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## Health Literacy and Sources of Health Information for Caregivers of Urban Children with Asthma

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### Abstract

Little is known about the resources urban caregivers of children with asthma use to obtain health information. We analyzed data for 304 families of children with persistent asthma to describe: 1) sources of health information, 2) access and use of Internet resources, and 3) the association between caregiver's health literacy (HL) and use of health information sources. Overall, 37% of caregivers had Limited HL. Most families received health information from: a health care professional (94%); written sources (51%); family/friends (42%); non-print media (34%); and Internet (30%). Less than ½ of caregivers had access to Internet at home, but 73% reported Internet use in the past year. Caregivers with Adequate HL were more likely to obtain information from multiple sources, and to use and have access to the Internet. Our results suggest that HL is associated with where caregivers obtain health information for their children and their use of the Internet.

### Keywords

asthma; inner-city; health literacy; health information; Internet

## INTRODUCTION

Asthma is a leading cause of childhood morbidity,<sup>1–3</sup> and disproportionately affects children from poor and minority backgrounds.<sup>4–6</sup> Despite the availability of standard guidelines for the treatment of asthma and prevention of symptoms, asthma care is often suboptimal. Caregivers play a key role in their children's asthma care; however, in order to provide optimal care for their children with asthma caregivers must be able to access, understand and act on quality asthma care information. There is limited information regarding where parents seek health information,<sup>7</sup> and to our knowledge, there are currently no data available to describe where urban caregivers of children with asthma obtain health information.

Impoverished children with asthma are at greatest risk for inadequate preventive care,<sup>8, 9</sup> and families living in poverty are also at risk for limited health literacy<sup>10</sup> which is a barrier to effective asthma self-management.<sup>11</sup> Health literacy (HL), defined by the Institute of Medicine, is "the degree to which individuals have the capacity to obtain, process, and

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understand basic health information and services needed to make appropriate health decisions."<sup>12</sup> Adults with less than a 9<sup>th</sup> grade reading level are considered to have basic or below basic literacy and have inadequate health literacy.<sup>11, 13</sup> Limited HL may influence access to accurate health information, and the ability to understand and evaluate health information and follow recommended therapies correctly.<sup>14</sup> Among adult asthmatic patients, limited HL is associated with poor inhaler technique, less frequent use of asthma action plans, and higher rates of emergency visits and hospitalizations, as well as a reduced desire to participate in health care decision making.<sup>11</sup> In children, limited parental HL is associated with adverse health outcomes including greater incidence of emergency department visits, hospitalizations, missed school days, and greater use of rescue medications.<sup>15</sup> Limited parental HL is also associated with persistent symptoms,<sup>15</sup> less parental asthma knowledge,<sup>15</sup> and perceived greater overall burden of childhood asthma.<sup>15, 16</sup>

Individuals can access health information from multiple sources which have varying degrees of usefulness and accuracy. For example, caregivers may gather health information from physicians and nurses, as well as personal contacts such as family and friends. They may also find health related information in medical literature, magazine articles and televised programs and commercials. Further, while there are concerns regarding the quality of health information that is posted on unregulated websites on the World Wide Web (Web),<sup>17-19</sup> in recent years the Internet has become a growing and easily accessible source of health information, with approximately 113 million Americans using the Internet for health related questions.<sup>20</sup> It is unclear how often the Internet is used for health information among urban families of children with asthma.

For this study, we surveyed caregivers of children with asthma living in an urban community with high rates of poverty to better understand where these families obtain health information about asthma. The objectives of this study were to; 1) describe the sources of health information used by caregivers of urban children with asthma, 2) describe caregivers' access to and use of the Internet, and 3) determine the association between caregivers' health literacy and use of various health information sources, including the Internet. We hypothesized that caregiver's use of and preference for health information sources would vary by their health literacy.

## METHODS

### Participants and Setting

This study uses baseline data collected from a community-based sample of 304 children, ages 3–10 years, enrolled in the School-Based Asthma Therapy (SBAT) trial in Rochester, New York (participation rate=73%).<sup>21</sup> We identified children with asthma through school health forms. A screening form was administered by telephone with the child's primary caregiver to determine eligibility for the intervention. Children with physician diagnosed asthma and persistent symptoms in the past year based on national guidelines<sup>22</sup> were eligible to participate. The University of Rochester's Institutional Review Board approved the study protocol.

