

**Final Report**  
**The Impact of Caregiver's (Parent's) Health Literacy on Pediatric Asthma Outcomes**  
*Funded by: HRSA-MCH R40MC08725*

**I. Introduction**

**A. Nature of the research problem.** Asthma prevalence and its associated morbidity among children are increasing, with minority and low-income inner city US children at increased risk. Access to care for this vulnerable population has not explained this health disparity, suggesting other modifiable factors should be examined. Low health literacy has been associated with inadequate utilization of preventive services, increased emergency visits, increased risk of hospitalization, and poor health outcomes. Furthermore, low health literacy is prevalent among those with lower socioeconomic status as well as minorities, mirroring trends in asthma morbidity. It is estimated that approximately half of US adults have health literacy limitations. These literacy limitations may affect how patients, or their caregivers (e.g., parents), understand their health care practitioner's treatment recommendations and may also affect the recommendations that the health care practitioner prescribes, potential sources of asthma health disparities. Parent health literacy is a factor that has modifiable potential, yet has received only limited attention in the childhood asthma literature. Inasmuch as parents have primary responsibility for management of the child's asthma, it is important to know what effect parent's health literacy has on child's asthma outcome.

**B. Purpose, scope, and methods of the investigation.** The primary goal of this study was to examine the role of parent health literacy in pediatric asthma health outcomes and associated disparities. The hypotheses examined in this study are:

Primary Hypothesis:

1. Higher parent health literacy will be associated with better asthma control in the child.

Secondary Hypotheses:

2. Concordance between healthcare provider's perception of parent health literacy and parent health literacy as assessed by TOFHLA will be positively associated with asthma control.
3. Higher parent health literacy will be associated with asthma outcomes such as better adherence, fewer school days missed and less urgent health care utilization.
4. Children whose parents are perceived to have lower health literacy by the provider will receive fewer treatment recommendations than those perceived to have higher literacy.
5. Parent's self-assessment of their health literacy will be moderately associated with their measured health literacy.

This project was to enroll children with asthma and their primary caregiver in a retrospective cohort design study to test the above hypotheses. In addition, the role of health literacy in the provider-parent interaction was explored with qualitative methods.

Quantitative data were collected by research staff during one session immediately after a child's clinic visit for asthma care; the modes of data collection are provided in Section III-D. Health care providers completed self-administered surveys immediately after the child's clinic visit. Qualitative data were collected via in-depth interviews from a sub-sample of participants and health care providers to assist in understanding patient-practitioner communications.

**C. Nature of the findings**

Higher parent health literacy was associated with greater asthma knowledge and better asthma control for the child, as assessed both by clinicians and the Asthma Control Questionnaire<sup>1</sup>. Additional findings are detailed in section IV below.

**II. Review of the Literature**

**A. Prevalence of Low Health Literacy.** National estimates indicate 26% of adults have low health literacy, 20% have marginal health literacy and 54% have adequate health literacy<sup>2</sup>. The annual cost of low health literacy in the U.S. is estimated to be between \$106 billion and

\$238 billion in avoidable health care utilization. Black and Hispanics have significantly lower levels of health literacy than Whites, and those living in poverty are more likely to have Below Basic (inadequate) health literacy<sup>3</sup>.

**B. Asthma disparities among children.** In the United States, nine million children under the age of 18 have been diagnosed with asthma<sup>4</sup>. Trends in increasing disease prevalence and morbidity disproportionately affect non-white children living in urban areas and children in lower socioeconomic groups<sup>5-10</sup>. Minority children have greater severity of asthma symptoms, more sleep disturbances, and more activity limitations than White children<sup>5</sup>. Black and Hispanic children have been reported to miss more days of school and had more emergency room visits than White children<sup>11</sup>. Hospitalizations were highest for children from inner-city areas, wherein most residents are of racial and ethnic minorities<sup>9</sup>.

