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What Really Happens in the Home: the Medication Environment of Urban, Minority Youth

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Abstract

Background—Asthma disproportionately affects minority youth. Understanding the home medication environment and its relation to medication adherence can shape interventions to improve health outcomes.

Objective—To describe the asthma medication environment in the homes of urban minority youth and to determine predictors of medication use and technique in this population.

Methods—Baseline data from two cohorts of minority youth with asthma in Chicago were combined for cross-sectional analysis. Bilingual research assistants (RAs) collected data in the home. RAs asked caregivers and children to self-report medications using pictures and observed children's asthma medications and inhaler technique.

Results—The sample contained 175 mainly Latino youth (85.6%) ranging from 5–18 years old. Most were on public insurance (80%) and had uncontrolled asthma by self-report (89.7%). Only 27.4% had a spacer, 74.9% had a quick relief medicine and 48.6% had any controller medicine. RA observations of controllers agreed with children (36%) and parental self-report (42.3%) but did not match the specific observed controllers. Children reported less parental help with medications (43%) than their parents (58.1%). One child was able to properly demonstrate 100% of the inhaler steps and 35.6% achieved >70% of inhaler steps. Better medication technique was associated with having a controller (b=12.2, SE=3.0, p <0.0001), quick reliever (b=8.05, SE=3.5, p=0.023) and a spacer (b=9.3, SE=3.54, p=0.009).

Conclusions—This rigorous evaluation of the home medication environment of high risk youth demonstrated that many families lack critical medications, devices, and technique for proper management of asthma.

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Keywords

Asthma; Pediatric; Health disparities; Inhaler technique; Cultural Competency; Latino; Puerto Rican

The burden of asthma is significant, with the national prevalence in 2010 reaching 8.5% of the United States population.[1] This burden is not borne equally. African American and Puerto Rican children suffer disproportionately higher asthma prevalence and morbidity.[2] These disparities are salient in Chicago where nearly one-third of children with asthma reported having a life-threatening exacerbation and over half have sought emergency care.[3–4]

The Expert Panel Report 3 (EPR-3) guidelines site four components key to asthma management including pharmacologic therapy.[5] Medication non-adherence to inhaled corticosteroid therapy is common[6–10] and is linked to increased risk of asthma exacerbations.[11–15] Non-adherence is more likely to be seen in non-white populations.[11, 16]

Interventions to improve medication adherence have mixed results.[17–28] Those studies that reported improvement in adherence were in small sample sizes using self-reported adherence which has been demonstrated to over-report actual medication usage. [9,29–31] Improper inhaler technique is also common[32] and associated with severe asthma and exacerbations.[33] Interventions such as “Teach to Goal” have been successful in improving inhaler technique[34–37] but most of these have not been tested in children.

Clinicians currently rely on patients and their families to provide the medication usage information that informs their clinical decision-making. The many layers of non-adherence[38] make it difficult for clinicians to determine where the breakdown in this process may be occurring. For this reason, we focused this analysis on defining the home medication environment in our predominantly Latino cohort of children and adolescents in Chicago. Our aims were to determine the accuracy of child and caregiver medication recall by comparing caregiver and child self-report to observation of medications in the home, to assess actual medication technique, and to measure medication adherence.

Methods

Design

A cross-sectional analysis of baseline data from two asthma intervention studies was performed. The original cohort, the Community United to Challenge Asthma (CURA, Clinical Trials ID NCT01065883 and NCT01061424), was a randomized controlled trial in Puerto Rican youth.[39–42] CURA recruited 51 elementary and 50 high school participants from December 2009 to January 2011.[39] Participants were between 5–18 years old, self-identified as Puerto Rican, and had uncontrolled and/or persistent asthma over the past year.[5,39] The second cohort, Community United to Raise Awareness: Asthma and Active Living (CURA 2), was a follow-up study for children with both asthma and obesity. Seventy-seven children were recruited from November 2011 to December 2013. Inclusion criteria were children between 5–12 years old, physician diagnosis of asthma, and body

mass index ≥85% predicted for age. Only one child per family could participate. Caregivers and children provided written informed consent and assent (when able). Institutional Review Board approval was obtained from Rush University Medical Center.

