visits.<sup>8</sup> Hospitalizations are highest for inner-city poor children.<sup>6</sup> Additionally, each year, one-third of all children with asthma are treated in an ED for asthma,<sup>9</sup> with many visits being unnecessary, due to poor asthma home management.<sup>10</sup>

Mandated federally funded programs have improved healthcare access, but have not eliminated disparities for those most vulnerable to poor health outcomes. Among

Medicaid-insured children, black and Hispanic children have worse asthma status<sup>8</sup> and more hospitalizations,<sup>5</sup> and are less likely to use daily inhaled anti-inflammatory medications than white children.<sup>8</sup> Medicaid-covered children are significantly less likely than non-Medicaid children to have asthma prescriptions filled or obtain refills,<sup>11,12</sup> disparities not accounted for by prescribing variations.<sup>12</sup> Even when filled, adherence to prescribed asthma medications remains low.<sup>13</sup> One possible source of these asthma disparities is the parents' understanding and use of health information, that is, the parents' health literacy. Studies among adults with asthma indicate that lower health literacy predicts worse asthma outcomes,<sup>14</sup> medical decision making, knowledge, and self-management skills, such as correctly using a meter-dose inhaler and communicating with their healthcare provider.<sup>15,16</sup> Parents need these same skills, as well as reading and numeracy skills, to manage their children's asthma successfully in order to achieve better asthma health outcomes.<sup>17</sup>

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National estimates indicate that 28.7% of parents have low health literacy, with black and Hispanic parents and poor parents more at risk than whites.<sup>18</sup> Parents attending an ED with their child had similar (30%) rates of low health literacy.<sup>19</sup> Low health literacy, prevalent among low socioeconomic status and minority adults,<sup>20–22</sup> has been associated with a host of poorer health outcomes,<sup>17</sup> including inadequate use of preventive services,<sup>23,24</sup> increased ED visits,<sup>25</sup> risk of hospitalization,<sup>26</sup> and poorer asthma outcomes among adults.<sup>27,28</sup> Findings for pediatric asthma outcomes are inconsistent. Lower parent health literacy has been associated with more healthcare utilization by children with asthma in some studies,<sup>29,30</sup> but not in others.<sup>31,32</sup> Two studies examining parent health literacy and child asthma control have disparate findings: one reports an indirect relationship between health literacy and asthma control through satisfaction with shared decision making,<sup>33</sup> while the other found no relationship.<sup>32</sup>

This study examines the role of parent health literacy in pediatric asthma health outcomes, including asthma control, healthcare utilization, and school days missed due to asthma. The primary hypothesis is that higher parent health literacy will be associated with better child asthma control. Secondary hypotheses are that lower parent health literacy will be associated with greater child healthcare utilization and more school days missed. Furthermore, the associations among parent asthma knowledge, child asthma control, and health literacy were examined. Finally, relationships between demographic variables and health literacy, asthma control, and asthma knowledge were explored. This study adds to the limited literature about the role of parent health literacy in child asthma control and related healthcare utilization. This is the first study to examine both symptom-rated and clinical judgment measures of asthma control.

## Methods and Materials

This cross-sectional study assessed children with asthma and their parents during a single visit at the child's asthma care clinic. English-speaking parents (or primary caregivers) and their children, aged 6–12 years with physician-diagnosed asthma, were eligible for this study. The Rapid Estimates of Adult Literacy Measure (REALM) was used to screen parents to aid recruitment of equal numbers of parents with adequate and less than adequate health literacy. Between March 2008 and July 2010, parent-child dyads were recruited from two clinic groups: Children's of Alabama Asthma and Allergy Clinics (Children's;  $n=3$ ) and County Public Health Pediatric Clinics (Health Department;  $n=3$ ). Visa gift cards were given to cover participation costs (e.g., parking, loss of pay) and as an incentive to participate. Parents signed informed consents, and children signed assents or parents signed for the child if judged too immature to consent. This study was approved and monitored by the Institutional Review Boards for Human Use at the University of Alabama at Birmingham and the University of Arizona.

