## **REGULAR ARTICLE**

## **Explanatory Model for Asthma Disparities in Latino Children: Results from the Latino Childhood Asthma Project**

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#### Abstract

**Background:** Little research has been conducted that integrates, in one explanatory model, the multitude of factors potentially leading to disparities among Latino children.

**Purpose:** A longitudinal, observational study tested an explanatory model for disparities in asthma control between Mexican and Puerto Rican children with persistent asthma requiring daily controller medication use. **Methods:** Mexican and Puerto Rican children aged 5–12 years (n = 267) and their caregivers (n = 267) were enrolled and completed interviews and child spirometry at baseline and 3, 6, 9, and 12 months postenrollment.

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A 12 month retrospective children's medical record review was completed. Participants were recruited from two school-based health clinics and the Breathmobile in Phoenix, AZ, and two inner-city hospital asthma clinics in the Bronx, NY.

**Results:** Statistically significant differences in the social/ contextual predictors of asthma illness representations (IRs) were noted between Mexican and Puerto Rican caregivers. The structural equation model results revealed differences in asthma control over time by ethnicity. This model accounted for 40%-48% of the variance in asthma control test scores over 12 months. Caregivers' IRs aligned with the professional model of asthma management were associated with better children's asthma control across 1 year. These results also supported the theoretical notion that IRs change over time impacting caregivers' treatment decisions and children's asthma control.

*Conclusions:* These findings extend a previous cross-sectional model test using a more comprehensive model and longitudinal data and highlight the importance of considering within-group differences for diagnosis and treatment of children coming from the vastly heterogeneous Latino umbrella group.

Trial Registration: Trial number NCT 01099800

# Keywords: Asthma $\cdot$ Child $\cdot$ Latino $\cdot$ Health status disparities

Racial and ethnic disparities in asthma health outcomes have been increasing in the USA. These disparities are so striking that researchers and public health officials have issued a call for action to understand why this is occurring [1, 2]. Especially noteworthy has been the increasing disparities in asthma within the population of Latino children (primarily Puerto Rican vs. Mexican) [3, 4]. Asthma disproportionately affects Puerto Rican children who exhibit the highest rates of asthma prevalence and mortality among all ethnic groups while Mexican children have the lowest rates [3, 4]. Studies also reveal that island-born Puerto Rican children have higher asthma prevalence than U.S.-born Puerto Rican children [3, 4].

Little research has been conducted that integrates, in one explanatory model, the multitude of factors that can lead to disparities among Latino children. Perhaps of critical importance, but not well examined, is the role that culture, acculturation, and illness representations (IRs) may play in caregivers' asthma treatment decisions and children's asthma control. Because caregivers are the gatekeepers for their children's health care and ultimately make the final treatment decisions, it is caregivers' representation of their children's illness that is associated with caregivers' treatment decisions and children's asthma health outcomes.

It has been demonstrated that caregivers and health care providers (HCPs) think about asthma differently [5-8]. The Expert Panel 3 has identified four key components for achieving optimal control that comprise the "professional model" of asthma management. They are (a) measures of assessment of severity and monitoring asthma control; (b) education for a partnership in asthma care; (c) control of environmental factors and comorbid conditions that affect asthma; and (d) pharmacologic therapy [9]. The professional model views asthma as a chronic illness and the disease is present even when symptoms are controlled and currently not apparent. Parents typically describe asthma as episodic, acute, and not readily controllable, or a combination of these, commonly referred to as "lay models" of illness management [6-8, 10, 11]. Arcoleo et al. [11] reported that the majority of Mexican mothers believed that their child's asthma was present only when the child had symptoms and that asthma was unpredictable and only administered their child's controller medication when symptomatic. Tumiel-Berhalter and Zayas [7] conducted focus groups among Puerto Rican caregivers of children with asthma, and their findings also support caregivers' lay model representations. Caregivers reported their child's asthma as "being deceiving" and stated that 1 min their child was feeling fine and the next they were having trouble breathing, that emergency department visits were inevitable, and expressed concerns about asthma medication side effects [7]. A review article by Kaptein et al. [6] provided empirical support for the role of illness perceptions in individuals' beliefs about asthma and its treatment. The authors report that across the included studies, individuals were likely to hold beliefs that asthma is episodic or an acute illness (lay model) [6].

There is mixed evidence that IRs are a factor in asthma outcomes (i.e., asthma control, medication adherence, and

acute health care utilization) [5, 7, 8, 12]. Yoos et al. [8] showed that parental IRs that were congruent with the professional model led to a greater probability that the child was on an adequate medication regimen. Findings by Sidora-Arcoleo et al. [13] revealed that IRs congruent with the professional model led to a greater probability of controller medication use and a concurrent decrease in the probability of complementary and alternative medicine (CAM) use. Kaptein et al. reported that individuals who held lay model beliefs had poor adherence to their controller medication regimen and, subsequently, poor lung function and asthma control [6]. Results from the REcognise Asthma and Link to Symptoms and Experience (REALISE) survey among 8,000 individuals with asthma revealed that 79% of the respondents classified as uncontrolled per Global Initiative for Asthma guidelines [14] did not view themselves as "sick" and 44% ignored their symptoms in order "to feel normal" [15]. For those individuals who reported having a controller medication, greater than 50% reported not using it daily as prescribed. Additionally, among those who perceived their asthma to be well controlled, 88% had to use oral steroids, 85% had an emergency department visit, and 82% were hospitalized [15]. In the only study found that examined caregiver and child asthma IRs, it was shown that caregivers who held beliefs about the necessity of medication and perceived treatment efficacy reported greater adherence to their child's medication regimen [12]. For children, only their belief about the necessity for medication was associated with greater self-reported adherence. It was also reported that children felt they had little control over their asthma symptoms and duration. The results of this study also revealed weak correlations between caregivers' and children's IRs, suggesting that caregiver and child IRs are not interdependent [12]. A major limitation of previous research is that many of these studies were cross sectional. One longitudinal study conducted by Tiggelman et al. [16] that examined the relationships between illness perceptions, asthma control, and emotional concerns among adolescents with asthma revealed that in a cross-sectional model, adolescents who perceived less control over their asthma and attributed more complaints to their asthma had poorer asthma control. However, in the longitudinal model, none of the illness perception domains were associated with changes in asthma control over time [16].