Measures

All data were collected by bilingual research assistants (RAs) in patient homes. Assessments were orally administered with the exception of the paper and pencil based depression screening instrument.

Asthma Medications—The RAs first showed caregivers color pictures of all the inhaled asthma medicines, prednisone, prednisolone, montelukast, and a nebulizer and then asked what medications the child had used in the past 4 weeks. The child was shown the same pictures and asked the same question separately. Then the RA asked to see all of the child's asthma medications. All non-expired medications were recorded. We intended to measure adherence using electronic medication monitors (Doser CT, MediTrack, Inc., South Easton, MA) based on the dosage prescribed by the children's provider; however, almost no participants had medication boxes or prescription labels indicating the prescribed dosing regimen. For metered dose inhalers (MDIs), electronic medication monitors were placed on the inhalers to document the number of times the inhaler was actuated daily and this was recorded, but no further calculations will be reported secondary to the uncertainty of the intended dose..[31]

Asthma Medication Technique—Children were asked to show exactly how they use their inhalers using their own inhaler or a demonstrator inhaler. Children with multiple devices were asked to demonstrate technique for each. The 8 steps for determining technique were composed from clinical guidelines[5] and experts in the field through the literature since no standard protocol exists.[43–44] RAs watched the child use the inhaler and marked whether they performed each of the 8 steps accurately. They received a point for each step they completed correctly, 0 points for incorrect steps. We then calculated the percent correct of 8 steps. We also generated a variable called "better medication technique" which dichotomized technique as correctly demonstrating 6 or more of the 8 steps (or greater than or equal to 75%).

Asthma Control—The CURA cohort reported the Asthma Therapy Assessment Questionnaire (ATAQ) where scores of 1 or greater indicates poor control over the past 4 weeks and a score of 0 indicates well-controlled asthma.[45] The CURA 2 cohort utilized the Childhood Asthma Control Test (c-ACT) where scores of 19 or less indicated poor control over the past 4 weeks.[46] Asthma control was also assessed using the National Heart, Lung, and Blood Institute (NHLBI) EPR 3 guidelines clinical control cut points regarding daytime symptoms, nighttime symptoms, short-acting beta-2 agonists and missed activities[5, 47]. "Not well controlled" in any of these categories caused the individual to be labeled as uncontrolled over the past 4 weeks. Participants were coded as uncontrolled if they indicated lack of control on any of the NHLBI control symptoms, [5] or reported emergency room visits, hospitalizations or prednisone use over the past 12 months.

Other Variables—Caregivers completed an acculturation scale.[48] Caregiver depressive symptoms were assessed using the Patient Health Questionnaire 9.[49–53] Child height and weight were measured by research assistants and Body Mass Index (BMI) was calculated using the Center for Disease Control and Prevention age and sex specific growth charts. In children, a BMI less than 85% was considered normal, greater than or equal to 85% but less than 95% was considered overweight and 95% or greater was obese.

Analysis

Descriptive statistics were run for both continuous and categorical variables. Distributions of continuous variables were checked to assess normality. No transformations of the data were needed. Three participants were in both cohorts; their data from the second cohort (CURA 2) were dropped from the combined dataset.

Descriptive statistics were run by cohort producing means and standard deviations for continuous variables and frequencies and percentages for categorical variables. Correlations were run to check relationships between acculturation and asthma medication technique. A series of t-tests were run to assess differences on asthma medication technique between ethnic groups, caregiver education levels and asthma medication use. Analysis of variance was used to test whether education predicts asthma medication technique. In addition to the above analysis, mixed effects models were run to assess the same relationships wherever statistical significance was found, adjusting for cohort as a random effect.

Logistic regression models were used to test whether ethnicity, education, acculturation, caregiver depression, asthma medication use and parental help with medications predicted asthma control. A series of mixed effects models were conducted to test previously found statistically significant differences between controlled and uncontrolled asthma, adjusting for cohort as a random effect. Model fit was evaluated with appropriate diagnostics. The diagnostics used to evaluate the model fit include a) running residual plots to explore influential observations that may have an impact on parameter estimates or model and b) checking log likelihood (in logistic regression models) and information criteria (AIC, AICc, BIC) (mixed models). All statistical analyses were conducted using PC-SAS, version 9.3 (SAS Institute, Cary, NC). All p-values were considered to be significant at alpha level of 0.05 or less.