While mandated federally funded programs have improved access to health care, they have not eliminated disparities for those most vulnerable to poor health outcomes. Even among children enrolled in managed Medicaid programs, Black and Hispanic children had worse asthma status<sup>11</sup>, were less likely to be using daily inhaled anti-inflammatory medications<sup>11</sup>, and were at greater risk for multiple hospitalizations than White children<sup>8</sup>. Children with Medicaid coverage are significantly less likely than non-Medicaid children to have asthma prescriptions filled<sup>12, 13</sup> or obtain refill medications and prescribing variations were not found to account for differential dispensing of medications<sup>13</sup>. Even when prescribed in this population, parent adherence to prescribed medication treatment remained low<sup>14</sup>.

**C. Health Literacy and its potential role in asthma management and health disparities.** Low health literacy, prevalent among individuals with lower SES and those of minority status<sup>15-17</sup>, is associated with inadequate utilization of preventive services<sup>18, 19</sup>, increased ED visits<sup>20</sup> and risk of hospitalization<sup>21</sup>, and poorer health outcomes<sup>22, 23</sup>. Among inner city children with asthma, parent health literacy was linked to ED visits, hospitalizations and missed school<sup>24</sup>.

Contributing to underutilization of asthma medications are beliefs that asthma medications have limited usefulness<sup>25, 26</sup> and have addictive properties<sup>27, 28</sup> factor into parent's decisions about medication regimens, underlying decisions for limiting or discontinuing medications<sup>26, 29</sup>. Among minority populations where such beliefs are coupled with low literacy<sup>30</sup>, adherence to asthma management is compromised. In addition, inadequate literacy has been associated with poor asthma knowledge and poor Metered Dose Inhaler (MDI) technique<sup>31</sup>. To make matters worse, asthma management plans are typically written at literacy levels above the reading levels of many minority individuals<sup>32</sup>.

Identifying low health literacy is challenging. Only 21% of Pediatricians rated themselves as very good to excellent at identifying low health literacy parents<sup>33</sup> and only moderate agreement between provider and objective measures has been found<sup>34</sup>. Health care provider perceptions affect the time spent in the interaction and the type and number of questions asked.<sup>35</sup> As well, variations in asthma treatment of minority populations have been documented<sup>36-39</sup> possibly because treatment recommendations may be influenced by the provider's perceptions of the patient's ability to carry them out<sup>40</sup>. Health care providers' perceptions of patients (parents) play a role in health care delivery<sup>41, 42</sup> as they are not immune from cultural influences that prompt bias or stereotyping<sup>43</sup>.

### III. Study Design and Methods

**A. Study design.** This study used cross-sectional data collection in a retrospective cohort design study to assess children with asthma and their parents, and that day's health care provider. This study was approved by the Institutional Review Board for Human Use at the University of Alabama at Birmingham.

**B. Population studied.** The study sample consisted of parents (or the primary caregiver) and their children with physician-diagnosed asthma, between the ages of 6 and 12 years old.

The parent-child dyads were primarily recruited from Children’s Hospital of Alabama Asthma and Allergy Clinics and three County Public Health Pediatric Clinics where the children were attending to receive medical care for asthma. Participant inclusion criteria were:

- Primary caretaker of a child aged 6-12 with physician-diagnosed persistent asthma. This age range was chosen because spirometry is not reliable prior to age 6 and after 12 responsibilities for care often shifts away from the parent.
- Has a working home or cell telephone
- Speak and Read English

**C. Sample selection.** Parents of all children attending a pediatric clinic while study recruiters were in attendance (1 to 2 days per week), who met eligibility criteria, were approached for study participation. Only one child per family could be enrolled; therefore, when multiple children with asthma from the same family were present, the oldest child meeting eligibility was enrolled. Initial plans were to recruit an even number of parents scoring in each of the three health literacy categories (inadequate, marginal and adequate) on the REALM screener; however, low rates of parents scoring in the lower categories made this impossible. Therefore, the screener was abandoned and while health literacy was measured, it was not used for sample selection.

