Provider Perceptions of Parent Health Literacy and Effect on Asthma Treatment Recommendations and Instructions

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Little is known about how pediatric providers assess parental health literacy, how concordant they are with validated measures of health literacy, and how these perceptions may influence treatment recommendations, how instructions are given or how reliable they perceive parents to be in carrying out instructions. Two hundred and eighty-one parents of 6–12-year-old asthma patients attending a pediatric clinic visit were recruited to a cross-sectional study of health literacy and asthma outcomes. Fourteen pediatric healthcare providers participated. Parents completed surveys that included 2 measures of health literacy: the Test of Function Health Literacy in Adults (TOFHLA) and the Rapid Estimate of Adult Literacy in Medicine (REALM). Immediately postvisit, pediatric providers completed a brief survey asking their assessment of the parent's health literacy and how it impacted treatment instructions and recommendations. Kappa statistics tested concordance; chi square and logistic regression tested associations among provider ratings, rating concordance, and demographic factors. Six providers were interviewed regarding the bases for their ratings. Providers' perceptions influenced asthma treatment recommendations (p=0.001) and how treatment instructions were given (p=0.001). Providers indicated that their perceptions were shaped by parent's verbal communication skills and patterns of past behavior related to children's asthma management. Data from 277 parents indicated that most had adequate health literacy with a lower percentage scored as adequate by the REALM versus the TOFHLA. Pediatric provider estimates of parental health literacy had low concordance with the validated measures. Providers were more likely to designate whites as adequately health literate. Pediatric asthma providers' perceptions of parents' health literacy can influence treatment recommendations and instructional practices.

Introduction

A STHMA AFFECTS 9.6% OF ALL CHILDREN in the United States, with higher prevalence among poor (13.5%) and black (17.0%) children.¹ Primary caregivers, usually parents, play an important role in children's disease management, including communicating children's disease status, needs, and experiences to their health care providers. In addition, the parents have a primary responsibility for supervising children's asthma management plans and medication regimens.²

Health literacy has been identified as a key factor affecting asthma management in children and adults.³ Health literacy's definition encompasses an individual's capacity to access, understand, communicate, evaluate, utilize, and make decisions based on health information.^{4–6} A systematic review of health literacy studies found ~25% of study samples to have inadequate health literacy,⁷ consistent with popula-

tion-level findings from the 2003 National Assessment of Adult Literacy, wherein 26% of adults were at basic or below basic literacy.³ Minorities, elderly, and those with lower education levels had even higher rates of low literacy. Low health literacy has been related to poor asthma management among adults⁸ and low parental health literacy has been associated with more emergency department visits, school absences, medication use, and inappropriate medication use among their children with asthma, even after controlling for income and race.⁹ Further, lower parental health literacy has correlated slightly with lower self-efficacy for managing their children's asthma.¹⁰

Two suggested sources of disparities in patient outcomes have been the provider attitudes that impact communication and interaction with the patient¹¹ and racial concordance between providers and patients.¹² Patients can address racial concordance in their choice of a provider, whereas the providers can address communication and interaction issues.

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Universal precautions call for treating all patients as at risk for low health literacy and is one strategy recommended to reduce the disparities in health literacy-related health outcomes¹³ and while most effective for patients with inadequate health literacy, patients with adequate health literacy also benefit.^{14–16} Universal precautions for health literacy entail providing bite-size chunks of information at a time, prioritizing health information, and confirming patient comprehension with iterative educational methods.

This study's primary objectives were to examine how provider perceptions of parental health literacy influenced pediatric asthma treatment recommendations and instructions, and perceptions of the parental ability to implement treatment plans. Secondary objectives included examining provider ratings with parent demographics, racial concordance, 2 validated health literacy measures' ratings, and a qualitative assessment of how pediatric providers assess the health literacy of their asthma patients' parents.

Materials and Methods

Native English-speaking parents or primary caregivers (hereinafter parents) of 6–12-year-old asthma patients were recruited to a cross-sectional study of health literacy and asthma outcomes while attending pediatric clinics in Birmingham, Alabama, during 2008–2010. Parents provided written informed consent, and children assented, before study activities. The study protocol was approved and monitored by the Institutional Review Boards for Human Use at the University of Alabama at Birmingham and the University of Arizona.