During the Fall of 2007 and 2008, we conducted home visits with each participating family to collect baseline data. Written consent from caregivers and verbal assent from children older than 6 years of age were obtained during the home visit. We verbally administered multiple surveys to collect demographic information, asthma symptom severity, use of health information sources, and additional covariates.

## Assessment of Primary Outcomes

**Health Information Sources**—We administered a questionnaire to each primary caregiver to determine where he/she obtains health information. The term “health information” was left open-ended and could encompass many health-related issues such as medications, treatments, symptoms, specific diseases, physician information, and alternative therapies. Each caregiver was asked if he/she obtained health information (yes/no) for their child from the following sources in the past 12 months: 1) health care professionals (doctor, nurse, other), 2) family or friends, 3) Internet, 4) non-print media (television, radio) or 5) written/print sources (books, magazines, newspapers). Caregivers were asked to choose all that applied to them.

**Use of Internet**—Using questions adapted from the Health Information National Trends Survey (<http://hints.cancer.gov>), we also asked caregivers about their access to and use of the Internet. We inquired about having access to the Internet in the home (yes/no), having an e-mail account (yes/no), use of the Internet in the past year (yes/no), and the average number of days they access the Internet each week (range 0–7). We also asked whether they accessed health information while browsing the Web (yes/no), and whether they searched for health information online for their children in the prior 12 months (yes/no). We inquired about the ease of reading and ease of understanding health information found on the Internet using a 4-point Likert scale (very easy, easy, difficult, or very difficult) that was later dichotomized into Easy (very easy/easy) or Difficult (difficult/very difficult) for this analysis.

**Health Literacy**—Caregiver’s health literacy (HL) was assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM),<sup>13</sup> a validated tool to measure adult health literacy. Caregivers were asked to read aloud a list of 66 health related words. The list contains common words such as “Pill” and “Flu”, as well as more difficult words such as “Osteoporosis” and “Impetigo”. For each word that the caregiver pronounced correctly, the caregiver received one point for a possible total score of 66. A score of 60 and below indicates Limited HL, or less than a 9<sup>th</sup> grade reading level. A score of  $\geq 61$  indicates Adequate HL.<sup>13</sup>

**Trust of Health Information Sources**—We also asked caregivers to rate their level of trust for each of the five sources of health information included in our survey. Caregivers were asked to rate their level of trust for each source on a 4-point Likert scale by stating either, *a lot*, *some*, *a little* or *not at all*. We divided level of trust into High (*a lot*) and Low (*some*, *a little*, *not at all*) levels for this analysis.

## Assessment of Covariates

Covariates in this study consist of standard demographic variables for each caregiver including, gender, race (white, African American, or other), ethnicity (Hispanic/non-Hispanic), and age (<30/ $\geq$ 30 years). We also included the child’s insurance status (Medicaid/Not Medicaid) and current asthma severity (intermittent or persistent). Children with  $\geq 5$  days of daytime symptoms or  $\geq 2$  nights with asthma symptoms during the past two weeks were considered to have persistent asthma symptoms based on national guidelines.<sup>22</sup> Additional covariates include caregiver’s education (<high school/ $\geq$ high school), caregiver’s employment status (yes/no) and the caregiver’s relationship status (single or married/domestic partner).

## Analysis

Analyses were performed using SPSS version 17.0 software (Statistical Product and Service Solutions 17.0; SPSS Inc, Chicago, Ill). We used bivariate t-tests and Chi-Square statistics to compare demographic variables, sources of health information, Internet use, and level of trust for information sources between caregivers with and without Adequate HL. We also conducted multivariate logistic regression analyses to determine whether HL is independently associated with 1) use of specific health information sources, and 2) use of the Internet in general. We adjusted for parent characteristics (race, ethnicity, age, gender, education, marital status, and employment) and child characteristics (Medicaid insurance and asthma severity) in the multivariate analyses. A 2-sided alpha <.05 was considered statistically significant.