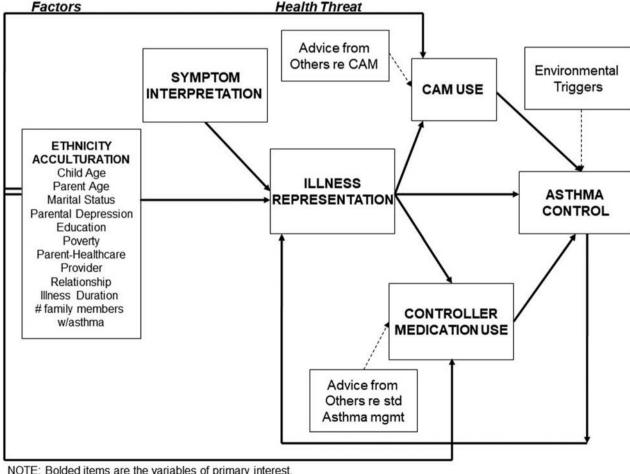
Although these findings begin to shed light on potential explanatory models for the observed asthma health disparities between Mexican and Puerto Rican children, it is necessary to gain a more thorough understanding of the interaction over time of intragroup differences, individual characteristics, cultural and experiential factors, socialenvironmental context, and health care system factors. The purpose of this study was to test an integrated, multifactorial model, which examined how the interaction of these factors impacted caregivers' IRs, the use of CAM and controller medications, and, subsequently, children's asthma health control over a 1 year period. There were two hypotheses for this study: (H1) Differences in social and contextual factors (ethnicity, age, education, poverty, depression, acculturation, social support, number of family members with asthma, child's illness duration, and quality of the relationship with the HCP) between Mexican and Puerto Rican caregivers will be associated with differences in IRs between the two groups. (H2) Differences in caregivers' treatment decisions (CAM and controller medication use) and changes in IRs over a 1 year period will be associated with disparities in asthma control between Mexican and Puerto Rican children within the context of acculturation, social and contextual factors, and environmental triggers.

## **Theoretical Framework**

The Common Sense Model (CSM) of IR [17–22] underpins the conceptual model for this study. It is an integrated model that takes into account environmental, social, and cultural factors and patients' beliefs about

health and illness. Figure 1 illustrates the conceptual model for this study derived from the CSM. The column headings in italics represent the constructs from the CSM. The caregiver's and child's interpretation of the child's symptoms are the stimuli that initiate the process of IR. The caregiver's social and contextual factors (i.e., ethnicity, age, education, poverty, acculturation, number of family members with asthma, child's illness duration, and quality of the relationship with the HCP) along with their own experiential health events lead to the formation of their individual asthma IRs. The social/contextual factors produce variations in IRs that will lead to caregivers choosing one of four treatment decisions: (a) no treatment; (b) use of alternative medicine (no controller medication use); (c) use of only controller medication; and (d) use of complementary medicine (alternative + controller medication). The caregiver then evaluates the results of his/her treatment decision based on whether the child's symptoms have been alleviated and stores that in memory for the next illness episode. This is a process whereby the IR is constantly being evaluated and revised for each new illness episode.

Social/Contextual Situational Stimuli Representation of Treatment Decision Outcome Factors Health Threat



NOTE: Bolded items are the variables of primary interest. Fig. 1. Conceptual model.

The majority of studies using the CSM have been conducted among adults with a variety of chronic conditions, including asthma, that reveal support for the CSM [8, 23, 24]. A recent meta-analysis of 254 studies using the CSM model in chronic illness was carried out by Hagger et al. [25] to examine the correlations among the key constructs of the model, investigate whether the process model association between IRs and outcomes is mediated by coping strategies, and explore moderating effects. Their results supported the theory of a direct effect of IRs on outcomes and the mediating effect of coping. Findings also revealed several key moderators (illness type and severity, whether the illness is symptomatic or asymptomatic, and whether symptoms are medically explained or unexplained), which led to the authors proposing a revised CSM model [25]. A recommendation was made to examine the CSM in longitudinal and interventional studies targeting IRs to better capture the changes in IRs, coping strategies, and outcomes over time [25]. Sonney et al. [26] conducted a systematic review of parent and child asthma IRs. Interestingly, only 15 studies met inclusion criteria, all were descriptive cross-sectional studies, none included child asthma IRs, and only 3 included parental IRs pointing to a paucity of data on IRs in childhood asthma irrespective of whether caregiver or child IRs are being assessed.

Few studies were found examining the CSM in Latino populations [11, 27-30]. With the exception of our previous qualitative study, the other studies focused on depression, diabetes, Post-traumatic stress disorder, and tuberculosis. Overall, these studies lend support to the theoretical constructs of the CSM [11, 27-30], but there is an opportunity to further examine the CSM among Latinos with asthma.

