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To cite this article: Paula Jo Belice, Giselle Mosnaim, Stanley Galant, Yoonsang Kim, Hye-Won Shin, Naomi Pires-Barracosa, Julianne P. Hall, Rabia Malik & Ellen Becker (2019): The impact of caregiver health literacy on healthcare outcomes for low income minority children with asthma, Journal of Asthma, DOI: [10.1080/02770903.2019.1648507](https://doi.org/10.1080/02770903.2019.1648507)

To link to this article: <https://doi.org/10.1080/02770903.2019.1648507>



Accepted author version posted online: 25 Jul 2019.
Published online: 08 Aug 2019.



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The impact of caregiver health literacy on healthcare outcomes for low income minority children with asthma

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ABSTRACT

Objectives: The aim of this exploratory study was to assess the impact of caregiver health literacy (HL) on health care outcomes for their child with asthma.

Methods: Caregiver dyads across two different healthcare delivery systems completed a battery of validated asthma outcome instruments, including the Newest Vital SignTM as a measure of HL for the caregivers of children ages 7–18y. Utilization history was obtained through the electronic medical record. Descriptive analysis with bivariate associations was conducted.

Results: There was no direct relationship between HL and asthma outcomes in the 34 Hispanic and African American caregiver-child dyads. However, caregiver health literacy was significantly related to language ($p = 0.02$). African American English-speaking caregivers, seen in an urban emergency department, demonstrated adequate health literacy. Hispanic Spanish-speaking caregivers, seeking care in a mobile asthma van, showed limited health literacy. There was no significant association between caregivers' HL and routine asthma care visits when language and child age were controlled.

Conclusions: Assessing patient factors can identify persons at risk who need additional support to negotiate the healthcare system when providing care for a child with asthma.

ARTICLE HISTORY

Received 18 March 2019
Revised 12 July 2019
Accepted 21 July 2019

KEYWORDS

Health literacy; asthma; caregivers; children; health care utilization

Introduction

The Institute of Medicine defines health literacy (HL) as “the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions.”⁽¹⁾ Components of HL include reading, writing, numeracy, critical analysis, listening, communication and cultural factors. Health Literacy assessments may include one or more of these skills. Adequate HL is necessary to correctly interpret provider instructions, complete medical forms, and access appropriate services. Limited HL among adults is linked to high healthcare utilization, poor medication adherence, and overall poor health status ⁽²⁾. Similar associations were found specific to adults with asthma ^(3,4).

Identifying and evaluating factors linking HL to health outcomes is an important first step. A conceptual

model proposed by Rosas-Salazar et al. ⁽⁵⁾ helps to frame our understanding of the link between HL and asthma outcomes. The model identifies system and individual pathways relative to patients, providers and the healthcare system that connect HL to asthma outcomes.

Patient factors, such as race, ethnicity, language, socioeconomic factors, and educational attainment impact HL and the complexity of health outcomes ⁽⁵⁾. Important health care decisions and access to care for a child is predicated on a parent's ability to understand and interpret health care information. At least one in four parents have limited HL skills ⁽⁶⁾. In a study examining parent HL with a range of pediatric health risks, including nonadherence to asthma treatment, parents with low HL were more likely to be Spanish-speaking than parents with adequate HL ⁽⁷⁾.

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Provider factors included communication skills, teaching abilities, available time, educational resources and cultural competencies (5). Caregivers of children with asthma are the primary communicators with providers. Their ability to understand, interpret, and follow through with written or verbal instructions is crucial to children's asthma health care outcomes.

The healthcare system defined to include complexity of the system, delivery model, acute care orientation, and cultural sensitivity brings another element to the relationship between HL and asthma outcomes (5). Asthma outcome studies primarily recruit from provider clinics, emergency departments, and schools. In a recent review of 13 caregiver HL studies, most studies had a cross-sectional design, centered on children with asthma (8 of 13), and recruited participants from pediatric clinics in academic medical centers (8). Few studies analyzed the connection between healthcare utilization and caregiver HL (8). A second systematic review that focused on caregiver HL and emergency department (ED) utilization for children 0 to 18 years of age included 17 studies. The authors concluded that 1 in 3 parents presenting to the ED had low HL. For those studies specific to children with asthma, results indicated a relationship between low parental HL and increased ED use.