Results

Demographics (Table I)

Children—The sample contained 175 mainly Latino (85.6 %) youth ranging from 5–18 years old; 42.9% were female. In the 5–12 year old range, 37.5% were female and in the 13 year old and over range, 54.6% were female. The majority were on public insurance (80%). Of the 113 participants with BMI data, 62.8% were obese and 24.8% overweight. This was not unexpected as this obesity was an inclusion criterion for the CURA 2 study.

Caregivers—Caregivers were mostly female (93.1%) and ranged from 22–62 years of age. The majority were single with only 37.7% reported living with a spouse or partner and 62.3% were born in the mainland United States. Almost one third (31%) of caregivers had

less than a high school education and 32% reported symptoms of depression. The sample was well established in the neighborhood with 61.7% reporting that they own a home or paying a mortgage. The predominant language spoken in the home was also a mixture of English and Spanish (mean of 3.2, standard deviation 1.3) using an acculturation scale ranging from 0 (lowest acculturation) to 5 (highest acculturation)[48].

Asthma Morbidity (Table II)

A majority of children reported uncontrolled symptoms based on the NHLBI/EPR-3 control questions over the last four weeks (69.1% for any question) with nighttime awakenings being the most common (53.7%) in the combined cohort. Self-reported health care utilization was high with 38.2% of the participants having an emergency room visit, 9.1% hospitalized and 36.6% having used prednisone in the last 12 months. Over the past 12 months, a total of 89.7% of the combined cohort had uncontrolled asthma.

Asthma Medication Environment (Table III)

When assessing which medications were present in the homes of the children, 74.3% of children had a quick relief medicine and only 48.6% had any controller including montelukast; 41.7% had an inhaled controller. There was more than one inhaled controller in 8% of homes as well as more than one quick relief medicine in 10.9%. Caregivers and children self-reported similar numbers for the presence of inhaled controllers (42.3% vs 36%) and quick relief medicines (83.4% vs 74.9%); however, caregivers often did not correctly identify the actual controllers present with parents agreeing with RA observations in 32% of cases and with their children 27.4% of the time. Correct identification of quick relief medicines was much better for caregivers; they agreed with RA observations and with their children in 84% and 83.4% of the cases. Forty-three percent of children reported caregivers helped them with their medicine all or most of the time while their caregivers said they helped the children 58.1% of the time; children and caregivers agreed on this question only 35.5% of the time. Adherence to inhaled corticosteroids could not be adequately assessed because of a lack of prescription data.

Inhaler Technique (Table IV)

For the MDI alone (n=152), one person completed all steps correctly and 36.8% were able to properly demonstrate ≥ 6 correct steps (out of 8 total). When looking at the specific steps and where deficiencies were occurring, 31.6% did not actuate the medication and 34.2% did not inhale. Eight children did not remove the cap before use. Technique results were the same for the MDI with a chamber without mask but improved with chamber and mask (median 83.3%) with only nine children demonstrating this method. No comparisons could be made with the DPI versus MDI technique since very few children had the DPI. Devices to aid inhaler particle delivery were also deficient with only 27.4% of participants having a spacer.

Associations with Medication Technique and Asthma Control

Significant associations were detected between medication use and medication technique. According to a series of mixed effects models, better medication technique was associated

with having an observed controller (b=12.2, SE=3.0, p <0.0001), an observed quick relief medicine (b=8.05, SE=3.5, p=0.023) and having a spacer (b=9.3, SE=3.54, p=0.009) but was not found to be associated with caregiver education, baseline control, child ethnicity, or parental help with medications. Asthma control was associated only with caregiver education (p=0.006). Those who had a high school education or equivalent degree had higher odds of having children with good asthma control compared to those with less than a high school education [OR 2.68 (1.24, 5.80)]. No other significant associations were found between control, technique, adherence, and covariates.