**D. Instruments used**

<b>Table 1. Summary of Measures and Collection Mode</b>			
Measure	# items	Measure	# items
<i>Interview of Parent</i>			
Demographics- Parent and child race & gender; relationship to child; persons in home/with asthma; parent education, income, employment	10	Pediatric Asthma Health Outcome Measure (PAHOM) <sup>44</sup>	28
Admitted non-Adherence <sup>45</sup>	9	Prescribed Treatment understanding	2
Child’s exposure to smoke	2-4	Treatment beliefs <sup>46</sup>	8
Asthma Responsibilities Questionnaire <sup>47</sup>	10	Asthma Knowledge <sup>48</sup>	8
<i>Interview of Child</i>			
Asthma Responsibilities Questionnaire <sup>47</sup>	10	Prescribed Treatment understanding	2
PAHOM <sup>44</sup>	28		
<i>Parent Self-completed with Interviewer Assistance</i>			
Marlowe-Crowne Social Desirability Scale – Form C <sup>49-51</sup>	13	Health Literacy Self-rating	1
Juniper Asthma Control Questionnaire <sup>1</sup>	7		
<i>Health Literacy Measures</i>			
TOFHLA – Test of Functional Health Literacy for Adults <sup>52</sup>	2	REALM – Rapid Estimate of Adult Literacy Measure <sup>53</sup>	66
<i>Health Care Provider Self-administered</i>			
perceived parent health literacy, effect on treatment recommendations; child’s asthma control and severity			6
<i>Chart Abstraction</i>			
Child’s DOB (to calculate age)		Spirometry	
Smoking exposure status		Triggers	
Recent Pulmonary symptoms		Number of clinic visits to date	
Past year- asthma urgent health care visits		# School days missed	
Age of onset of asthma symptoms		Asthma education given at visit	

**Table 1. Summary of Measures and Collection Mode**

Measure	# items	Measure	# items
Insurance status / method of payment for medicines		Treatment recommendations (medications, etc.)	

**E. Statistical techniques employed.** A variety of statistical methods were employed, depending on the type of data and question of interest. Specific tests and purposes for quantitative data are:

- Descriptive statistics were used to depict the study population.
- Logistic and linear regressions were used to examine relationships between health literacy and asthma measures
- Chi square and ANOVA statistics were used to compare differences among categorical variables (e.g., perceived level of parent health literacy, parent ability to carry out treatment recommendations, affect on recommendations given)
- A generalized linear model was used to examine the relationship between the TOFHLA score and health care utilization (number of PCP visits/year due to asthma, number of hospitalizations due to asthma, number of ED visits due to asthma) and the number of school days missed since the child’s last clinic visit. Also, for provider-TOFHLA concordance and asthma control.
- Spearman rank correlations were used to assess the relationship between different health literacy measures (e.g., TOFHLA, REALM, provider, parent self-assessment) of categories (inadequate, marginal and adequate). Kendall's tau correlations were used to examine raw score relationships between the TOFHLA and REALM.

Qualitative data were digitally recorded, transcribed and analyzed using standard methods for this type of data<sup>54</sup>. The interviews were analyzed by first memo-ing transcripts and then an open coding process was used through a line-by-line analysis of the raw data. Using a method of constant comparison across the transcripts<sup>55</sup> these coding categories and themes were continually revised and refined based on an examination of homogeneity.<sup>56</sup> Finally, themes were given priority rankings based on the frequency of their appearance. Parent’s responses to open-ended questions about asthma action plans were scored for articulation of the plan by five individual raters (the PI, 2 Nurse Practitioners and 2 physicians). Ratings were “1=very poor,” “2=poor,” “3=okay,” “4=good,” and “5=very good.” Mean ratings were computed for each participant after 3 of 5 raters agreed on rating and no rater was more than one rating above or below the consensus. .

#### **IV. Detailed Findings**

**A. Sample:** A total of 281 children, average age of 8.8 years (sd=1.9), and their parents (or primary giver) consented to and completed study measures. Participants were given Visa gift cards to serve as an incentive to participation and to cover any additional costs related to participation (e.g., parking, babysitting, loss of pay).