Asthma outcome studies are grounded in investigating asthma control, medication adherence and healthcare utilization through the factors described. Studies examining the relationship of caregiver HL with medication adherence and injury prevention in children with chronic conditions have been reported (7,10,11). Low parental HL was associated with limited understanding of medication instructions (10), at-risk behaviors associated with child injury (7) and poor adherence to child safety (11). Studies reporting the impact of caregiver HL on a child's asthma control produced varied results. In one cross-sectional study, there was no association found between parental HL and a child's asthma control (12). In contrast, a second cross-sectional study reported higher parental HL was significantly associated with well-controlled asthma (13). There were notable dissimilarities in the study populations and the HL instrument for these results. Studies specific to children with asthma have demonstrated associations between parental HL and child self-efficacy and asthma control (14), while there are mixed results on the impact on child healthcare utilization (13–16).

Contrasting findings were reported in two studies examining an association between caregiver HL and child healthcare utilization (15,16) The Rapid Estimate

of Adult Literacy in Medicine (REALM) was used in both studies to measure HL in English speaking caregivers of children with persistent asthma. Caregiver HL and child health care utilization, defined as an urgent care visit, showed no association in one study ($p = > 0.999$) (15). The second study reported an association between caregiver HL and child health care utilization, defined as ED visits and hospitalizations (IRR 4.6, 95% CI 1.8, 12) (16). Low parental asthma-related knowledge was associated with low HL in both studies (15,16).

Presently, strong conclusions cannot be drawn on the exact relationship between caregiver HL and the impact on the child with asthma because consistent measures were not applied and outcome variables differed. As more attention is directed to the importance of caregiver HL, its' impact on a child's asthma health outcomes is unknown. Our study will add to the discussion by evaluating how caregiver HL impacts asthma outcomes, such as asthma control, medication adherence, and health care utilization. Further, our study identifies patient factors, specifically language, and healthcare system factors which are essential when addressing health outcomes in children with asthma in diverse low-income minority populations.

Methods

Setting and participants

We conducted a two-site, cross-sectional study characterizing caregivers' health literacy and its association with their child's healthcare utilization. Child and caregiver dyads were recruited from two distinct delivery models: Rush University Medical Center ED (Site 1) and The Children's Hospital of Orange County (CHOC) Breathmobile, a mobile asthma van in Orange County, CA (Site 2) between June 2015 and March 2016. The Institutional Review Boards at Rush University Medical Center and the Children's Hospital of Orange County approved the study protocol.

To be eligible for the study, children had to be between 7 and 18 years of age and have a diagnosis of asthma and active prescriptions for both a short-acting, beta-agonist (SABA) and an inhaled corticosteroid (ICS). The age range was predicated on the child's ability to meet the age parameters of the assessments. A caregiver was defined as an adult who accompanied the child to the clinical encounter and reported to be responsible for coordinating the child's medical care. Both the caregiver and child were enrolled as a dyad. Site 1 participants had to be proficient in English. Site 2 participants were eligible if proficient in English or

Spanish. Informed consent was obtained from all caregivers and assent was obtained from those children age 7 years and older in English at Site 1 and English or Spanish at Site 2.

Procedure

For Site 1, a review of the electronic medical record (EMR) tracking board identified children, between 7 and 18 years of age, with a diagnosis of asthma and their caregivers who presented to the ED. The EMR was further reviewed for active SABA and ICS prescriptions to confirm eligibility. With physician agreement to approach the patient, a research assistant provided asthma inhaler education to each eligible caregiver and child. Following the education session, the caregiver was asked to participate in the study during their wait time in the ED. For Site 2, caregivers and their children were asked to participate at the time of their visit to the mobile asthma van after eligibility was determined. For both sites, consent procedures and study implementation took place in a private area.