Discussion

While poor maintenance controller use is not a new concept, this study specifically sent research staff into the homes to document all medications available and directly observe technique with children using their own devices. Our goal was to rigorously describe the home medication environment in terms of caregiver/child medication recall, and medication technique to better inform clinicians of the challenges to comprehensive medication adherence. In this sample of urban, minority children with uncontrolled asthma, caregiver medication recall did not match the actual medication environment encountered in the homes which lacked the medications, devices, and skills key to controlling asthma. While 89.7% of the cohort self-reported uncontrolled asthma over the past 12 months, less than half had an inhaled controller and a quarter lacked a quick relief inhaler. Caregivers and children could not correctly identify many inhalers. Only one child was able to correctly demonstrate proper inhaler technique. While waiting at least 30 seconds prior to the next dose was the most frequently missed step, 34.4% forgot to inhale the medicine for the MDI alone. Most children did not have pharmacy prescription labels for their medications which not only made determination of adherence impossible, but also meant the families had no reference for how they should be using the medications.

The low percentage of inhaled controllers and quick-relief medications in the home coupled with medication confusion helps explain why, in part, this high-risk population experiences high exacerbation rates. Ensuring the proper medications and devices are prescribed, picked up from the pharmacy, and are available for use is crucial for proper asthma care. Many roadblocks interfere with this process, including parent-child relationships,[54] disjointed care, providers not prescribing necessary medications,[55–56] familial beliefs, understanding or attitudes regarding the prescribed medications themselves or their necessity,[57–58] caregiver stress and depression, language barriers, and cost of medications. Leading open discussions to patient specific barriers to medications, encouraging medications to be brought with on every visit and addressing the medication reconciliation in a deliberate way may address some of these concerns.

The inhaler technique demonstrated in our data is consistent with others reported in the literature.[32,34, 59] Reznik, et al recently reported misuse in a Latino cohort where caregivers of children with asthma demonstrated inhaler technique using a doll with spacer/mask. Only one caregiver of 169 was able to properly demonstrate all 10 steps with only 6 (3.6%) able to complete what the authors described as the essential steps.[59] Comparing misuse to that seen in an adult population with asthma or chronic obstructive pulmonary disease (COPD),

our rates were similar to Press, et al.[32,34] The technique we observed demonstrated failure to master key steps including actuation and inhalation; however, we were not able to associate what factors may be related. Poor inhaler technique is important because it has been associated with as much as a four-fold increase in uncontrolled asthma, more asthma exacerbations, and more oral steroid use.[33]

A unique strength to our data is it measures technique directly inside the home. The poor inhaler technique seen may be related to the lack of provider training[60] and/or failure of providers to review technique.[59] Inhalers come with written instructions but these may be difficult to understand due to limited health literacy[54,57] or language barriers.[56,58] Frequent changes in formularies by insurance companies result in patients receiving inhalers that look different, but are not. Many inhalers require the addition of a device to improve delivery (ie. spacer) and new devices with different techniques continue to be released.[55] Lack of standardization of correct inhaler technique steps is an additional problem. National guidelines for technique and systematically measuring inhaler technique in the office are necessary to improve medication delivery in asthma. In practice, likely few people think specifically about each step as they are doing them, but they should be taught them all when learning how to properly use an inhaler.

There are several limitations to our analysis. Our cohort was intended to be predominantly Latino, poorly controlled, and obese. Because our combined cohort spans a wide age range, behaviors specific to certain age ranges (mainly adolescents) may have skewed results slightly. No universal standard for inhaler technique exists, therefore we used the steps recommended by the manufacturers and the American College of Chest Physicians but further standardization of steps is required. Children demonstrated using their own medications or trainers but the act of demonstration for the RA may have changed their behavior slightly. We compared inhaler technique across different types of inhalers but we did so by standardizing to percentages first. This is a necessary limitation due to the many different devices for asthma management. We relied on self-report for asthma symptoms and healthcare utilization due to the challenges associated with spirometry for children in the home. Self report of data is associated with recall bias. Data on utilization of asthma specialty care was unavailable and if available to families, may benefit adherence in this at risk population. Because prescription labels were not available, we could not reliably run adherence numbers without accurate knowledge of prescribed doses. Although we did not have the resources to do so in these studies, verification of dosage regimens with providers and/or the individual’s pharmacy in future studies would be needed. It is important to recognize that the more significant complication of not having medication labels is that families in these studies typically administer medications without clear dosing instructions, they are unsure about dates of fill or numbers or refills, and they cannot even be sure whose medicine it is. This presents an opportunity for providers and educators to help families by reinforcing the need to keep medication labels. Lastly, causality cannot be implied from cross-sectional analysis data.