## RESULTS

Overall, 96% of the caregivers were female, 59% were African American, 26% were Hispanic, and 34% were less than 30 years old. Most caregivers were single (74%), 37% were unemployed and 42% had less than a high school education. Most children were insured by Medicaid (73%), and 66% had persistent asthma symptoms at the time of assessment (Table 1). More than a third (37%) of caregivers had Limited HL. Caregivers with Limited HL were more likely to have less than a high school education, be unemployed, and of a minority race or ethnicity. HL level was not associated with child insurance status or asthma severity, or with caregiver's age, gender or relationship status.

We explored how caregivers obtain health information for their children, and found that the majority (94%) of families reported obtaining health information from a health care professional in the past 12 months (Table 2). Half (51%) of the caregivers also obtained health care information from written sources, 42% from family/friends, 34% from non-print media, and 30% from the Internet. Caregivers with Adequate HL were significantly more likely to report obtaining health information for their child from family/friends (48% vs. 31%,  $p=.004$ ), the Internet (36% vs. 21%,  $p=.006$ ), and written sources (56% vs. 43%,  $p=.043$ ) compared to parents with Limited HL (Table 2). Furthermore, caregivers with Adequate HL were also more likely to obtain health information from a greater number of source types (range 0–5) compared to caregivers with Limited HL (Adequate HL: mean=2.70 (SD 1.3); Limited HL: mean=2.20 (SD 1.2),  $p=.001$ ).

Most caregivers stated that they had a high level of trust in the health care information obtained from health care professionals (81% reported “a lot” of trust). Fewer caregivers reported a high level of trust in health information obtained from written sources (12%), family/friends (12%), the Internet (6%), and non-print media (5%). Caregivers with Adequate HL were significantly less likely to trust health information found through non-print media compared to parents with Limited HL (2% vs. 10%,  $p=.004$ , results not shown).

Almost half (45%) of families reported having access to the Internet in their homes, and 54% of parents reported having an e-mail account (Table 3). Most caregivers (73%) had utilized the Internet in the past year, with an average frequency of 2.6 days per week. Fifty-two percent of caregivers stated they had ever accessed health information on the Internet. Of this group, 62% reported looking up general health information for their children in the past year. In addition, 90% of these caregivers stated that health information found online was easy to read and 85% said it was easy to understand (Table 3). Overall, caregivers with Adequate HL were significantly more likely to have access to the Internet in their home (50% vs. 36%,  $p=.017$ ) and have an e-mail account (59% vs. 43%,  $p=.008$ ). Compared to caregivers with Limited HL, caregivers with Adequate HL used the Internet more frequently (3.05 days vs. 1.9 days,  $p<.001$ ), were more likely to use the Internet in the past year (81%

vs. 60%,  $p < .001$ ), and more frequently reported having ever accessed health information online (60% vs. 38%,  $p < .001$ ).

Table 4 shows the results of multiple multivariate logistic regressions to determine the independent association between HL and where caregivers obtain health information. Each regression controlled for caregiver's age, gender, education, race, ethnicity, employment, marital status, and child's insurance status and asthma severity. Caregivers with Adequate HL were more than twice as likely to receive health information from family/friends (OR=2.25, 95%CI: 1.29, 3.91) compared to caregivers with Limited HL. In a similar multivariate model, we found that caregivers with Adequate HL were also twice as likely to have used the Internet in the past year (OR=2.31, 95%CI: 1.24, 4.30) and to have ever looked-up health information online (OR=2.00, 95%CI: 1.16, 3.44, results not shown). Because there were very few male caregivers in this sample, we reran all analyses excluding male caregivers and found consistent results.

## DISCUSSION

We found that urban caregivers of children with asthma obtain health information primarily from health care professionals, such as physicians and nurses, and report high levels of trust in their health care providers. In addition to obtaining information from health care professionals, many caregivers sought information from other resources. Approximately half of the caregivers sought health-related information from books, magazines or newspapers, and many acquired health-related information from family and friends in the past year. Additionally, about one third of caregivers had obtained health information from the Internet and non-print media sources, such as the television and radio. Caregivers with Adequate HL were more likely to obtain information from family or friends, the Internet, and written sources compared to caregivers with Limited HL.