After the child's clinic visit, research staff assisted each parent in completing assessments that included demographics, the child's asthma history/treatment, and 2 validated measures of health literacy [Test of Function Health Literacy in Adults (TOFHLA) and Rapid Estimate of Adult Literacy in Medicine¹⁷ (REALM)]. The TOFHLA contains 50 cloze passage reading comprehension items and 17 numeracy items and takes up to 22 min to complete.18 The REALM takes ~3 min to administer and tests correct pronunciation of 66 health-related words.¹⁷ At the end of the clinic visit, the attending provider completed a short survey that assessed, their perception of the parent's health literacy level (adequate, marginal, or inadequate), if this perception influenced how they provided treatment instructions or influenced the treatment recommendations made, and the provider's assessment (5-point scale-poor to excellent) of the parental ability to carry out the treatment recommendations. Treatment instructions and recommendations varied by individual child and providers were not given any training regarding these questions to ensure that usual clinical judgments were used.

The providers who rated the majority (58%) of the parents participated in poststudy in-depth interviews. Providers were asked to describe the factors they considered when assessing parents' health literacy and ability to carry out treatment. Providers also were asked how they altered instructions and recommendations.

Analyses

Chi squares were used to test associations between providers' ratings of the parental health literacy and parental

TABLE 1. SAMPLE DESCRIPTION

	n=277	%
Race		
Black	241	87.0
White	36	13.0
Ethnicity		
Hispanic	6	2.2
Non-Hispanic	270	97.8
Sex		
Female	264	95.3
Male	13	4.7
Education level		
Less than high school	47	17.0
High-school diploma/GED	104	37.5
Post-high school/technical school/some college	82	29.6
College degree or higher	44	15.9
Income		
Less than \$20,000	139	50.2
\$20,000-\$39,000	63	22.7
\$40,000-\$59,000	14	5.1
Over \$60,000	16	5.8
Declined to answer	44	15.9
Child's asthma severity ^a		
Intermittent	13	4.6
Mild persistent	106	37.7
Moderate persistent	137	48.8
Severe persistent	24	8.5

^aAs rated by Provider (1 missing).

GED, general educational development diploma.

ability to carry out treatment recommendations, changing how treatment instructions were given, and what recommendations were given; provider perceptions of parental ability to carry out treatment and what recommendations were given; providers' ratings of adequate health literacy and parent demographics and concordance between provider's and parent's race; and, parent race, education and income, and concordance between provider's ratings of parents' health literacy level with the TOFHLA and with the REALM. Variables found significant in the last set of bivariate tests were then entered into multinomial logistic regression models. Kappa coefficients tested the concordance between each pair of parent's health literacy ratings: the TOFHLA, the REALM, and the pediatric provider's categorization of the parent's health literacy. Significance was set at p < 0.05.

Themes from interview responses were identified and prioritized using stages 1 and 2 proposed by Thomas and Harden.¹⁹ Stage 1 involved coding interview responses based on patterns of meaning within the text, and stage 2 consisted of establishing descriptive themes from these patterns.⁶ We used constant comparative methods to examine data across cases at the same time and reviewed interview responses after coding to ensure no themes were overlooked.²⁰

Results

Subjects

Of 281 parents of children with asthma enrolled in the study, complete data were available for 277 parents.

PROVIDER PERCEPTIONS OF PARENT HEALTH LITERACY

	Parent health literacy			
	Inadequate n=19	Marginal n=80	Adequate n=178	p-Value
Changed recommendations	21.1%	48.8%	25.8%	0.001
Changed instruction method	97.7%	77.5%	61.2%	0.001
Ability to carry out treatment				
Poor or fair	84%	53%	7%	< 0.0001
Good	16%	35%	35%	
Very good or excellent	0%	13%	57%	

TABLE 2. PROVIDER RATINGS OF PARENT HEALTH LITERACY AND INFLUENCE ON TREATMENT RECOMMENDATIONS AND HOW THEY ARE GIVEN, AND PERCEPTION OF PARENT ABILITY TO CARRY THEM OUT

Children ranged from 6- to 12-year olds [mean/standard deviation (SD) = 8.84/(1.88)]. The vast majority of parents were black, woman, and biological or adoptive parents (see Table 1). Almost 83% of children were covered by governmentsubsidized medical plans (Medicaid or All Kids). About half of the parents were assessed at general pediatric public health clinics, while the other half were assessed at academic hospitalbased pediatric asthma clinics. Fourteen providers, 4 nurse practitioners, and 10 physicians, participated in this study.