Eighty-six percent of parents were African-American, 11% White and 3% Other (1.5% Hispanic). Two percent of children did not match their parent’s race with 1.5% being listed as White and .5% as African-American rather than Other. The majority (95%) of parents were mothers, 55% had high school or less education, and 63% of children were males. Almost half (48.2%) the parents worked full time outside the home while 30.8% were unpaid full time at home. Half (50.4%) of participants had annual total household incomes of less than \$20,000. The majority of children (74.7%) had Medicaid coverage while 15.7% had private insurance.

Health Care provider surveys were collected for 277 of the children/parent dyads. A total of 14 providers completed surveys, with 11 providers reporting on the majority of children; between 13 and 36 patients each. Four providers were Pediatric Nurse Practitioners specializing in asthma care while the remaining 10 were Pediatricians.

**B. Primary results:**

Parent Health Literacy was a primary variable of interest for this study. Health Literacy was measured several ways and the proportions in each health literacy category varied across measures. All parents with Inadequate or Marginal Health Literacy based on the TOFHLA were of minority race.

*Table 2. Distribution of Health Literacy Categories by Four Sources of Measurement*

Health Literacy Category			
Source	Inadequate	Marginal	Adequate
TOFHLA	1.9%	7.5%	90.7%
REALM	7.5%	44.5%	48.0%
Provider	6.9%	28.9%	64.3%
Self-assessment	0.5%	3.2%	96.3%

Health Literacy Measures (TOFHLA and REALM) data were used in analyses in two ways: categorical classifications (inadequate, marginal and adequate) and as raw scores (to enhance variability as categorical classifications were not evenly distributed). The data are differentiated by the use of *score* or *category*. Spearman correlation between the REALM and TOFHLA scores was 0.717 ( $p < 0.0001$ ) with the TOFHLA score used as the indicator of health literacy, unless otherwise indicated.

Primary Hypotheses:

1. *Higher parent health literacy will be associated with better asthma control in the child.*

Parental health literacy was significantly associated with provider's rating of child's asthma control ( $p = 0.025$ ), with parents who had the highest health literacy score having children with best asthma control. The parent's TOFHLA score was negatively associated the Asthma Control Questionnaire (ACQ) score ( $p = 0.013$ ), with each one point increase in health literacy score indicating a decrease of 0,015 in ACQ score (lower score is better control). This relationship was also found when examining the provider's rating of parental health literacy's association with ACQ; each higher levels of health literacy rating was associated with improved asthma control (decrease of 0.198 on ACQ score). Correlation between the ACQ and provider's rating of asthma control was significant, showing moderate correlation (0.517,  $p < 0.001$ ).

Secondary Hypotheses:

2. *Concordance between healthcare provider's perception of parent health literacy and parent health literacy as assessed by TOFHLA will be positively associated with asthma control.*

Correlation between the healthcare provider's perception of parent health literacy category and the TOFHLA-category was significant but low concordance (0.227;  $p < 0.0001$ ). According to the TOFHLA-category, providers under-rated 31% of parents, over-rated 4% and rated 65% of parents the same ( $n = 277$ ). Controlling for the TOFHLA-category, concordance on the parent's health literacy was significantly related to the child's asthma control as assessed by the health care provider ( $p = 0.002$ ): 76.2% of children who were well-controlled, 54.6% of those not well controlled and 58.6% of those poorly controlled had concordant ratings of parent health literacy. Based on provider ratings of control, those who were well controlled were more likely to have concordant ratings of health literacy. However, when using the ACQ to measure the child's asthma control, there was no significant difference for concordance ( $p = 0.218$ ).

3. *Higher parent health literacy will be associated with asthma outcomes such as better adherence, fewer school days missed and less urgent health care utilization.*

Parent health literacy score (TOFHLA) was not associated with number of PCP visits/year due to asthma, number of hospitalizations due to asthma, number of ED visits due to asthma and number of school days missed since last visit ( $p = 0.148, 0.722, 0.658$  and  $0.329$ , respectively). Using the REALM score instead, the results are similar ( $p = 0.886, 0.658, 0.341$  and  $0.766$ , respectively).