Despite these limitations, our study has several major strengths in that it objectively determined the types of medications in the homes of these high risk families, assessed technique in a wide age group, and discovered major challenges in medication adherence. In

this minority urban cohort of youth with mostly uncontrolled asthma, we found poor caregiver and child identification of medications, a lack of proper medications and devices, poor inhaler technique, and limited information in the home to guide families on when to use their medications. While barriers to presence of controllers, relievers and devices need further investigation along with adherence to inhaled corticosteroids, these data point to some starting areas for intervention. Inhaler technique education models such as "Teach to Goal"[32,34] in children and adolescents should be targeted as a further area of study. Use of pictorial prompts to identify medications in the home and when to use them, as well as culturally tailored inhaler technique education, may help circumvent some of the disparities seen in at risk youth with asthma. Lastly, approaching care of children with asthma may require multi-level interventions addressing several barriers at once in order to be successful.

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Abbreviations

AIC	Akaike Information Criterion
AICc	Akaike Information Criterion corrected
ATAQ	Asthma Therapy Assessment Questionnaire
c-ACT	Childhood Asthma Control Test
BIC	Bayesian Information Criterion
BMI	Body Mass Index
CURA	Community United to Challenge Asthma
CURA 2	Community United to Raise Awareness: Asthma and Active Living
DPI	Dried powdered inhaler
EPR-3	Expert Panel Report 3
MDI	Metered dose inhaler
NHLBI	National Heart, Lung and Blood Institute
RA	Research Assistant

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Highlight Box

What is already known about this topic?

Urban minority youth with asthma have a disproportionately high burden of asthma morbidity and mortality.

What does this article add to our knowledge?

The home medication environment of our high risk pediatric cohort reveals lack of proper medications, devices, and poor inhaler technique.

How does this study impact current management guidelines?

This study encourages frequent objective review of medications available in the home, reinforced inhaler technique training for children and caregivers, and highlights the need for multi-level interventions to help address adherence.

Table I

Participant Demographics (N=175)

Child Data	**Total**	**CURA 1**	**CURA 2**	**p-value**
Female sex, N (%)	75 (42.9)	49 (48.5)	26 (35.1)	0.077
Age, mean (SD)	11.1 (3.7)	12.6 (3.8)	8.9 (2.2)	<.0001
Public health insurance	140 (80.0)	72 (71.3)	68 (91.9)	0.0008
Ethnicity/Race (n=174)				<.0001
Puerto Rican	75 (43.1)	75 (75.0)	0	
Mixed Hispanic	55 (31.6)	0	55 (74.3)	
Other Hispanic	19 (10.9)	19 (19.0)	0	
Other non-Hispanic	11 (6.3)	5 (5.0)	6 (8.1)	
Black non-Hispanic	14 (8.1)	1 (1.0)	13 (17.6)	
Born in mainland US	166 (94.9)	96 (95.1)	70 (94.6)	0.694
BMI category (N=113)				<.0001
Normal (5–85%)	14 (12.4)	12 (30.8)	2 (2.7)	
Overweight (85–95%)	28 (24.8)	8 (20.5)	20 (27.0)	
Obese (95% or greater)	71 (62.8)	19 (48.7)	52 (70.3)	
Caregiver Data				
Age	38.7 (8.0)	39.5 (7.6)	37.7 (8.4)	0.154
Female sex	163 (93.1)	94 (93.1)	69 (93.2)	0.964
Marital status				<.0001
Married/Live with Partner	66 (37.7)	29 (28.7)	37 (50.0)	
Divorced/Separated	16 (19.2)	9 (8.9)	7 (9.5)	
Widowed	27 (15.4)	26 (25.7)	1 (1.4)	
Single	66 (37.7)	37 (36.6)	29 (39.2)	
Education level				0.072
Less than High School	54 (30.9)	25 (24.8)	29 (39.2)	
High School Diploma/GED	49 (28.0)	28 (27.7)	21 (28.4)	
Greater than High School	72 (41.1)	48 (47.5)	24 (32.4)	
Place of Birth				
Mainland United States	109 (62.3)	67 (66.3)	42 (56.8)	0.197
Language in the home (n=161) **	3.2 (1.3)	3.5 (1.2)	2.6 (1.3)	<.0001
Home Ownership				<.0001
Own/Mortgage	108 (61.7)	99 (98.0)	9 (12.2)	
Rent	59 (33.7)	2 (2.0)	57 (77.0)	