Parents were interviewed in the clinic immediately after the child's healthcare visit. Children completed spirometry tests the same day. Parents provided demographic information and completed the Test for Functional Health Literacy in Adults (TOFHLA),<sup>34</sup> the Asthma Knowledge Quiz (AKQ),<sup>35</sup> and the Juniper Asthma Control Questionnaire

(ACQ).<sup>36</sup> The TOFHLA contains 50 self-completed cloze passage reading comprehension items and 17 interviewer-administered numeracy items, and takes up to 22 minutes to complete. It has good internal reliability (Cronbach's  $\alpha=0.98$ ), concurrent validity (0.84 vs. REALM<sup>37</sup> and 0.74 vs. WRAT-R<sup>38</sup>), and predictive validity for health outcomes.<sup>39,40</sup> A score of 70 or above represents adequate health literacy. The AKQ was developed by the National Heart, Lung, and Blood Institute under the title "Check your Asthma IQ" and is found widely on health Web sites as a self-assessment tool for patient education. It has moderate scale reliability (Cronbach's  $\alpha=0.45$ ).<sup>41</sup> Twelve statements, written at a 7th grade level, are evaluated as true or false, with higher scores indicating more accurate asthma knowledge. The ACQ is a 7-item measure evaluating the presence of the five top asthma symptoms and bronchodilator use over the previous week and the child's current FEV1%, on a 7-point scale. This measure has been validated for asthma symptom change in adults (reliability=0.90)<sup>36</sup> and children (reliability=0.79).<sup>42</sup> We asked parents to report on symptoms, with the child available to consult. Lower scores indicate less impairment. Categorical classifications are: <0.75 adequately controlled asthma, 0.75–1.25 not well-controlled asthma, and >1.5 poorly controlled asthma. The previous year's healthcare utilization and missed school days were collected by medical chart audit. Immediately following the clinic visit, the healthcare provider was asked to use their clinical judgment to rate the child's asthma severity (intermittent, mild persistent, moderate persistent, or severe persistent) and control (well controlled, not well controlled, or poorly controlled).

Descriptive statistics were computed to portray the study population. Our primary hypothesis was tested with two measures of asthma control: simple linear regressions tested the TOFHLA with the ACQ, and logistic regression tested the TOFHLA with provider-rated control (controlled vs. not controlled). Due to large variances, negative binomial regression tested our secondary hypotheses, the association of parental health literacy with healthcare utilization, measured by asthma-related hospitalizations, ED visits and doctor's appointments, and missed school days. Simple linear regressions examined parent asthma knowledge association with child asthma control (ACQ) and the TOFHLA. Spearman rho correlations were also computed. Relationships between each demographic variable (including asthma severity) and each of the three variables of interest—parent health literacy, child asthma control (ACQ), and parent asthma knowledge—were explored with analyses of variance. Multiple regression comparisons used stepwise entry.

The correlation between the provider-rated asthma control and the ACQ categories was examined with Spearman's rho. Listwise deletion was used for missing data. For variables with substantial data missing not-at-random (healthcare utilization and missed school days, primarily missing from Health Department charts), *t*-tests examined our primary variables (ACQ, provider-rated asthma control, AKQ, and TOFHLA) for differences between the clinic types.

## Results

A total of 281 children, with an average age of 8.8 years ( $SD=1.9$ ), and their parents (or primary caregiver) consented to and completed study measures. Half were recruited from

children's clinics and half from health department clinics. Thirteen healthcare providers, four nurse practitioners, and nine pediatricians clinically rated children's asthma severity and control. The majority of adults was mothers (86.8%) and African American (87.2%), and had a high school education or less (54.8%). A slight majority of the children were male (62.3%) and about three-fourths (74.7%) of them had Medicaid coverage. Based on the REALM, used for screening only, about half (48%) of parents had less than adequate health literacy, while only 9.3% tested as such on the TOFHLA, the study health literacy assessment (see Table 1).

As hypothesized, better parent health literacy was significantly associated with better child asthma control for both provider ratings and the ACQ (see Table 2). Parents with

TABLE 1. STUDY SAMPLE DESCRIPTORS

	n	%
Relationship to child		
Parent	256	91.1
Grandparent	19	6.8
Other relative	6	2.1
Gender—parent		
Male	13	4.6
Female	268	95.4
Race—parent and child <sup>a</sup>		
African American	245	87.2
White	36	12.8
Gender—child		
Male	175	62.3
Female	106	37.7
Health insurance—child		
Medicaid	210	74.7
All Kids	20	7.1
Private	44	14.7
None or unknown	7	2.5
Employment status—parent <sup>b</sup>		
Full time outside of home	133	47.3
Part time outside of home	39	13.9
At home—full or part time	11	3.9
Not employed	93	33.0
Education level—parent		
Less than high school	48	17.1
High school diploma or GED	106	37.7
Some post-high school	83	29.5
College graduate or higher	44	15.7
Annual household income		
< \$20,000	141	50.2
≥ \$20,000	95	33.5
Refused	45	16.3
Parent health literacy		
REALM (scored adequate; >60 of 66)	135	48.0
TOFHLA (scored adequate; >75 of 100)	255	90.7
Child's Asthma Severity <sup>b</sup> (clinician rating)		
Intermittent	13	4.7
Mild persistent	106	38.0
Moderate persistent	136	48.7
Severe persistent	24	8.6

<sup>a</sup>One child was reported as white with African American parent.