## Methods

## **Research Design and Sample**

This was a longitudinal, observational study testing an explanatory model for disparities in asthma control between Mexican and Puerto Rican children aged 5–12 years who had persistent asthma requiring daily controller medication use. The sample was recruited from two school-based health clinics and the Breathmobile in Phoenix, AZ, and two inner-city hospital asthma clinics in the Bronx, NY. These sites were specifically selected to examine the Mexican–Puerto Rican disparity given the high number of Mexican children in Phoenix and Puerto Rican children in the Bronx. A total of 534 participants were enrolled (267 caregivers and 267 children); 83% of the Mexican families were in Phoenix and 99% of the Puerto Rican families were in the Bronx. We attempted to recruit equal numbers of families from Phoenix and

the Bronx but Hurricane Sandy struck during our final year of recruitment displacing many families in the Bronx and, thus, we had to oversample in Phoenix in order to achieve our overall target sample size. Structured interviews occurred with caregivers and shorter interviews with the children, and spirometry assessments, objective measures of medication adherence, and a 12 month retrospective review of children's medical records were completed. Interviews and assessments were conducted at enrollment and 3, 6, 9, and 12 months postenrollment. The study was approved by the institutional review boards of the Arizona State University, Phoenix Children's Hospital, Scottsdale Healthcare, Ohio State University, and Albert Einstein College of Medicine. Caregivers provided written consent for their participation and separate consent for their child's participation and children also provided assent/consent for their participation. All procedures performed in this study were in accordance with the ethical standards of the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. This project has been registered at clinicaltrials.gov (ClinicalTrials.gov identifier: NCT 01099800).

#### Eligibility criteria

Children must have met the following criteria: (a) age 5–12 years, (b) had a diagnosis of persistent asthma documented in their medical record, (c) identified as Mexican or Puerto Rican as reported by the child's primary caregiver, and (d) had no other significant pulmonary complications or conditions. Participating caregivers must have had the majority responsibility for the child's day-to-day asthma management. Caregivers and children had to have no cognitive learning disability that would interfere with the ability to participate in the interview process. Electronic medical records within each recruitment site were used to identify children who met the diagnosis, age, and ethnicity criteria.

## Recruitment and enrollment

Eligible families were recruited through face-to-face invitations during clinic visits by mailing recruitment letters from the HCP to potential families and by phone calls from clinic staff inviting families to participate. The research nurse/assistant at each practice site explained the study and reviewed eligibility criteria with each family before obtaining verbal assent to participate. An appointment was made for the caregiver and child to complete written informed consent, child verbal assent, interviews, and spirometry. All consent forms were available in English and Spanish. All participants were reimbursed for their time and travel for each interview session. Interviews were conducted in English or Spanish based on the caregiver's and child's preference. Spirometry was done after the interview per the American Thoracic Society guidelines [31].

#### Measures

All measures, excluding the sociodemographic/contextual characteristics, were administered at each visit. For measures that did not have a validated Spanish version, translation, back translation, assessment of cultural equivalency (using five Spanish-speaking caregivers and their children), and reliability analyses were completed per accepted methodologies [32].

## Social/Contextual Factors

#### Demographic measures

To assess socioeconomic status, a measure adapted by Gore et al. [33] was used. Caregivers were asked, "What best describes your family's standard of living?" Response choices ranged from "very well off" to "poor." Due to sociolegal concerns in Phoenix, questions specific to income were not asked. For the caregiver interview, the caregiver's age, ethnicity, marital status, and educational level were obtained. From the child's medical record, the child's age, sex, date of asthma diagnosis (if known), and asthma medications prescribed were abstracted.

## Caregiver depressive symptoms

Caregiver depressive symptoms were measured with the Center for Epidemiological Studies Depression (CES-D) 20-item instrument that has been validated in English [34] and Spanish [35–37]. This instrument was designed to assess the severity of depressive symptoms in community samples and is intended as a screening tool. It has good internal reliability ( $\alpha = .88-.91$ ) [34], and reliability in this sample was  $\alpha = .82$  (English) and  $\alpha = .78$  (Spanish). Higher scores indicate greater symptomatology and a cutoff score of  $\geq 16$  is indicative of "significant" depressive symptomatology.

## Acculturation

Acculturation was measured by the 32-item Stephenson Multigroup Acculturation Scale (SMAS) [38]. The SMAS assessed degree of immersion in the native and dominant cultures. This instrument was developed, refined, and psychometrically tested during three studies (n = 436) across five ethnic groups and demonstrated acceptable reliability ( $\alpha = .86$  total scale;  $\alpha = .97$  Ethnic Society Immersion [ESI] Scale; and  $\alpha = .90$  Dominant Society Scale [DSI]). Cronbach's alpha coefficients in this sample were:  $\alpha = .84$  (English) and  $\alpha = .79$  (Spanish) total scale;  $\alpha = .71$  ESI (English) and  $\alpha = .63$  ESI (Spanish); and  $\alpha = .70$  DSI (English) and  $\alpha = .68$  DSI (Spanish).

## Asthma duration

The caregiver was asked how old the child was when his/ her asthma first started. Using the child's date of birth, the estimated start date for the child's asthma was computed. Asthma duration was calculated by subtracting the start date from the interview date. This yielded the number of days converted to months by dividing by 30.44 days.

## Number of family members with asthma

Caregivers were asked about other family household members with asthma and a count of these household members was created.