Outcome measures

Health literacy was measured using a validated instrument, The Newest Vital SignTM (NVS). The NVS assesses prose literacy, numeracy and document literacy through the interpretation of an ice cream nutrition label. Prose literacy is the ability to read and follow written instruction; numeracy is reflected in the patient's ability to take medication properly; and document literacy is the ability to interpret and make decisions. For example, prose, numeracy and document literacy are critical to effective use of a written asthma action plan. Prose is required to read the plan instructions, numeracy is required to understand and properly follow inhaled medication regimens (e.g. how many inhalations/dose, dosing frequency) and document literacy is required to make decisions regarding what actions to take when transitioning between the different zones (e.g. green, yellow and red zones). It is quick and easy to administer and validated for persons 12 and above in English and Spanish against the Test of Functional Health Literacy (TOFHLA) (17,18). The NVS is scored with a 6-point scale. A high likelihood of limited literacy is indicated by a score of 0–1 and possible limited literacy is indicated by a score of 2–3. Adequate literacy is almost always demonstrated by a score of 4–6 (18). Asthma outcomes were examined through asthma control, medication adherence,

quality of life and healthcare utilization. Asthma control was measured with the Asthma Control Test (ACT) and Childhood Asthma Control Test (C-ACT). The ACT and the C-ACT are validated self-administered questionnaires to establish the level of self-reported asthma control. The ACT is for persons 12 years and older; the C-ACT is for children ages 4 to 11 years (19,20). Adherence was measured using the Medication Adherence Report Scale (MARS A-10). MARS A-10 is a validated 10-item scale in which respondents rate the frequency of medication use and intentional and nonintentional non-adherent behavior with ICS medication (21). Quality of life was evaluated with the Pediatric Asthma Quality of Life Questionnaire (PAQLQ). PAQLQ is a validated quality of life instrument measuring the functional problems most troublesome to children with asthma, 7–17 years of age (22). The PAQLQ utilizes a 7-point scale, with one being maximum impairment and seven indicating no impairment (22). Caregivers completed demographic, asthma history and asthma control questionnaires, and the MARS A-10. Children, age 7–11 years, completed the C-ACT, MARS A-10 and the PAQLQ. Children ages 12 years or greater completed the ACT, MARS A-10 and the PAQLQ. The NVS was administered to each caregiver and child over the age of 12 in our study. Trained research assistants administered all forms and assessments in the participants' preferred language. The research assistant at Site 2 was fluent in both English and Spanish.

Healthcare utilization data were extracted from EMRs for the 12 months prior to the date of study enrollment. Asthma-related healthcare utilization encounters included ED visits, hospitalizations, and unplanned clinic and routine encounters where asthma was the primary reason for the visit. Following NHLBI NAEPP EPR-3 Asthma guideline criteria, the following were abstracted for each encounter: asthma severity, asthma control, asthma symptoms, nighttime awakenings, SABA use for symptom control, interference with normal activity and required oral systemic corticosteroids (23). Participants were asked to sign a release of information form to obtain medical records from other institutions in the case that patients received care at multiple sites.

Analysis

Descriptive statistics were compiled on caregiver and child demographics, assessment results and child's

healthcare utilization. To examine the relationships between HL and asthma outcomes, bivariate associations were conducted between the caregivers' health literacy scores and their adherence and child's asthma control and quality of life scores. Bivariate associations were also conducted between the child's HL score and child's adherence scores. To assess the impact of caregiver HL on patient and healthcare utilization factors, bivariate associations of caregivers' HL scores with language, race, ethnicity, and routine visits were also conducted. Multiple Poisson regression analyses were performed to examine how caregivers' HL scores (adequate ≥ 4 vs. inadequate < 4), associated with routine visits, adjusting for the child's age and caregiver's language preference (Spanish vs. English). A chi square test evaluated how caregiver's HL was related caregiver language. All associations were tested at $\alpha = 0.05$. The analysis was completed using IBM SPSS Statistics (Version 22.0).