Our results vary somewhat from prior reports investigating where adults seek health information. For example, one study found that adults living in the United States obtained health information from television (56%) and written sources, such as newspapers and magazines (69%), at higher rates compared to our study (34%, 51% respectively).<sup>23</sup> Other studies report that the proportion of adults who browse for health information online varies from 32% to 80%.<sup>20, 23, 24</sup> When caregivers of children attending an epilepsy clinic were surveyed, rates of accessing epilepsy-related information from health care professionals, family/friends, non-print media, and written sources were similar to what was found in our study, yet twice as many caregivers accessed health information from the Internet.<sup>7</sup> Our findings may differ from previous reports due to the characteristics of the urban population sampled, the recall period, and the year in which the data were collected.

Less than half of caregivers in our sample had access to the Internet in their homes, compared to 70% found in the PEW Internet and American Life Project,<sup>20, 25, 26, 20</sup> The lower percentage of in-home Internet access seen in our study is likely due to the lower socioeconomic status of our participants. However three-quarters of caregivers in our sample reported using the Internet in the past year, which is higher than the 63% of adults who reported ever using the Internet in larger and nationally representative samples.<sup>26, 27</sup> While our population is predominately low-income, they also represent a younger group of adults (mean age 34.1 years) who may be more likely to go online.<sup>28</sup> In addition, 96% of the caregivers included in our study are female, and women are more likely to search for health information online compared to men.<sup>25</sup>

We found that 37% of the caregivers in our study had Limited HL, or less than a 9<sup>th</sup> grade literacy level. The rate of Limited HL found in our study is similar to the 2003 National

Assessment of Adult Literacy (NAAL) assessment of health literacy which reported that 36% of adults over the age of 16 have basic or below basic health literacy.<sup>29</sup> Similar to other reports, we also found that race, ethnicity, and education are associated with health literacy.<sup>14, 29</sup> Although a prior study found that limited parent HL was associated with more severe asthma symptoms,<sup>15</sup> severity level at the time of the baseline survey was not associated with caregiver's HL in this study. However, eligibility for this study required children to have persistent asthma symptoms in the prior year, and thus the limited range of severity may have prevented us from detecting an association between symptoms and caregiver's health literacy.

Our study suggests that urban caregivers seek information regarding asthma care from multiple sources. Sorting through a variety of information sources and making informed health care decisions may be a daunting task for some caregivers, and particularly for those with limited literacy.<sup>30</sup> As an often sought-out and trusted resource among caregivers in our study, health care professionals should be mindful of potentially limited HL among their patients and patients' caregivers. There is evidence that low literacy levels are associated with poor communication between providers and patients.<sup>31</sup> Furthermore, providers may be unaware of limited health literacy of caregivers, which may hinder communicating effective treatment plans for their pediatric patients.<sup>32</sup> Prior research has found that tailored education for asthma self-management may help to reduce health literacy disparities,<sup>33</sup> and therefore health care providers should guide patients and caregivers towards quality resources and make certain that they understand recommended therapies.

This study is unique in that it explores sources of health information for a community-based sample of urban caregivers of children with persistent asthma. To our knowledge there are no other studies that have described caregivers' use of health care information sources while taking into consideration the caregiver's health literacy. Our results also describe urban caregivers' use of the Internet in general, a statistic that is not readily known.

There are some potential limitations to this study. First, we used a brief survey administered during the baseline visit of a large intervention. Due to limited time during the baseline assessment, and for simplicity, we were not able to provide a comprehensive list of sources of health information, but rather combined some sources together into categories. Therefore, we may not have a complete view of where urban caregivers obtain health information. In addition, we were unable to obtain additional detail regarding the frequency in which caregivers obtain health information or the reasons why caregivers choose to obtain health information from specific sources. We measured HL using the REALM which, though well-established and commonly used, measures pronunciation without assessing understanding of the words used in the scale. Lastly, this is a cross sectional study of urban families participating in an asthma intervention in Rochester, New York, and these findings can only be generalized to a similar population.