<sup>b</sup>Data missing from medical record for some participants.

REALM, Rapid Estimates of Adult Literacy Measure; TOFHLA, Test for Functional Health Literacy in Adults; GED, General Equivalency Diploma.

higher health literacy were more likely to have a child the provider rated as having well-controlled asthma ( $p=0.007$ ). TOFHLA scores were negatively associated with ACQ scores ( $p=0.013$ ); each one-point increase in health literacy score indicating a decrease of 0.015 in asthma control score (lower score = better control).

Our secondary hypotheses were not confirmed. Parents' TOFHLA scores were not associated with the number of clinic visits, hospitalizations, or ED visits due to asthma during the past year or the number of school days missed (see Table 2). Prior healthcare utilization and missed school days data were not available for almost one-third of the sample due to a lack of documentation in the children's health records. Missing data were from 49% of Health Department patients compared to 15% of Children's patients. A *post hoc* comparison of the ACQ, asthma control, AKQ, and TOFHLA scores between the two clinic groups revealed no significant differences ( $p=0.732$ ,  $0.076$ , and  $0.141$  respectively).

AKQ scores were generally high, with 76.2% scoring 10 of 12 or better. Parents' asthma knowledge was significantly associated with their health literacy; each one-point increase in AKQ meant TOFHLA scores increased by 2.8 points ( $p<0.0001$ ; see Table 2). The scores were moderately correlated ( $\rho=0.334$ ,  $p<0.0001$ ). Furthermore, increased parent asthma knowledge is associated with better child asthma control. As the AKQ score increased by one point, ACQ scores decreased by 0.091 ( $p<0.05$ ). Scores were negatively correlated ( $\rho=-0.130$ ,  $p=0.03$ ), indicating improved asthma control.

The multiple regression results shown in Table 3 compare scores on the TOFHLA, ACQ, and AKQ with demographics and asthma severity. TOFHLA scores were higher for whites ( $p=0.003$ ), those with higher education ( $p<0.0001$ ), and those with All Kids insurance (compared to private insurance;  $p=0.022$ ). All white parents had adequate health literacy compared to the majority of African Americans (100% vs. 89.4% respectively). ACQ scores were higher for whites ( $p=0.011$ ) and those rated by the healthcare provider with severe compared to mild ( $p=0.004$ ) or moderate ( $p=0.030$ ) persistent asthma. AKQ scores were higher for whites ( $p=0.001$ ) and those with higher education ( $p=0.002$ ).

For the 271 children who had healthcare provider-rated asthma control, the provider-rated control and ACQ category were moderately correlated ( $\rho=0.408$ ;  $p<0.001$ ). Healthcare providers rated 51% of the children as having controlled asthma, whereas the ACQ scores only classified 33.1% of children as controlled (see Table 4).

## Discussion

This study represents findings from a predominately African American urban sample. Higher parent health literacy was associated with more parent asthma knowledge and better child asthma control, but not with child healthcare utilization or missed school days. Furthermore, more parent asthma knowledge was associated with better asthma control.

We found only two other studies that assessed parent health literacy's association with child asthma control. Wood et al. assessed parent health literacy with the Newest Vital Sign,<sup>43</sup> and asthma control with a single 1–10 scale provider rating in 198 African American children. They found no relationship between parent health literacy and child asthma control or healthcare utilization.<sup>32</sup> Ghandi et al.<sup>33</sup> report an indirect relationship only between parent health literacy

TABLE 2. PARENT HEALTH LITERACY (TOFHLA SCORE) ASSOCIATION WITH CHILD ASTHMA-RELATED HEALTHCARE UTILIZATION, MISSED SCHOOL DAYS, ASTHMA KNOWLEDGE, AND ASTHMA CONTROL