## Caregiver-HCP relationship

The caregiver-HCP relationship was assessed using the caregiver-HCP relationship subscale from the Asthma Illness Representation Scale (AIRS) instrument [39, 40]. Caregivers were asked 10 questions covering topics such as continuity of care provider, shared communication with the provider, and instructions about medication use. Questions were scored on a five-point Likert-type scale with responses ranging from 1 (strongly agree) to 5 (strongly disagree). Several questions were reverse scored prior to aggregation so that higher scores represented a more favorable relationship with the HCP. The overall score was calculated as the mean of the nonmissing items. The English and Spanish versions were developed and validated among an ethnically diverse sample and have shown good internal consistency ( $\alpha = .82$ ). This scale also significantly predicted illness representations congruent with the professional model of asthma management [8, 13]. Cronbach's  $\alpha = .75$  (English) and  $\alpha = .72$ (Spanish) in this sample.

## Social support

Social support was measured using the 12-item Social Networks (SN) questionnaire from the National Latino and Asian American Study [41]. The SN questionnaire yields a total score and two subscale scores reflecting family and friend support. Each of these scores has acceptable internal consistency among Latino subgroups ( $\alpha = .71$  SN-total score;  $\alpha = .71$  SN-family support;  $\alpha = .75$  SN-friend support). Adequate internal consistency was also obtained using a Spanish version ( $\alpha = .72$  SN-family support;  $\alpha = .78$  SN-friend support). Reliability estimates in this sample were SN-total score  $\alpha = .74$  (English),  $\alpha = .75$  (Spanish); family support  $\alpha = .59$  (English),  $\alpha = .62$  (Spanish).

#### Situational Stimuli

#### Symptom interpretation

Interpretation of symptoms by child and caregiver was assessed at each visit using the Childhood Asthma Symptom Checklist (CASCL and P-CASCL, respectively) [42]. The P-CASCL/CASCL is a 47-item measure of the frequency that children experience physical symptoms, irritability, and panic-fear during asthma attacks. Items are scored on a four-point scale with anchors of 1 (never) to 4 (always). Caregivers' reports across these three subscales of the P-CASCL have been associated with asthma morbidity among children aged 6 and older [43, 44]. The instrument has demonstrated good internal consistency for both versions ( $\alpha = .81-.94$ ) and adequate construct validity when examining the correlation between the subscales and use of oral corticosteroids, health care and ER visits, and perceived asthma control [43, 44]. A latent variable for symptom interpretation with these indicators was created.

#### **Representation of Health Threat**

#### Asthma illness representations

The construct of IR is comprised of the five subscales of the AIRS and the total score. This instrument is designed to identify barriers and risk factors for underutilization of controller medications [8]. The English and Spanish versions of the AIRS were developed and validated among ethnically diverse samples [39, 40]. The AIRS subscales and their reliability estimates are: treatment expectations ( $\alpha = .75$ ); attitudes toward medication use ( $\alpha = .78$ ); facts regarding asthma ( $\alpha = .71$ ); nature of asthma symptoms ( $\alpha = .61$ ); and emotional aspects of medication use ( $\alpha = .55$ ). The alpha for the total score was  $\alpha = .84$  and, in this sample,  $\alpha = .79$  (English) and  $\alpha$  = .77 (Spanish). Each item is scored on a five-point Likert-type scale from 1 (strongly agree) to 5 (strongly disagree). Select items within each subscale were reverse scored and scores were calculated as the mean of the nonmissing items. Higher values (mean score >3) indicated closer alignment with the professional model for asthma management while average scores falling below 3 reflect beliefs more closely aligned with the lay model of asthma management.

## **Treatment Decision**

## CAM use

CAM use was derived from structured questions asking about specific CAM therapies. Examples were herbal supplements and teas, breathing exercises, prayer for health purposes, syrups, and rubs. For each therapy, the caregiver was asked if he/she had ever used the therapy with the child. If "Yes," the type of therapy used in that category (e.g., for syrups the caregiver would indicate the type, such as Jarabe 7), the caregiver's assessment of effectiveness, frequency of use, and whether he/she was still using the therapy were recorded. A count of all CAM therapies currently being used was created and dichotomized to any current CAM use "Yes" for n > 0 and "No" for n = 0.

## Controller medication use

Caregivers were asked to list all prescribed medications that the child was currently taking for asthma management. Medications were coded as "controller medication" or "quick relief" medication. For each medication, caregivers were asked to indicate the last time the child took their medication. A dichotomous variable for controller medication use in the past 24 hr was created.

## Outcome

#### Assessment of asthma control

Children's asthma control was assessed through caregiver and child interviews using the Asthma Control Test (ACT) [45–47]. The Childhood Asthma Control Test (C-ACT) consists of questions for children (aged 4–11 years) and parents. The ACT consists of five items for adolescents 12 years and older. Both versions assess interference with activities, asthma symptoms, and nighttime awakenings. The C-ACT ( $\alpha = .79$ ) and ACT ( $\alpha = .84$ ) exhibit good reliability and validity and classify children as poorly controlled or well controlled. The Spanish ACT has good reliability ( $\alpha = .84$ ) and validity.

#### **Additional Mediating Variables**

#### Advice received from others

We wanted to model the influence friends and family members may have in the treatment decisions that caregivers make; thus, we assessed advice that they received from others (besides their HCP) regarding their children's asthma management. If the caregiver indicated that they obtained advice, we asked from whom and for a description of the advice they received. The type of advice was coded as "CAM related," "standard asthma management," or "other." Examples of CAM-related advice from our previous study were: boil bark and drink as tea, shark oil, and massage. Examples of standard asthma management advice were: see a specialist, know signs of an asthma attack, and learn how to use inhaler.