In conclusion, we found that urban parents of children with asthma seek health information primarily from their health care providers, but also obtain health information from several additional sources. Health literacy may influence where urban caregivers obtain health information and their use of the Internet. As the most sought after and trusted health resource, health care providers should guide families to appropriate sources for health information and spend time making sure families understand the health information they receive, regardless of source.

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**Table 1**

## Population Demographics by Health Literacy\*

	Overall (N=304)	Adequate HL (N=192)	Limited HL (N=112)	P-value
<i>Child Characteristics</i>				
Medicaid Insurance	221 (73)	134 (70)	87 (78)	.145
Persistent Asthma	199 (66)	126 (66)	73 (65)	1.00
<i>Caregiver Characteristics</i>				
Caregiver Age: <30yrs	102 (34)	58 (30)	44 (39)	.131
Caregiver Gender: Female	292 (96)	186 (97)	106 (95)	.369
Caregiver Education <High School	128 (42)	63 (33)	65 (58)	<.001
Caregiver Race	31 (10)	24 (12)	7 (6)	<.001
White	178 (59)	123 (64)	55 (49)	
African American	95 (31)	45 (23)	50 (45)	
Other				
Caregiver is Hispanic	78 (26)	37 (19)	41 (37)	.001
Single Caregiver	224 (74)	140 (73)	84 (75)	.504
Caregiver Unemployed	108 (37)	53 (28)	55 (52)	<.001

\* Results shown as: N (%)

**Table 2**

Sources of Health Information Utilized by Caregivers in the Past Year\*

	<b>Overall (N=304)</b>	<b>Adequate HL (N=192)</b>	<b>Limited HL (N=112)</b>	<b>P-value</b>
Health Care Professional	286 (94)	183 (95)	103 (92)	.313
Family or Friends	128 (42)	93 (48)	35 (31)	.004
Internet	92 (30)	69 (36)	23 (21)	.006
Non-print Media	104 (34)	66 (34)	38 (34)	1.00
Written Sources	155 (51)	107 (56)	48 (43)	.043

\* Results shown as: N (%)

**Table 3**

## Caregivers' Internet Use\*

	<b>Overall (N=304)</b>	<b>Adequate HL (N=192)</b>	<b>Limited HL (N=112)</b>	<b>P-value</b>
Access to Internet in home	137 (45)	97 (50)	40 (36)	.017
E-mail account	162 (54)	114 (59)	48 (43)	.008
Number of days use Internet in a week (range 0–7) <sup>^</sup>	2.63 (2.8)	3.05 (2.9)	1.9 (2.6)	.001
Used Internet in past year	222 (73)	156 (81)	66 (60)	<.001
Ever accessed health information on the Internet	157 (52)	115 (60)	42 (38)	<.001
<b>Of those who have ever accessed health information on the Internet</b>	<b>Overall (N=157)</b>	<b>Adequate HL (N=115)</b>	<b>Adequate HL (N=42)</b>	<b>P-value</b>
Looked-up health information for child on Internet in past year	97 (62)	71 (62)	26 (62)	1.00
Health information online is easy to read	141 (90)	108 (94)	33 (79)	.017
Health information online is easy to understand	133 (85)	103 (90)	30 (71)	.013

\* Results shown as: N (%)

<sup>^</sup> Results shown as: Mean (SD)

**Table 4**

Logistic Regression Models: Adequate Health Literacy Predicting Where Caregivers Obtain Health Information\*

Dependent Variables	Exp(B)	95% CI	P-value
Health Care Professional	1.29	.44–3.80	.65
Family or Friends	2.25	1.29–3.91	.004
Internet	1.83	.99–3.37	.05
Non-print Media	1.23	.71–2.15	.46
Written Sources	1.32	.78–2.23	.29

\* Adjusted for: caregiver characteristics (age, gender, education, race, ethnicity, employment, marital status), child characteristics (asthma severity, Medicaid insurance)