Note: the health care utilization and missed school days data were collected from a chart audit. Variations in how these data were collected and the amount of missing data may have biased these findings.

4. *Children whose parents are perceived to have lower health literacy by the provider will receive fewer treatment recommendations than those perceived to have higher literacy.*

Note: As it was not possible to “count” treatment recommendations the way most were documented (e.g., “continue regimen” or “continue meds”) we opted to examine a different hypothesis in the same content area: Children whose parents are perceived to have lower health literacy by the provider will be more likely to have treatment recommendations changed due to this perception.

Inadequate and marginal health literacy categories were combined for these analyses as 64% of the parents were perceived to have adequate health literacy. Providers reported that their perception of the parent’s health literacy influenced what treatment recommendations they made for 43.4% of those with lower health literacy and 25.8% of those with adequate health literacy ( $p=0.003$ ). In addition, they also reported this changing how they gave treatment recommendations for 80.8% of those with lower health literacy and 61.2% with adequate health literacy ( $p=0.001$ ). There was a significant difference in how well parents were judged by the provider to be able to carry out treatment recommendations by perceived health literacy level with 92.6% of parents perceived to have adequate health literacy rated as good to excellent while 89.9% of those with lower health literacy being rated as poor to good.

Follow-up qualitative interviews with the six providers providing care for the majority (66.5%) of patients in this study (2 Nurse Practitioners and 4 Physicians with 5-22 years practice experience) were conducted to provide more understanding what criteria they used to answer the questions about the parent’s health literacy, impact on what and how treatment recommendations were given, and confidence in parent’s ability to carry out recommendations. Primary and secondary themes were identified for each of four questions: parent’s health literacy rating was primarily influenced on the parent’s ability to articulate the child’s treatment plan or health history and secondarily by the parent’s previous adherence to treatment recommendations and their ability to read. They indicated treatment recommendations were started slower, one at a time, for patients with parents they felt had lower health literacy, and they felt they spent more time, and used more tech back methods with lower literacy parents. Finally, they tried to keep recommendations simpler, with more concern about cost and tried to engage the child more when parent’s were perceived to have low health literacy.

5. *Parent’s self-assessment of their health literacy will be moderately associated with their measured health literacy.*

Parent’s self-assessment of their health literacy was in response to a single question: “rate your ability to read and understand medical information, especially instructions for medications and treatments. The response option was to mark along a continuum from 1-7 with 1, 3, and 7 anchored as “I cannot read or understand health information,” “I find it hard to read and understand some health information,” and “I can read and understand most health information,” respectively. Scores of 1-2, 3-4, and 5-7 were categorized as inadequate, marginal and adequate health literacy, respectively.

Spearman’s rho correlation for the health literacy categories was significant at 0.213 ( $p<0.0001$ ). Kendall’s tau correlation was 0.174 ( $p<0.0001$ ).

**C. Additional Findings:** In addition to testing the hypotheses proposed for this study, we examined some additional research questions:

How is parent asthma knowledge related to their health literacy (TOFHLA score) and asthma control? Parents’ asthma knowledge was correlated with health literacy and as asthma knowledge improved so did the child’s asthma control. Parents’ Asthma Knowledge scores were significantly correlated with TOFHLA scores ( $r=.365$ ,  $p<.0001$ ) and for each one point increase in knowledge score, Asthma Control Questionnaire scores decreased by 0.091 ( $p<0.05$ ), indicating improved asthma control.