Results

A total of 34 caregiver-child dyads were enrolled in the study. Caregivers at Site 1 were predominately African American (72.7%), English-speaking (100%), with high levels of high school completion (100%) and had a mean HL score of 4.18 (SD 1.94) indicative of adequate health literacy. Caregivers at Site 2 were predominately Hispanic (100%), Spanish-speaking (91.3%), with low levels of high school completion (39.1%) and had a mean HL score of 2.09 (SD 1.76) suggesting limited health literacy. Results of the MARS A-10 showed consistent scoring below the demarcation for good adherence (mean 4.5) between caregivers and children for both sites. Asthma control, as measured by the ACT and the C-ACT, indicated child participant's asthma was controlled with the exception of Site 1 for children 12 and older. The PAQLQ showed median scores between 6.13 and 5.53, which fall below a score of 7 (no impairment of quality of life). The overall number of acute visits, i.e., ED visits, hospitalizations, and unplanned clinic visits, was low across both sites, but higher at Site 1. The number of routine or preventive asthma care visits, however, was notably higher at Site 2 (Table 1).

Asthma outcomes analyzed were asthma control, medication adherence, quality of life, and healthcare utilization. No association was found between caregiver HL and the child's asthma control, $r = -0.037$, $n = 34$, ($p = 0.838$). Also, there was no association between the caregiver HL score and perceived adherence $r = 0.10$, $n = 34$ ($p = 0.575$) and between the

child's HL score and child's perceived adherence $r = 0.459$, $n = 18$ ($p = 0.055$). Similarly, caregiver's HL and the child's quality of life were not related, $r = -0.206$, $n = 34$ ($p = 0.242$).

For healthcare utilization, no significant association between caregivers' HL and routine asthma care visits emerged ($r = -0.391$, 95% confidence interval: -0.64 – 0.06) (Figure 1). The mean number of routine asthma care visits was lower for caregivers with adequate HL ($RR = 0.63$, 95% confidence interval: 0.41 – 0.93 , $p = 0.03$). However, when caregiver language and child age were added as covariates in the model, the relationship between HL and routine asthma care visits disappeared ($RR = 0.97$, 95% confidence interval: 0.60 – 1.53 , $p = 0.89$). Caregiver HL was significantly related to language ($\chi^2 = 5.09$, $p = 0.02$). Sixty-nine percent of English-speaking caregivers had adequate literacy whereas only 24% of Spanish-speaking caregivers had adequate literacy. This suggests that the effect of caregiver's HL on child routine asthma care visits is largely explained by the caregiver's language.

Discussion

This was an exploratory study designed to seek preliminary information on the impact of caregiver HL on his/her child's asthma outcomes. The study looked at two primary factors linking caregiver HL to asthma outcomes: language (patient/caregiver factor) and delivery model (healthcare system factor). Site 1 caregivers were English speaking and recruited from an ED and Site 2 caregivers were Spanish speaking and recruited from a mobile asthma van. The results did not demonstrate associations between caregiver HL and the outcomes asthma control, medication adherence, or child's quality of life. However, there was a link between caregiver HL and healthcare utilization. Children of caregivers with adequate HL had fewer routine care visits for asthma.

In examining patient factors, when caregiver language and child age were added as covariates to the analysis, the relationship between caregiver HL and routine visits disappeared, indicating language to be a significant component in caregiver HL. Using the Spanish Parental Health Literacy Activities Test (PHLAT), one study showed low acculturation and low literacy contributed to a caregiver's struggle to understand basic health instructions, such as interpreting a written antibiotic prescription and preparing formula using package instructions (95% CI: 0.11 – 1.21 , $p = 0.02$) (24). The ability to attend to

Table 1. Characteristics of child and caregiver.