#### Environmental triggers

The 32-item Asthma Trigger Inventory (ATI) [48, 49] assessed triggers across six domains: emotions, animal allergens, pollen, physical activity, air pollution/irritants, and infections. Caregivers were asked how frequently a particular trigger was related to their children's experience of asthma symptoms. Items were rated on a fivepoint scale ranging from 0 (*never*) to 4 (*always*). Higher scores indicated greater frequency of those triggers. The subscales were the average of the items for that scale. A latent variable for asthma triggers comprised of the six subscales was included as a mediator in the model. The ATI for pediatric populations has demonstrated excellent reliability and validity ( $\alpha = .72-.90$ ) [48, 49]. The alpha for the total score in this sample was  $\alpha = .94$  for the English and Spanish versions [48, 49].

## **Sample Power**

Growth modeling was used for model testing; therefore, a method of calculating study power based on covariance structure modeling was used. This procedure was developed by MacCallum et al. [50] and is based on evaluating the goodness of fit for the model. This method uses the root mean square error of approximation (RMSEA) and makes use of the noncentral  $\chi^2$  distribution. This approach tests the null hypothesis of close fit. Sample size is estimated by specifying the RMSEA fit index for a null and alternative model, desired alpha, and power. The RMSEA method is highly desirable because of its sensitivity to the number of estimated model parameters and a confidence interval can be calculated around its value [51, 52].

A computer program has been developed by Preacher and Coffman [53] to compute study power and sample size based on this method. Based on  $H_0:\varepsilon = .05$ ,  $H_4:\varepsilon = .08$ ,  $\alpha = .05$ , n = 267, and df = 182, power was .98.

#### Statistical Models and Methods of Analysis

Eligible participants who declined to participate were compared with those enrolled on sociodemographic/ contextual characteristics to check for sample bias. Descriptive statistics identified the distribution of the data and total instrument scale scores for each of the study measures. Means and standard deviations were examined for continuous variables and proportions for categorical variables. Effect sizes were computed for continuous variables and odds ratios for categorical variables. A two-group (Mexican and Puerto Rican) latent variable structural equation model was used to address the cross-sectional Hypothesis 1, and a single group latent variable structural equation growth model assessed Hypothesis 2. Time-varying exogenous variables for both models were child's age and asthma duration, caregiver age, caregiver-HCP relationship, caregiver depression, social support, acculturation, AIRS scores. and CAM and controller medication use. Invariant endogenous variables for each model were the number of family members with asthma, marital status, child sex, poverty, and caregiver education. Adjusted standard errors were examined and model fit indices computed using maximum likelihood estimation. Following conventions outlined by Kline [54, 55], our criteria for assessing adequacy of fit were:  $\chi^2/df$  ratio of less than 2, comparative fit index (CFI), and Tucker-Lewis Index (TLI) at or above .90, an RMSEA at or below .05 and standardized root mean square residual (SRMR) <.08. SAS version 9.4 of the SAS System for Windows (copyright 2017, SAS Institute Inc.) was used for the descriptive analyses and MPlus version 8.1 [56] was used for the standard error of the mean (SEM) analyses.

#### Missing data

SEM allows for missing data on the endogenous variable using full maximum likelihood methods, which assume that the data are missing at random. Multiple imputations were done when exogenous variables were missing [56].

## Results

## Sociodemographic/Contextual Characteristics of the Sample

There were no differences between those caregivers and children who enrolled versus declined on any of the baseline sociodemographic/contextual characteristics. Table 1 presents the sample characteristics. Mexican caregivers were significantly more likely to be married, poor, be born outside the USA, have more family members with asthma, receive more support from family and friends, and report treatment expectations aligned with the professional model of asthma management. Puerto Rican caregivers were significantly older, had higher education levels, lived longer in the USA and had greater acculturation to the mainland USA, reported higher depressive symptomatology, and reported very high rates of current CAM use. More Mexican children were classified as having wellcontrolled asthma compared to Puerto Rican children. Puerto Rican children had longer duration of asthma and reported more animal triggers than Mexican children. There were no statistically significant differences in the total AIRS score between ethnic groups at baseline. The mean scores for both groups were not strongly