Quantitative results

Pediatric providers' treatment recommendations were influenced by their perceptions of parental health literacy (χ^2 p = 0.001). Changes in treatment recommendation were more common when parents were perceived to have marginal health literacy versus perceived to have inadequate or adequate health literacy. Providers' perceptions of parental health literacy were significantly associated with their perceptions of the parents' abilities to carry out treatment recommendations ($\chi^2 p < 0.0001$). Those perceived as poor or fair in their ability to carry out treatment recommendations were most often assessed as having inadequate health literacy, while those perceived as very good or excellent were more often assessed as having adequate health literacy. Providers reported changing how they gave treatment instructions with a greater percentage of parents as perceived health literacy lowered ($\chi^2 p = 0.001$). A change in instructional method was reported for 98% of parents perceived as having inadequate health literacy (see Table 2).

More parents scored as having adequate health literacy on the TOFHLA than on the REALM (90.6% versus 48.7%, respectively). The REALM and TOFHLA had concordant categorizations of health literacy for 52.7% of parents, with the REALM providing lower ratings than TOFHLA for 46.2% (κ =0.097; p=0.001). Healthcare providers rated 64.3% of parents as having adequate health literacy (see Table 3).

Compared to TOFHLA classifications, provider classifications were concordant for 65.0% of parents, lower discordant (providers rated lower than TOFHLA) for 30.7%, and higher discordant (providers rated higher than TOFHLA) for 4.3% ($\kappa = 0.113$; p = 0.003). The parental race, education level, and income were significantly associated with concordance at the bivariate level, whereas only race (p=0.045) and education (p = 0.016) remained significant in the multinominal model. Those with higher education and whites were more often rated concordantly by the provider and the TOFHLA (see Table 4).

Compared to REALM classifications, provider classifications were concordant for 49.8%, lower discordant for 17.7%, and higher discordant for 32.5% ($\kappa = 0.097$; p = 0.044). The parental race and income were significantly associated at the bivariate level with concordance, whereas only race (p < 0.0001) remained significant in the multinominal model. Whites were more often rated concordantly (see Table 4).

Providers were more likely to rate parents as having adequate health literacy if they had higher education levels (χ^2 p < 0.0001), their incomes were > \$20,000 versus \leq \$20,000 (χ^2 p = 0.005), and they were white versus black ($\chi^2 p = 0.009$). Concordance between the provider and parental race was not associated with adequate health literacy ratings. When entered into a multivariate logistic regression model, only the race remained significant (p = 0.011) (see Table 5).

TABLE 3. COMPARISON OF PROVIDER PERCEPTIONS OF PARENT HEALTH LITERACY WITH TEST OF FUNCTION HEALTH LITERACY IN ADULTS AND RAPID ESTIMATE OF ADULT LITERACY MEASURE SCORES

		Provider rating			
		Inadequate	Marginal	Adequate	%
TOFHLA ¹	Inadequate (0–59) Marginal (60–74) Adequate (75–100)	$\begin{array}{c} 0^{a} \\ 4^{b} \\ 15^{b} \end{array}$	$\begin{array}{c} 4^{\rm c} \\ 10^{\rm a} \\ 66^{\rm b} \end{array}$	1° 7° 170 ^a	1.8 7.6 90.6
REALM ²	Inadequate (0–35) Marginal (36–60) Adequate (61–66) %	2 ^a 12 ^b 5 ^b 7.6	10 ^c 38 ^a 32 ^b 28.9	9° 71° 98° 64.3	6.0 43.7 48.1 100

⁽¹⁾ ^aConcordant (180/277=65.0%); ^bhigher discordant (12/277=4.3%); ^clower discordant (85/277=30.7%). ⁽²⁾ ^aConcordant (138/277=49.8%); ^bhigher discordant (90/277=32.5%); ^clower discordant (49/277=17.7%).