	Summary mean (SD)	Negative binomial regression		
		Coefficient (SE)	Rate ratio	p-Value
Asthma healthcare utilization in past year <sup>a</sup>				
Outpatient clinic visits	3.4 (4.6)	-0.02 (0.01)	0.98	0.192
ED visits	1.3 (2.9)	-0.008 (0.02)	0.99	0.661
Hospitalizations	0.5 (1.4)	-0.007 (0.03)	0.99	0.796
School days missed <sup>a</sup>	6.2 (10.5)	0.02 (0.02)	1.02	0.327
		Simple linear regression		
		Coefficient (SE)	p-Value	
Asthma knowledge	10.1 (1.3)	0.05 (0.01)	<b>&lt;0.0001</b>	
Child asthma control ACQ	1.6 (0.98)	-0.015 (0.006) <sup>b</sup>	<b>0.013</b>	
	n (%)	Logistic regression		
		Coefficient (SE)	p-Value	
Clinician rating				
Controlled	143 (51)	-0.04 (0.01) <sup>b</sup>	<b>0.007</b>	
Not controlled	128 (45)			

<sup>a</sup>Data missing from medical record for some participants.

<sup>b</sup>Per one point increase in score.

ACQ, Asthma Control Questionnaire; ED, emergency department.

measured by the s-TOFHLA<sup>34</sup> and child asthma control measured by 10 items.<sup>44</sup> The discrepancy in our findings with these previously reported results may reflect differences in the samples or the measures used to assess health literacy and/or asthma control. Finding that parent health literacy is associated with child asthma control is consistent with other

studies that report health literacy's effects on asthma care and morbidity among minorities. African American parents' health literacy has been found to be associated with self-efficacy to manage their children's asthma,<sup>32</sup> and minority parents' self-efficacy has been related to child asthma symptoms,<sup>45</sup> which are markers of asthma control.

TABLE 3. MULTIPLE REGRESSION ASSOCIATIONS OF SAMPLE DEMOGRAPHICS WITH HEALTH LITERACY, ASTHMA CONTROL, AND ASTHMA KNOWLEDGE SCORES

	n	Health literacy (TOFHLA)			Asthma control (ACQ)			Asthma knowledge (AKQ)		
		Mean (SD)	Regression model		Mean (SD)	Regression model		Mean (SD)	Regression model	
			Coefficient	p-Value		Coefficient	p-Value		Coefficient	p-Value
Race										
White	36	94.5 (4.6)	.	<b>0.003</b>	1.08 (0.96)	.	<b>0.011</b>	10.9 (1.1)	.	<b>0.001</b>
African American	245	87.1 (10.2)	-6.06		1.67 (1.00)	0.52		10.0 (1.3)	-0.85	
Education										
≤ High school	154	85.1 (11.6)	-6.51	<b>&lt;0.001</b>	1.78 (0.98)	0.27	0.052	9.8 (1.3)	-0.56	<b>0.002</b>
> High school	127	91.8 (5.9)	.		1.36 (0.94)	.		10.4 (1.1)	.	
Income										
< \$20,000	141	87.1 (10.3)	.	0.839	1.76 (0.94)	.	0.227	10.0 (1.2)	.	0.822
≥ \$20,000	95	90.1 (9.6)	-0.30		1.32 (1.00)	-0.18		10.4 (1.4)	0.04	
Insurance										
None	6	86.3 (14.8)	0.82		1.50 (0.48)	0.03		10.7 (0.5)	1.11	
Medicaid	210	87.8 (10.1)	0.59	<b>0.033</b>	1.70 (1.00)	0.20	0.681	10.0 (1.3)	0.10	
All Kids	20	82.0 (11.5)	-6.73		1.48 (0.99)	0.01		9.9 (1.5)	-0.20	0.179
Private	45	92.5 (6.1)	.		1.13 (0.87)	.		10.6 (1.2)	.	
Asthma severity										
Intermittent	13	84.9 (12.8)	-1.34		1.56 (0.78)	-0.67		9.6 (1.7)	-0.20	
Mild persistent	106	87.6 (11.0)	-3.96	0.349	1.47 (0.88)	-0.68	<b>0.034</b>	10.1 (1.3)	-0.01	0.263
Moderate persistent	136	88.6 (9.2)	-2.81		1.60 (1.04)	-0.50		10.2 (1.2)	0.30	
Severe persistent	24	89.7 (8.5)	.		2.11 (1.09)	.		9.8 (1.4)	.	

., the base level.



TABLE 4. ACQ AND PROVIDER RATINGS OF ASTHMA CONTROL\*

	ACQ			Total
	Adequately controlled ( $\leq 0.75$ )	Not well controlled (0.75–1.25)	Poorly controlled ( $> 1.25$ )	
Provider rating				
Well controlled	55	27	61	143
Not well controlled	10	13	85	108
Poorly controlled	0	2	18	20
Total	65	42	164	271

\* $n=271$ ; provider rating data missing for 10 participants.  $\rho=0.408$ ,  $p<0.0001$ .