	Site 1 <i>n</i> = 11	Site 2 <i>n</i> = 23	Total <i>n</i> = 34
Child			
Gender, male, <i>n</i> (%)	6 (54.5)	16 (69.6)	22 (64.7)
Age, median (Q1,Q3)	13.0 (9.0, 14.5)	10.0 (8.0, 13.0)	11.5 (8.0, 13.8)
Race			
African American, <i>n</i> (%)	8 (72.7)	0 (0)	8 (23.5)
White, <i>n</i> (%)	1 (9.1)	1 (4.3)	2 (5.9)
Other, <i>n</i> (%)	2 (18.2)	22 (95.7)	24 (70.6)
Ethnicity			
Hispanic, <i>n</i> (%)	2 (18.2)	23 (100)	25 (73.5)
Non-hispanic, <i>n</i> (%)	9 (81.8)	0 (0)	9 (26.5)
Other, <i>n</i> (%)	0 (0)	0 (0)	0 (0)
Language			
English, <i>n</i> (%)	11 (100)	23 (100)	34 (100)
Spanish, <i>n</i> (%)	0	0	0
Caregiver			
Gender, female, <i>n</i> (%)	10 (90.9)	21 (91.3)	31 (91.2)
Age, median (Q1,Q3)	35.0 (29.0, 43.0)	38.0 (34.0, 42.5)	38.0 (33.0, 42.8)
Race			
African American, <i>n</i> (%)	8 (72.7)	0 (0)	8 (23.5)
White, <i>n</i> (%)	1 (9.1)	1 (4.3)	2 (5.9)
Other, <i>n</i> (%)	2 (18.2)	22 (95.7)	24 (70.6)
Ethnicity			
Hispanic, <i>n</i> (%)	2 (18.2)	23 (100)	25 (73.5)
Non-hispanic, <i>n</i> (%)	9 (81.8)	0 (0)	9 (26.5)
Other, <i>n</i> (%)	0 (0)	0 (0)	0 (0)
Language			
English, <i>n</i> (%)	11 (100)	2 (8.7)	13 (38.2)
Spanish, <i>n</i> (%)	0 (0)	21 (91.3)	21 (61.8)
Education			
< High School, <i>n</i> (%)	0 (0)	14 (60.9)	14 (41.2)
≥ High School, <i>n</i> (%)	11 (100)	9 (39.1)	20 (57.1)
Health literacy^a			
Caregiver's NVS score, mean (SD)	4.18 (1.94)	2.09 (1.76)	2.76 (2.05)
Children's NVS score, mean (SD)	2.86 (0.90)	2.90 (1.52)	2.88 (1.27)
	<i>n</i> = 7	<i>n</i> = 10	<i>n</i> = 17
Adherence^b			
Caregiver's MARS A-10 score, <i>n</i> , mean (SD)	3.70 (0.66)	3.97 (0.54)	3.88 (0.58)
	<i>n</i> = 10	<i>n</i> = 23	<i>n</i> = 33
Children's MARS A-10 score, <i>n</i> , mean (SD)	3.63 (.60)	3.83 (.63)	3.78 (0.62)
	<i>n</i> = 8	<i>n</i> = 22	<i>n</i> = 30
Asthma Control			
Asthma Control Test (ACT), <i>n</i> , mean (SD)	18.56 (3.68)	22.10 (2.60)	21.11 (3.23)
	<i>n</i> = 8	<i>n</i> = 10	<i>n</i> = 18
Children Asthma Control Test (C-ACT), <i>n</i> , median (Q1,Q3)	20.5 (19.3, 23.3)	23.0 (20.5, 24.0)	23.0 (20.0, 23.5)
	<i>n</i> = 4	<i>n</i> = 13	<i>n</i> = 17
Quality of Life^c			
PAQLQ, median (Q1,Q3)	5.48 (4.13, 6.59)	6.13 (4.87, 6.69)	5.98 (4.86, 6.62)
Healthcare utilization			
ED visits, mean (SD)	0.64 (0.88)	0.17 (0.38)	0.32 (0.63)
Hospitalizations, mean (SD)	0.09 (.29)	0 (0)	0.03 (0.17)
Unplanned clinic visits, mean (SD)	0.36 (.64)	0.13 (.34)	0.21 (0.47)
Routine visits, mean (SD)	0.91 (.79)	4.26 (0.90)	3.18 (1.79)

^aHealth literacy was measured using the Newest Vital Sign™ (NVS). Score of 0–1 suggest high likelihood of limited literacy; 2–3 possibility of limited literacy; 4–6 adequate literacy. Children's NVS score only for children ≥ 12 years of age.

^bMean score of 4.5 or higher defined as good adherence.

^cPaediatric Asthma Quality of Life Questionnaire. Score is based on a Likert scale where 1 is maximum impairment and 7 indicates no impairment.

children's health-related tasks was determined to be associated with a caregiver's literacy level and achievement of cultural integration in a Spanish-speaking population (24). Our findings agree in that limited literacy was associated with Spanish language and higher use of routine asthma care services. While these caregivers may find it more difficult to navigate the healthcare system and follow written asthma self-management instructions, they may proactively

compensate for these challenges by attending frequent routine asthma care visits for their child.