Child Data	Total	CURA 1	CURA 2	p-value
Live with others rent free/Other	8 (4.6)	0	8 (10.8)	
Depression symptoms*	55 (32.0)	33 (32.7)	22 (31.0)	0.815

*PHQ-9: Patient Health Questionnaire[49]

**Acculturation scale where 0 (lowest acculturation, more Spanish spoken) to 5 (highest acculturation, more English spoken[48]

Table II

Asthma Morbidity (N=175)

	N (%) or mean (SD)
Uncontrolled over last 4 weeks using EPR3 Guidelines[5]	121 (69.1)
Uncontrolled Daytime Symptoms	61 (34.90)
Uncontrolled Nighttime Symptoms	94 (53.7)
Excess Quick relief Medication Use	60 (34.5)
Missed Activity	48 (27.6)
Control Test over last 4 weeks	
Childhood Asthma Control Test (ACT) score[47] (n=73)	21 (4.1)
ACT score uncontrolled (>19)	46 (63.0)
Asthma Therapy Assessment Questionnaire (ATAQ) score[46] (n=99)	3.5 (1.8)
ATAQ score uncontrolled (≥1)	97 (98.0)
Over last 12 months	
Any Emergency Department Visit	67 (38.2)
Any Hospitalization	16 (9.1)
Any Prednisone Use	64 (36.6)
Uncontrolled for any measure *	157 (89.7)

* This sums the subjects who demonstrated lack of control in any category measured: NHLBI questions, ACT or ATAQ score, or who had an emergency department visit, hospitalization or prednisone use over the last 12 months.

TABLE III

Observed Controllers

Medication*	**Number of Inhalers Observed (n=175 subjects)**
Beclomethasone dipropionate	5
Budesonide	1
Budesonide/formoterol	4
Cromolyn Sodium HFA	3
Fluticasone propionate	29
Fluticasone and salmeterol DPI	6
Fluticasone and salmeterol HFA	9
Mometasone furoate	2
Montelukast	25

* RA may have observed more than one controller per study subject

Table IV

Technique

	Individual steps	Number that performed step correctly (%)	Total percentage of steps correct, median (Q1, Q3)	Achieved 75% steps correct (%)
Inhaler Alone, N=152	Shake	81 (53.2)		
	Remove cap	144 (94.7)		
	Exhale prior to use	29 (19.1)	62.5 (50.0, 75.0)	56 (36.8)
	Mouthpiece placement	141 (92.8)		
	Actuate Medicine	104 (68.4)		
	Inhale	100 (65.8)		
	Hold breath	91 (59.9)		
	Wait before next puff	38 (25)		
Inhaler with chamber, N=44	Shake	17 (39.5)		
	Connect to chamber	39 (90.7)	62.5 (50.0, 75.0)	16 (36.4)
	Exhale prior to use	10 (23.3)		
	Mouthpiece placement	38 (88.4)		
	Actuate Medicine	38 (88.4)		
	Inhale	17 (39.5)		
	Hold breath	28 (65.1)		
	Wait before next puff	20 (46.5)		
Inhaler with mask, N=9	Shake	5 (55.5)		
	Connect to chamber	8 (88.9)	83.3 (66.7, 100.0)	6 (66.7)
	Mask cover	7 (75%)		
	Actuate Medicine	7 (77.8)		
	Breathe	6 (66.7)		
	Wait before next puff	6 (66.7)		
Dry Powder Inhaler, N=4	Position	4 (100%)		
	Load	4 (100%)	75.0 (50.0, 91.7)	2 (50.0)
	Exhale	2 (50%)		
	Mouthpiece	3 (75%)		
	Inhale	2 (50%)		
	Hold	2 (50%)		
Overall Inhaler Technique n=174			62.5 (50.0, 75.0)	62 (35.6)