What is smoking exposure among children being treated for asthma and how well it is documented in the medical record? Among 204 participants for whom all data was available, the

child's medical record documented smoking exposure in the home for 18.1% of children whereas parent's reports indicate 39.2% ( $p < 0.0001$ ). Forty-one percent of the patient records did not have smoking exposure in the home status documented. Of these with no documentation in the medical, 42% reported there was a smoker living in the home. For the 120 patients with both documented and self-reported smoking status available, there was a discrepancy in 22%, with 20% of those documented to have no exposure, reporting exposure and 24% of those documented as having exposure reporting no exposure.

How are parent health literacy, asthma treatment beliefs and child's asthma control associated? Higher parent health literacy was significantly associated with more positive Treatment Beliefs, as assessed by an 8-item scale ( $\alpha = .55$ ) ( $p < 0.0001$ ). Each one point increase in the TOFHLA score was associated with a 0.155 increase in Treatment Beliefs. (As well, each 1 point increase in REALM score was associated with 0.121 increase in Treatment Beliefs). In turn, higher Treatment Beliefs was significantly associated with better Asthma Control (ACQ) ( $p < 0.0001$ ; 2.04 decrease in Treatment Beliefs to 1 point increase in ACQ).

How well do parents understand and articulate their children's asthma action plans? Thirty six parents participated in individual in-depth interviews in which they were asked to explain their child's asthma action plan in response to a set of structured questions. 83% were African-American and all were mothers. The overall mean rating for correct articulation of the asthma action plan was 2.866 (between "poor" and "okay"); ratings were not different by health literacy scores ( $p = 0.40$ ). The major area for error was in the parents' reporting of management when the child was in the "red" zone, particularly appropriate medication timing and dosage as well as when to call the doctor or go to the emergency room.

## V. Discussion and Interpretation of Findings

### A. Conclusions to be drawn from findings (with reference to data supporting each).

Conclusions that can be drawn from the results of this study are:

- Higher parental health literacy is associated with higher parental asthma knowledge and children's better asthma control. Parents' Asthma Knowledge scores were significantly correlated with TOFHLA scores ( $r = .365$ ,  $p < .0001$ ) and for each one point increase in knowledge score, Asthma Control Questionnaire scores decreased by 0.091. Parental health literacy was significantly associated with provider's rating of child's asthma control ( $p = 0.025$ ), with parents who had the highest health literacy score having children with best asthma control. The parent's TOFHLA score was negatively associated the Asthma Control Questionnaire (ACQ) score ( $p = 0.013$ ), ( $p < 0.05$ )
- Higher parent health literacy is associated with better treatment beliefs and better treatment beliefs is associated with the child's asthma control. Higher parent health literacy was significantly associated with more positive Treatment Beliefs ( $p < 0.0001$ ) with each one point increase in the TOFHLA score associated with a 0.155 increase in Treatment Beliefs. Better Treatment Beliefs was significantly associated with better Asthma Control (ACQ) ( $p < 0.0001$ ).
- Healthcare providers' perceptions of parent's health literacy influence what and how treatment recommendations are given. Providers' judgment of parents' health literacy is primarily based on the parents' ability to articulate the child's health history and previous treatment prescribed. Providers reported parent's health literacy influenced what treatment recommendations they made for 43.4% of those with lower health literacy and 25.8% of those with adequate health literacy ( $p = 0.003$ ). In addition, they also reported this changing how they gave treatment recommendations for 80.8% of those with lower health literacy and 61.2% with adequate health literacy ( $p = 0.001$ ). There was a significant difference in how well parents were judged by the provider to be able to carry out treatment

recommendations by perceived health literacy level with 92.6% of parents perceived to have adequate health literacy rated as good to excellent while 89.9% of those with lower health literacy being rated as poor to good.

- A single question asking parents to self-rate their health literacy was not well correlated with currently used measures. Correlations, while statistically significant, indicated low correspondence. (Spearman's rho correlation =0.213; Kendall's tau correlation =0.174).
- Regardless of health literacy level, race or education, parents have difficulty articulating their child's asthma action plan which demonstrates poor understanding of home management, particularly for treating the child when having an asthma exacerbation. All parents need help to increase their understanding of how to follow the asthma action plan for home management of their child's asthma.