Increasing the frequency of routine asthma care visits to negotiate HL limits and complexity of the healthcare system has been explored previously. Caregiver limited HL has been associated with the inability to correctly follow their child's written asthma management plan supporting the notion they may seek assistance from a healthcare provider more

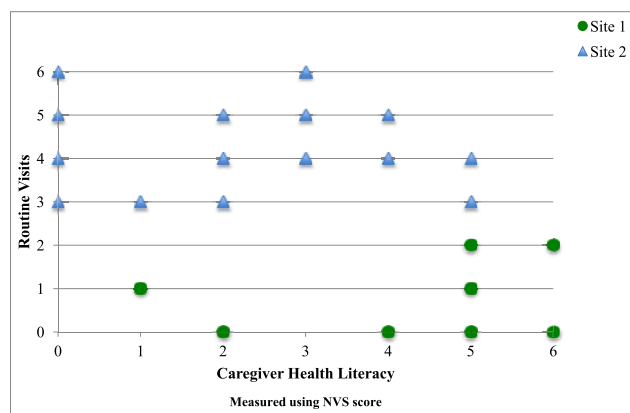


Figure 1. Scatterplot of routine visits and caregiver health literacy specified by site. NVS scores of: 0–1 indicate high likelihood of limited literacy; 2–3 indicate possible limited literacy; and 4–6 indicate adequate literacy. Some points on the scatterplot represent more than one participant. There were 11 participants at Sites 1 and 15 participants at Site 2.

frequently (12). Likewise, Wood and colleagues found parent HL was not associated with a child's asthma management or asthma control. They concluded that frequent visits to a physician's office due to asthma symptoms may provide the necessary repetitive verbal asthma instruction diminishing the impact of low literacy (14). The health system needs to proactively compensate by providing greater access to routine asthma visits when limited HL is a concern.

The mobile asthma van is one example of increased access. Studies demonstrate the success of mobile healthcare vans on decreased asthma morbidity, urgent care visits, and increased controller medication use in underserved children (25,26). In one study using a pre-post analysis, ED utilization decreased from 38% to 16% following routine visits to a mobile asthma van (25). Our results show children of Spanish-speaking caregivers had a higher number of routine asthma care visits through a mobile asthma van program compared to children of English-speaking caregivers who utilized the ED more frequently and had a greater number of unplanned clinic visits. Further studies are needed to determine if greater access to routine visits would impact health care utilization for children of English-speaking caregivers with adequate literacy.

The strength of our study included the use of a validated health literacy instrument that included multiple components of health literacy. Recruitment from two dissimilar healthcare delivery models with distinct patient/caregiver factors made additional comparisons possible. A limitation of the study was the need to combine the populations for analysis due to the small sample size. Including greater diversity in ethnic

groups and socioeconomic factors as well other health care delivery models would yield further clarity.

Conclusion

Understanding caregiver HL and the impact on child asthma management is important to support the development of strategies for those with limited HL. Identifying the effect of patient factors, such as caregivers' primary language, is also important. Innovative approaches tailored to the needs of disparate/diverse populations should be designed mindful of both the patient and healthcare system factors involved.

Acknowledgment

We thank Amanda Saylor, MS, for her assistance with data collection.

Declaration of interest

Dr. Mosnaim receives research grant support from Astra Zeneca, GlaxoSmithKline and Propeller Health; owns stock options in Electrocore; and serves as a consultant and/or member of a scientific advisory board for Electrocore, GlaxoSmithKline, Sanofi-Regeneron, Teva, Novartis, Astra Zeneca, Boehringer Ingelheim and Propeller Health. The following investigators: Dr. Belice, Dr. Galant, Dr. Kim, Dr. Shin, Dr. Pires-Barracosa, Dr. Hall, Dr. Malik, and Dr. Becker do not report conflicts of interest. The authors alone are responsible for the content and writing of this article.

Funding

Biostatistics assistance supported by University of Illinois at Chicago Center for Clinical and Translational Science, grant number UL1TR000050. This study is part of the Building Healthy Urban Communities Project funded by BMO Harris Bank.

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