DeWalt et al. found that parent health literacy was associated with ED visits, hospitalizations, and missed school days among inner-city children with asthma.<sup>29</sup> Shone et al. found similar findings for healthcare use.<sup>31</sup> In contrast, we did not find these relationships, similar to findings in urban upstate New York<sup>31</sup> and Midwestern urban African American<sup>32</sup> cohorts. The lack of association in our study may be real or may reflect a smaller sample or a bias in the analyses, as these data were missing for approximately 31.5% of our sample.

We used two measures of asthma control for our primary outcome: the ACQ and provider ratings. Both have limitations. The ACQ questions were answered by the parent, with the child present and completing the spirometry measure. Previous studies have found that parents may not accurately report on their children's asthma, partly because they are not always with the child, especially school-age children such as in our sample.<sup>46</sup> Providers' ratings of control are subjective and have been found to overestimate the improvement in asthma symptoms among their patients.<sup>47</sup> As children in this study were attending return visits, provider ratings may have been subjectively biased toward better control. This suggestion is strengthened by our finding that the majority (64%) of asthma control ratings was discordant, mostly due to a higher rating of control by the provider.

Similar to other disparity reports, we found higher rates of adequate health literacy among whites than African Americans.<sup>48</sup> We also found race significantly related to ACQ and AKQ scores, with African Americans scoring worse on asthma knowledge and control. This may, in part, explain why African American children suffer disproportionate asthma morbidity and mortality, as well healthcare use.<sup>8,49</sup>

The child's asthma control relies on the parent's ability for symptom management at home, which includes medication use, symptom monitoring, and following an asthma action plan. The parent needs to be able to read the asthma action plan, understand how to monitor symptoms, and use medication such as a metered-dose inhaler properly. Paradoxically, an appropriate asthma action plan relies upon the parent providing accurate information to the healthcare provider. Low literacy adults with asthma often lack these skills;<sup>14–16</sup> low literacy parents likely lack them as well. While health literacy may be difficult to change, how and what skills parents are taught has the potential to improve children's asthma outcomes.

There are several limitations to this study that should be noted. This sample had lower rates of inadequate (1.9%) and

marginal (7.5%) health literacy than has been reported in the literature (26% and 20% respectively),<sup>50</sup> as determined by scores on the TOFHLA, possibly reflecting the relatively high level of education of this sample (45.2% have education beyond high school). The ACQ was answered by the parent for the child, although the child could be consulted and did perform a spirometry test, but this deviated from the way the measure was validated and may overrepresent children's asthma control.<sup>51</sup> The AKQ used in this study has not been validated against other measures, although it contains many of the concepts found in longer more rigorously tested measures of asthma knowledge. Providers' ratings of child asthma control were clinical judgments, and inter-rater reliability was not assessed. However, all providers had treated these children before and therefore based judgments on both present and past experience with the child. Likewise, asthma severity was a clinical judgment based on the child's asthma history and medication required for symptom control. There is potential for error due to the clustering effect of patients per physician or clinic, which was not tested due to the unbalanced number of patients per physician and clinic. The large proportion of missing data for healthcare utilization and school days missed may have resulted in underpowered analysis. Furthermore, the outcomes for this study may be underreported, as the higher than anticipated proportion of adequate health literacy participants limited power for the primary analysis. Finally, these findings may not be generalizable to other populations or to other parts of the country.

This is the first study to report a direct relationship between parent health literacy and child asthma control. Studies done to date have been cross-sectional with relatively small samples. Studies may have been underpowered, the designs may limit the ability to draw causal inference, and are further limited by using self-reported healthcare utilization. Therefore, larger, prospective studies examining the role of parent health literacy's impact on pediatric health outcomes and potential mediating factors are needed.

Healthcare providers should be aware of health literacy barriers as a reason for poor asthma control, and should tailor education and treatment plans with this in mind. Alternatively, universal precautions for health literacy have been recommended; that is, treating each patient as at risk for low health literacy by providing simple language explanations and checking understanding.<sup>52,53</sup> Free health literacy toolkits are available to assist healthcare providers implement such methods.<sup>54</sup> Instituting universal precaution policies for asthma patients have the potential to improve parental understanding of asthma management, which may improve adherence and, ultimately, children's asthma control.

## Acknowledgments

This project was supported by the Maternal and Child Health Bureau of the Health Resources and Services Administration grant R40MC08725.

## Author Disclosure Statement

No competing financial interests exist.

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Received for publication May 2, 2014; accepted after revision September 17, 2014.