#### **Table 1.** Sample baseline characteristics (N = 267)

Variable	Mexican (n = 188)	Puerto Rican $(n = 79)$	Test statistic	Test of significance	
	n (%)	n (%)	Odds ratio	р	
Recruitment site					
Arizona	156 (83)	1 (1.3)	0.003	<.0001	
New York	32 (17)	78 (98.7)			
Married (% yes)	104 (55.3)	24 (30.4)	2.84	.0002	
Poor (% yes)	126 (67.0)	25 (31.7)	4.39	<.0001	
High school graduate (% yes)	85 (45.5)	48 (60.8)	0.54	.02	
Caregiver sex (% female)	180 (95.7)	74 (93.7)	1.52	NS	
Caregiver country of birth					
Mexico	173 (91.5)	0			
Puerto Rico	0	20 (25.0)	255.7*	<.0001	
USA	14 (7.41)	60 (75.0)			
Guatemala	1 (0.5)	0			
Peru	1 (0.5)	0			
Child sex (% female)	62 (33.0)	32 (40.5)	0.72	NS	
Any controller medication use past month (% yes)	108 (56.8)	50 (62.5)	0.75	NS	
Currently using CAM (% Yes)	102 (54.0)	56 (70.9)	6.59	.01	
	Mean (SD)	Mean (SD)	Effect size	р	
# Family members w/asthma	1.24 (0.73)	0.91 (1.09)	0.36	.02	
Asthma duration (Months)	67.94 (39.54)	88.46 (31.77)	0.57	<.0001	
Caregiver's age	35.47 (6.31)	38.42 (10.47)	0.34	.02	
Caregiver # years lived in USA	14.07 (7.71)	33.84 (12.9)	1.86	<.0001	
Study child's age (Years)	9.67 (2.15)	9.23 (2.23)	0.20	NS	
Social Network Score	3.19 (.47)	2.95 (.54)	0.47	.0004	
Parent-provider relationship	3.72 (.54)	3.78 (.55)	0.11	NS	
Parental depression	10.95 (10.15)	16.03 (12.03)	0.46	.002	
Asthma Control Test	19.94 (3.82)	16.44 (3.90)	0.91	<.0001	
Acculturation: ethnic society	3.23 (.35)	3.22 (.41)	0.03	NS	
Acculturation: dominant society	2.98 (.39)	3.40 (.44)	1.01	<.0001	
AIRS: total score	3.10 (.36)	3.03 (.30)	0.21	NS	
AIRS: treatment expectations	3.07 (.59)	2.75 (.45)	0.61	<.0001	
AIRS: nature of asthma symptoms	2.74 (.66)	2.72 (.63)	0.03	NS	
AIRS: facts about asthma	3.56 (.41)	3.58 (.34)	0.05	NS	
AIRS: negative attitudes toward medication use	2.66 (.62)	2.73 (.56)	0.12	NS	
AIRS: emotional aspects around medication use	2.98 (.79)	2.86 (.71)	0.16	NS	
Triggers—infection	1.81 (0.95)	1.75 (1.0)	0.06	NS	
Triggers—irritants	1.13 (1.0)	1.28 (0.94)	0.15	NS	
Triggers—psychological	0.47 (0.63)	0.40 (0.57)	0.12	NS	
Triggers—allergens (pollen)	1.75 (1.22)	1.73 (1.16)	0.02	NS	
Triggers—allergens (animal)	0.91 (1.04)	1.30 (1.10)	0.36	.006	
Triggers—allergens (pollen + animal + House)	1.36 (1.01)	1.56 (1.0)	0.20	NS	

*AIRS* Asthma Illness Representation Scale; *CAM* complementary and alternative medicine; *SD* standard deviation. \*Likelihood chi-square ratio.

aligned with either the lay or professional model. Overall attrition across the 12 month study period was 17.6% (Breathmobile = 8.7%; school-based health center = 3.8%; and hospital clinics = 32.7%). The higher than estimated attrition at the hospital clinics was primarily due to Hurricane Sandy displacing families whom we were unable to contact. To ascertain whether the higher reported depressive symptomatology among Puerto Rican caregivers may have been due to the effects of Hurricane Sandy, we examined the CES-D scores for those who completed interviews (all times periods) prior to the hurricane and after the hurricane (data not shown). At every time period, except Month 12, the CES-D scores posthurricane were actually lower than the prehurricane scores for the same time period.

## Hypothesis #1

Hypothesis 1 tested a cross-sectional structural equation model to identify the similarities and differences in predictors of asthma IRs between Mexican and Puerto Rican children. Table 2 presents the results of the model fit and trimming analyses to yield the final SEM model for the baseline analyses. Ethnicity was the grouping variable and, thus, is not a variable in the path. The first model included all theoretically based exogenous variables. Based on  $H_0/\varepsilon = .05$ ,  $H_A/\varepsilon = .08$ ,  $\alpha = .05$ , df = 182, and n = 267, power was .99 for rejecting the hypothesis of close fit. This model demonstrated adequate power but marginal fit statistics. Three additional trimming models were run removing paths that were not significant for both groups. The final model omitted three variables: child and caregiver ages and number of family members with asthma. Power was not compromised and the model fit improved.

Figure 2 illustrates the results of the SEM for the Mexican sample and Fig. 3 the SEM for the Puerto Rican sample. This model accounted for approximately 46% of the variance in IR scores for the Mexican caregivers but only 32% of the variance for Puerto Rican caregivers. The

Table 2. Test of model fit for theoretical factors associated with asthma illness representations

Path variables	Mexican $\beta$ ( <i>SE</i> )	Puerto Rican $\beta$ ( <i>SE</i> )	$\chi^2/df$	CFI	TLI	RMSEA	SRMR	Power
Model 1:			1.58	.87	.84	0.07	.06	.99
Child age	.07 (.06)	17 (.10)						
Child sex	.13 (.07)	03 (.13)						
Asthma duration	.06 (.06)	.06 (.13)						
Caregiver age	02 (.06)	002 (.10)						
Caregiver education	.04 (.06)	.12 (.10)						
Caregiver depressive symptoms	01 (.06)	19 (.11)						
Social support	.12 (.06)	.09 (.11)						
Marital status	004 (.06)	22 (.10)						
Poverty	10 (.06)	11 (.10)						
# Family members w/asthma	.07 (.06)	12 (.11)						
Relationship w/healthcare provider	.50 (.05)	.35 (.10)						
Ethnic society immersion	09 (.07)	.09 (.14)						
Dominant society immersion	.17 (.07)	10 (.14)						
Symptom perception	22 (.06)	12 (.10)						
Model 2: caregiver age omitted			1.54	.89	.86	.06	.06	.99
Model 3: caregiver and child age omitted			1.51	.90	.87	.06	.06	.99
Model 4: caregiver, child age, and # of family members w/asthma omitted			1.45	.92	.89	.06	.06	.99
Child sex	.14 (.07)	04 (.13)						
Asthma duration	.05 (.06)	.05 (.13)						
Caregiver education	.03 (.06)	.12 (.10)						
Caregiver depressive symptoms	03 (.06)	23 (.10)						
Social support	.11 (.06)	.05 (.10)						
Marital status	02 (.06)	22 (.11)						
Poverty	10 (.06)	15 (.10)						
Relationship w/healthcare provider	.51 (.05)	.37 (.10)						
Ethnic society immersion	10 (.07)	.10 (.13)						
Dominant society immersion	.17 (.07)	16 (.14)						
Symptom perception	01 (.003)	003 (.003)						

*CFI* comparative fit index; *RMSEA* root mean square error of approximation; *SE* standard error; *SRMR* standardized root mean square residual; *TLI* Tucker–Lewis Index.