### **B. Explanation of study limitations**

Using a retrospective cohort design has several limitations. First, data were collected cross-sectionally which limits conclusions to correlations and associations. As well, most of the data are self-reported which means they are subject to the usual potential biases related to recall and mis-reporting. As well, data from the medical records was found to be often missing or presented in an unusable way; this resulted in missing data in some analyses and may have created some bias in the findings. Finally, variations in the health literacy scores of participants on different measures limits the validity of the "health literacy" construct and associations with it. Based on the TOFHLA, this sample over-represents parents with adequate health literacy. For all measures, the sample likely under-represents rates of inadequate health literacy compared to a general pediatric asthma population.

### **C. Comparison with findings of other studies**

This study found lower rates of inadequate (1.9%) and marginal (7.5%) health literacy than has been reported in the literature (26% and 20%, respectively)<sup>2</sup>, based on the TOFHLA. As well, using rates found with the REALM, inadequate rates were lower (7.5%) while marginal rates were higher (44.5%). Similar to other reports, we found a higher rates of adequate health literacy among Whites than minorities (100% vs. 89.4% based on the TOFHLA; 92% vs. 49.2% based on the REALM)<sup>3</sup>.

We could not find another study that directly assessed parent's health literacy and its association with children's asthma control. However, these findings are consistent with other studies that examined the health literacy of parents of children with asthma and effects on asthma care and morbidity. A study of African-American parents found their health literacy associated with self-efficacy to manage their child's asthma<sup>57</sup> while parent self-efficacy has been found related to child asthma symptoms<sup>58</sup>, a marker of asthma control.

Consistent with other's reports<sup>59</sup>, we found that parents did not demonstrate good understanding of home management for their children's asthma, despite that we only interviewed parents whose children had asthma action plans.

Similar to a study by Kelly and Haidet, we found that health care providers generally overestimated patient (parent) health literacy as it was determined by the REALM.<sup>60</sup> We did not find any studies that addressed this potential discordance between the TOFHLA-determined patient health literacy and the provider's estimation.

DeWalt and others found that parent health literacy was linked to ED visits, hospitalizations and missed school among inner city children<sup>24</sup>. Our study did not find these relationships, similar to the finding from a study of parents in an urban population in upstate New York<sup>61</sup>.

We found lower rates of tobacco smoke exposure in the home reported by parents compared to a large general pediatric population study<sup>62</sup> (39.2% vs. 70%) and better rates of documentation (35% vs. 15.2%) for those with reported smoking. Given that our population of children all had a documented pulmonary disease, it is not surprising that rates of documentation are higher than the general population. However, both studies indicate poor

documentation of tobacco smoke exposure in the home for children, despite the known dangers of secondhand smoke for children<sup>63</sup>.

#### **D. Possible application of findings to actual MCH health care delivery situations**

Providers should be aware of health literacy barriers as a reason for poor asthma control and tailor education and treatment plans with this in mind. Alternatively, universal precautions for health literacy have been recommended<sup>64, 65</sup> and free generic materials are available.<sup>66</sup> Instituting such policies for asthma have potential to improve parental understanding of asthma, as well as prescribed treatments which may improve adherence and ultimately, children's asthma control.

#### **E. Suggestions for further research**

Several areas for future research were identified from this current study. First, while universal precautions for health literacy are being promoted, they have not been specifically tailored for a pediatric asthma clinical setting where the parent's health literacy, not the patient's is of concern. Interventions that adopt these methods to pediatric asthma settings are needed. These would include both interventions for health care providers to improve their abilities for "plain talk" and assessing patient (parent) understanding as well as to improve patient (parent) understanding. Second, we identified a gap between currently available health literacy measures (which measure numeracy and reading abilities) and the basis for clinical judgment about parent health literacy (verbal). Despite the increasing health information sources available, the patient (parent)–healthcare provider verbal interaction still represents the primary place where health information, including patient history and treatment instructions, is exchanged<sup>67</sup>. Given the importance of talking and hearing in the health care encounter, a measure that addresses these abilities on the part of the patients (parents) is critical to identify efficacious health literacy interventions. Finally, we noted great variation in and missing data from medical records, especially electronic medical records. To maximize optimal continuity of care, standardized approaches to documentation and training providers in these approaches is needed. This will require investigation into current practices and gathering consensus on what core data must be documented and by whom. For children with asthma, this particularly needs to include the assessment and documenting of the child's exposure to second-hand smoke.