TOFHLA, Test of Function Health Literacy in Adults; REALM, Rapid Estimate of Adult Literacy Measure.

	n		Concordant with TOFHLA			Concordant with REALM			
		К	% Concord	Bivariate p-value	Multivariate p-value	K	% Concord	Bivariate p-value	Multivariate p-value
Race									
Black	241	.109	62.2%	0.037	0.045	.060	45.2%	< 0.0001	< 0.0001
White	36	а	83.3%			.125	80.6%		
Education									
<high school<="" td=""><td>47</td><td>.008</td><td>42.6%</td><td>0.001</td><td>0.016</td><td>.070</td><td>46.8%</td><td>0.209</td><td>_</td></high>	47	.008	42.6%	0.001	0.016	.070	46.8%	0.209	_
High school/GED	104	.109	61.6%			.080	44.2%		
Some post HS	82	.101	73.2%			044	50.0%		
College or more	44	.192	84.1%			077	65.9%		
Income									
<\$20,000	139	.085	57.6%	0.013	0.513	.018	41.7%	0.004	0.089
\$20,000 or more	93	.148	76.3%			.163	63.4%		

TABLE 4. CONCORDANCE OF PROVIDER RATINGS OF PARENT HEALTH LITERACY WITH THE TEST OF FUNCTION HEALTH
Literacy and Rapid Estimate of Adult Literacy Measure Ratings by Parent Demographics

^aKappa not computed as TOFHLA category was a constant (adequate).

HS, high school.

Qualitative results

Of 14 providers, 6 (4 physicians and 2 nurse practitioners; 1 black and 5 white) who rated the majority of the parents participated in interviews. Two primary themes emerged from responses to "What sorts of things do you consider when you answer 'What is the parent's health literacy level?' ": parent ability to verbally communicate and previous knowledge of the parent. In assessing a parent's health literacy, providers particularly focused on the parent's ability to verbally communicate their child's asthma history, treatment plan, or responses to questions. Providers also mentioned a negative impression when parents provided contradictory information during the visit. Previous knowledge of the parent included a suspected educational level and previous clinical interactions, particularly the parent's adherence to prescribed treatments and filling prescriptions (based on parent self-report and/or review of Medicaid prescription database). One primary theme emerged from provider responses about how they changed treatment recommendations based on perceived health literacy: Keep it simple. For those patients they felt less able, providers were more likely to simplify the plan (e.g., giving siblings with asthma the same plan; changing controller medication dosing from twice to once a day). When asked how they changed their treatment instructions, 2 themes emerged: *use of color or photos to differentiate type of inhaler* and *reducing the amount of information given*. They also mentioned using a limited "teach-back" method, wherein the provider asked the parent to tell in "your own words" the information/instructions they just had been given.

Discussion

In this study, the provider's perception of the parental health literacy level was found to influence several aspects of pediatric asthma care. Interviews with providers suggested that parents' verbal communication skills and patterns of past behavior related to children's asthma management are important factors in shaping the providers' perceptions.

Not surprisingly, we found a significant relationship between the pediatric provider's perceptions of the parent's health literacy and ability to carry out the child's asthma treatment plan. This relationship is likely bi-directional as

TABLE 5. PROVIDER RATINGS OF PARENT HEALTH LITERACY AND PARENT DEMOGRAPHICS

	n	Inadequate or marginal %	Adequate %	Bivariate p-value	Multivariate p-value
Race					
Black	241	38.6%	61.4%	0.009	0.011
White	36	16.7%	83.3%		
Education					
<high school<="" td=""><td>47</td><td>57.4%</td><td>42.6%</td><td>< 0.0001</td><td>0.257</td></high>	47	57.4%	42.6%	< 0.0001	0.257
High school/GED	104	39.4%	61.6%		
Some post HS	82	28.0%	72.0%		
College or more	44	18.2%	81.8%		
Income					
<\$20,000	139	43.2%	56.8%	0.005	0.223
\$20,000 or more	93	24.7%	75.3%		
Race concordance					
Same	99	38.4%	61.6%	0.515	-
Different	178	34.3%	65.7%		

both assessments were influenced by the provider-parent past experiences related to adherence to medications or other prescribed treatments. Past experiences were expressed by providers as a consideration in assessing the parent's health literacy. Provider assessments also may be influenced by providers' knowledge of literature in which parents' health literacy has been found to mediate pediatric health outcomes^{9,21} as well as medication adherence.²² Providers also reported changing instruction methods more often when they perceived parents' health literacy as inadequate. They reported commonly recommended methods such as providing limited information, using visual materials, and modified teach back for these parents. Changing recommendations was more common when providers' perceived parents' health literacy as marginal; however, this association was not seen when providers' perceived parents' health literacy as inadequate. This is likely due to the small sample size.