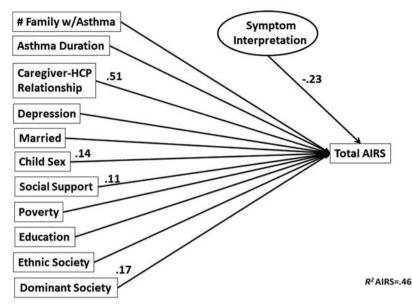


Fig. 2. Model test for AIRS-Mexicans.

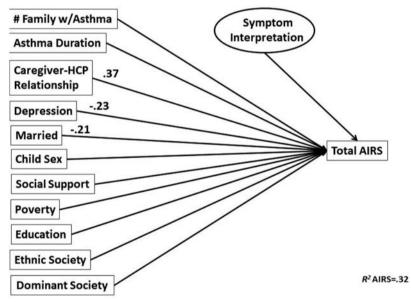
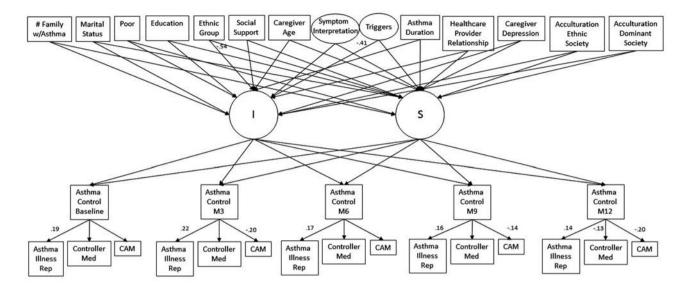


Fig. 3. Model test for AIRS—Puerto Ricans.

two-group SEM for the baseline analyses revealed that there were ethnic differences in sociodemographic/contextual predictors of asthma IRs congruent with the professional model. The data fit the model well:  $\chi^2/df = 1.45$ , CFI = .92, TLI = .89, RMSEA = .06, SRMR = .06. For all caregivers, better quality of the relationship with the HCP was related to IRs aligned with the professional model. This was the only exogenous variable common to both ethnic groups. For the Mexican sample (Fig. 2), caregivers whose children were female, were more acculturated, reported fewer asthma symptoms, and had greater social support from family and friends were more likely to hold asthma IRs aligned with the professional model. Puerto Rican caregivers who were married and reported lower levels of depressive symptoms were more likely to hold beliefs aligned with the professional model (Fig. 3). To test whether these ethnic differences were statistically significant, the two-group analysis was rerun constraining the model parameters to be equal across groups and model fit examined. Significant differences are evident when the model fit statistics decline and are no longer within acceptable limits. The results of the constrained model analysis revealed that the ethnic group differences were statistically significantly different due to none of the fit statistics meeting acceptable criteria:  $\chi^2/df = 2.97$ , CFI = .56, TLI = .54, RMSEA = .12, SRMR = .10.



NOTE: I=intercept for asthma control; S=slope for the growth factor of asthma control

Fig. 4. Latent growth model to identify changes in caregivers' illness representations, treatment decisions, and children's asthma health outcomes. I = intercept for asthma control; S = slope for the growth factor of asthma control.

#### Hypothesis #2

Hypothesis 2 investigated whether disparities in asthma control between Mexican and Puerto Rican children were due to differences in caregivers' treatment decisions (CAM and controller medication use) and changes in IRs over a 1 year period factoring in the effects of acculturation, social and contextual factors, and environmental triggers (Fig. 4). In this figure, "I" represents the intercept and "S" the slope for the growth factor for asthma control. This model accounted for 40%-48% of the variance in ACT scores over 12 months and the results revealed that there were differences in asthma control over time by ethnicity. A growth model examining changes in IRs over time supported the theoretical notion that IRs change over time impacting caregivers' treatment decisions and children's asthma control as evidenced by the statistical significance of the intercept  $(\beta = 3.08, p = <.0001)$  and slope coefficients ( $\beta = 0.02$ , p = <.0001). Caregivers' IRs aligned with the professional model of asthma management were associated with higher ACT scores (i.e., better control) across the 1 year period. Findings for CAM use revealed that children whose caregivers were not currently using CAM to treat asthma had higher ACT scores at 3, 9, and 12 months postenrollment. Current CAM use was not significantly associated with children's ACT scores at baseline or Month 6. Interestingly, children whose caregivers reported no controller medication use in the past month had significantly higher ACT scores at 12 months than those who reported controller medication use, but this finding was not evident at the earlier time periods.