## **VI. List of products**

### *Manuscripts Submitted*

Gerald JK, McClure LA, Harrington KF, Moore T, Gerald LB. Measurement Characteristics of the Pediatric Asthma Health Outcome Measure. Submitted to *J. Asthma*

### *Manuscripts in Progress*

Harrington KF, Zhang B, Magruder T, Bailey WC, Gerald L. Parent health literacy and children's asthma control.

Harrington KF, Magruder T, Johnston J, Bailey WC, Gerald LB. A qualitative assessment of how home-management instructions are understood by parents of children with asthma

Harrington KF, Zhang B., Magruder T, Bailey WC, Gerald LB. How pediatric providers perceive parents' health literacy and its Impact on asthma treatment recommendations and instructions (mixed methods)

### *Manuscripts Planned*

Gerald LB, Magruder T, Bailey WC, Harrington KF. Differences in medical record documentation and parent report of smoking exposure for children with asthma.

*Oral Presentations:*

Title: Agreement between Medical Record Documentation and Parent Report of Asthma Education given in Pediatric Asthma Clinic visit

Authors: Kathy F. Harrington, Janet Johnston, Lynn B. Gerald; Institutions: University of Alabama at Birmingham, Birmingham, Alabama; Children's Hospital of Alabama, Birmingham, Alabama

Conference: American Thoracic Society International Meeting; May 2009, San Diego, California

Title: Parent and Child Agreement on the Pediatric Asthma Health Outcome Measure

Authors: Joe K. Gerald, Leslie A. McClure, Kathy F. Harrington, T A Lee and Lynn B. Gerald; University of Alabama at Birmingham, Northwestern

Conference: American Thoracic Society International Meeting; May 2009, San Diego, California

Title: Health Care Provider Perceptions of Parents' Health Literacy and Effect on Treatment Recommendations for Children with Asthma

Authors: Kathleen F. Harrington PhD MPH<sup>1</sup>, Theresa Magruder MD MPH<sup>2</sup>, Janet Johnston CRNP<sup>2</sup>, Leslie A. McClure PhD<sup>3</sup>, William Bailey MD<sup>1</sup>, and Lynn B. Gerald, PhD, MSPH<sup>4</sup>. <sup>1</sup>Lung Health Center, Division of Pulmonary Medicine, University of Alabama at Birmingham; <sup>2</sup>Department of Pediatrics, University of Alabama at Birmingham; <sup>3</sup>Department of Biostatistics, School of Public Health, University of Alabama at Birmingham; <sup>4</sup>School of Public Health, University of Arizona

Conference: American Thoracic Society International Meeting; May 2010, San Francisco, California

**Posters:**

Title: The Pediatric Asthma Health Outcome Measure, Not Just a Quality-of-Life?

Authors: Joe K. Gerald, Leslie A. McClure, Kathy F. Harrington, T A Lee and Lynn B. Gerald; University of Alabama at Birmingham, Northwestern

Conference: American Thoracic Society International Meeting; May 2009, San Diego, California

Title: How well do parents explain their child's Asthma Action Plan?

Authors: Kathy F. Harrington PhD, MPH and Lynn B. Gerald, PhD, MSPH; University of Alabama at Birmingham

Conference: American Thoracic Society International Meeting; May 2009, San Diego, California

Title: How accurate is a single Health Literacy Question for assessing Parents of Pediatric Asthma Patients?

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*Abstracts Accepted:*

Title: Associations Among Parent's Health Literacy, Asthma Knowledge And Child's Asthma Control

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