Pediatric providers' ratings of parental health literacy was found to have low concordance with 2 validated measures of health literacy, including the TOFHLA. The previous study that examined pediatric asthma parents' health literacy with provider perceptions found moderate agreement between TOFHLA and provider ratings (κ =0.51).²³ That study had a significantly smaller sample (*n*=46 versus 277), fewer providers rating parents (*n*=3 versus 14) (Dr. Angie Wittich written communication, 4/22/12), and the sample was drawn from a children's hospital-based dedicated asthma clinic.

Parents and providers often have disparate ways of describing and communicating about pediatric asthma; the more discordant these representations are, the worse the disease management.²⁴ Patients with lower communicative health literacy have been found less likely to ask questions of health care providers.²⁵ Providers have a substantial challenge in recognizing low health literacy patients²⁶ leading to frequently overestimating health literacy,²⁷ potentially exacerbating an already existing source of disparity. Although providers express openness to more effective communication techniques, time constraints lead them to underutilize recommended methods, such as teach-back and using simple written materials.²⁶ Instead, as described in this study, for parents with low literacy, providers simplify verbal instructions,²⁶ a technique that, while helpful for increasing the understanding, has the potential to omit information and to overlook the important health literacy components of processing and communicating for those parents already less likely to ask questions.

Stevens et al. reported on the relationship between racial concordance between the provider and parent with pediatric asthma outcomes as a potential bias leading to disparity.²⁸ We examined the same predictor, but with the provider's rating of adequate health literacy as a potential source of bias. Consistent with Stevens et al., no significant effect for parent and provider racial concordance was found. Other studies of patient–provider racial concordance report mixed results.¹²

The health literacy measures used in this study have limitations. The TOFHLA measures reading comprehension and numeracy, while the REALM assesses word recognition and pronunciation.^{17,18} Providers did not report considering these skills, but rather verbal exchange skills when assessing parental health literacy. It is possible that the criteria mismatch between these health literacy measures and provider perceptions are the basis for the poor congruence found in this study. While health literacy encompasses reading, writing, numbers, speaking, and listening,²⁹ the measures available at the time of this study do not address the latter 2 skills which, in this study, appear to be upon what pediatric providers based their health literacy assessments. Developing more comprehensive health literacy measures may help to resolve the current gap between how health literacy is assessed and its more complex manifestation as an interplay of reading, writing, speaking, listening, and comprehending.^{8,24,30,31}

This study is limited by the unequal proportions of parents testing into the 3 health literacy categories. The findings from this study may not be applicable to samples that differ in demographic make-up, specifically those not primarily woman, black, having at least a high-school education, and living in the southeastern United States. Caution should be used in extrapolating findings regarding race from this study as the whites in this study were different from the blacks in several socioeconomic indicators [e.g., more likely to have salaried versus hourly paid jobs, have graduated from college, and have a higher household income (data not shown)]. These differences between white and black participants may help explain why race remained a significant predictor of the provider's rating of health literacy; that is, these factors may represent differences in how patients present themselves, including their ability to articulate the child's asthma history, and therefore, how they are perceived. Because health literacy may serve as a marker for other factors affecting health,⁹ it is difficult to tease it apart from socioeconomic status, education level, and other characteristics. Proposed causal pathways between low health literacy and poor health outcomes include discomfort with social interactions, shame, and passivity or avoidance asking questions.³² Parents of children with asthma with adequate health literacy have been found to utilize a variety of sources such as the Internet and social circles to aid in their children's disease management, but these sources are underutilized by parents with low health literacy, leaving the provider's communication as the primary source of information.³³ Given the importance of the provider's communication skills, utilizing methods demonstrated effective in improving outcomes, such as in the Physician Asthma Care Education study,³⁴ would be especially beneficial for those with low health literacy.

Pediatric providers should be aware of how their perceptions, including that of parents' health literacy, influence their clinical interactions and patient care. When accurate, these perceptions may result in more appropriate treatment recommendations and instructional methods. A common recommendation,^{3,26,32,35} is to engage low health literacy parents in teach-back methods,³⁶ as well as using visual and multimedia resources to facilitate instructions. Given the unknown accuracy of providers' perceptions, universal precautions for health literacy for all parents of pediatric asthma patients are recommended.

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Author Disclosure Statement

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