## Conclusions

These findings extend a previous cross-sectional model test [13] using a more comprehensive model and longitudinal data and support our hypotheses. Our results validate the CSM as an explanatory model for ethnic differences in caregivers' IRs and children's asthma control as evidenced by the model accounting for 46% and 32% of the variance in IRs for Mexicans and Puerto Ricans, respectively. It was demonstrated that, within the Latino population, there are ethnic differences in the predictors of Mexican and Puerto Rican caregivers' asthma IRs, their treatment decisions, and disparities in their children's asthma control. We demonstrated that, for children and caregivers of Mexican ancestry, being female, reporting fewer symptoms, and having greater social support and acculturation to the USA, led to asthma IRs aligned with the professional model of asthma management, but these factors were not significant for mainland Puerto Rican families. In addition, symptom interpretation was a significant predictor of caregivers' IRs but only among the Mexican sample. Given that caregiver depression was higher in the Puerto Rican sample and previous research has demonstrated the association between mental health symptomatology and symptom reporting [57–59], it is conceivable that the lack of relationship between symptom interpretation and IRs for the Puerto Rican caregivers was related to their depressive symptoms. In addition, mainland Puerto Ricans are not immigrants because Puerto Rico is a Commonwealth of the USA. Some of the protective factors associated with the immigration experience may

or may not be present among mainland Puerto Rican families.

Our findings also support the theoretical notion that caregivers' asthma IRs change over time based on their appraisal of previous outcomes (i.e., children's ACT scores) of their treatment decisions. Contrary to the findings by Tiggelman et al. [16], we demonstrated that caregivers' IRs congruent with the professional model were associated with greater asthma control in their children and this model accounted for 40%–48% of the variance in children's asthma control over 1 year. Interestingly, controller medication use was not associated with children's ACT scores except at Month 12. However, this finding was contradictory to what was expected as nonuse of controller medication was predictive of better asthma control. It is plausible that this was due to titration of medication use if the child had been well controlled or the effect of season (i.e., summer) when many children stop taking their controller medications because there is a lessening of symptoms.

The findings from this study illuminate the heterogeneity within the Latino population of children with asthma, the role of asthma illness representations in caregivers' treatment decisions, and the influence of those treatment decisions on children's asthma control. This explanatory model could be used to assess within and between groups differences among various ethnic populations. These results can also inform development and implementation of targeted interventions, aimed at reshaping IRs, which integrate the family's ethnomedical belief system (medical system based on the cultural beliefs of specific ethnic groups) into the biomedical model to improve children's asthma outcomes.

## Limitations

There are several important limitations. This study sample was limited to the Mexican American and mainland Puerto Rican Latino subgroups and, thus, these findings cannot be extended to other Latino subgroups. As the U.S. population of other Latino subgroups (e.g., Guatemalan, Salvadoran, and Dominican Republic) continues to grow, it will be important that future research examine these groups as well. At the time this study was conducted, we had not adapted and validated the AIRS instrument for children and, therefore, were not able to assess their asthma illness representations. Recent evidence demonstrates that 20% of 7 year old children and close to 50% of 11 year old children are responsible for the day-to-day management of their asthma [60]; thus, understanding their own representations and beliefs about their asthma will be critical. As Sonney and Insel point out, neglecting to account for children's illness perceptions in addition to their caregivers' results in an incomplete understanding of the child's asthma management [61]. Although these models predicted significant proportions of the variance in outcomes, there may be alternative models that do as well or better in explaining the within-Latino group asthma health disparities. In fact, Sonney and Insel have proposed and are testing a revised CSM of Parent–Child Shared Self-Regulation that includes parent and child IRs, which influence shared management of the child's asthma [61].

HCPs, regardless of their practice setting, can best treat children with asthma if they understand what beliefs caregivers hold about what causes asthma, the nature of asthma symptoms, its course of action (chronic versus episodic), medications and alternative therapies used in treatment, and expectations for symptom resolution. If caregivers' beliefs are discordant with the HCPs' beliefs and are not addressed when devising the management plan, there is increased risk for nonadherence [8, 11, 62, 63]. If caregivers feel they are part of the decision-making process regarding their children's asthma treatment, they may be more likely to adhere to the prescribed medication regimen [64-67]. HCPs have an opportunity to intervene at the individual level to affect changes aimed at improving adherence to the prescribed treatment regimen through improved communication, education, and partnership with the families.

Acknowledgments We would like to thank all of the families who generously shared their time and experiences with us, our clinician colleagues, and our incredible research staff at both locations.

Funding: This study was funded by the National Center for Complementary and Integrative Health (R01AT005216-01; PI K.A.).

#### **Compliance with Ethical Standards**

Authors' Statement of Conflict of Interest and Adherence to Ethical Standards The authors declare that they have no conflict of interest. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Authors' Contributions F.M. is an expert in Latino health and health disparities and assisted K.A. in framing the study hypotheses, interpretation of results, content of the Conclusions, and reviewed and provided approval for the final submission. D.S. provided clinical interpretation of the results, assisted in the content of the Conclusions, and reviewed and provided approval for the final submission. J.R. recruited, enrolled and conducted data collection for the project, assisted in the interpretation of the results and content of the Conclusions, and reviewed and provided approval for the final submission. C.M. assisted in conducting the literature review, drafting the Introduction, contributed to the interpretation of data and content of Conclusions section, and reviewed and provided approval for submission. J.F. participated in the design of the study, was site P.I. for the Bronx, assisted in the interpretation of the results and content of the Conclusions, and reviewed and provided approval for the final submission.

**Ethical Approval** The study was approved by the Institutional Review Boards of the Arizona State University, Phoenix Children's Hospital, Scottsdale Healthcare, Ohio State University, and Albert Einstein College of Medicine.

Informed Consent Caregivers provided written consent for their participation and separate consent for their child's participation and children also provided assent/consent for their participation.

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