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Abstract: ABSTRACT

Background: Despite significant advances in treatment modalities, morbidity due to childhood asthma has continued to increase, particularly for poor and minority children.

Objectives: The aim of this study was to describe the parental illness representation of asthma in juxtaposition to the "professional model" of asthma and to evaluate the impact of that illness representation on asthma management outcomes.

Methods: 228 parents of children with asthma were interviewed regarding illness beliefs using a semi-structured interview. The impact of background characteristics, parental beliefs, and the child's symptom interpretation on asthma management was evaluated.

Results: Parents and professionals think about asthma quite differently, with even less concordance in poor and minority families. Analysis indicated that demographic risk factors ($p < .005$), parental educational level ($p < .0001$), the child's symptom understanding ($p < .02$) and the parent/health care provider relationship ($p < .0001$) had a direct effect on the parental illness representation. The parental illness representation ($p < .05$), demographic risk factors ($p < .006$), and formal ($p < .02$) and informal ($p < .0003$) sources of asthma information had a direct effect on asthma outcomes. The parental illness representation mediated the impact of

demographic risk factors (p .10), parental educational level (p .07) and the parent/health care provider relationship (p .06) on disease management outcomes.

Discussion: Parents and health care providers may come to the clinical encounter with markedly different illness representations. Establishing a partnership with parents by eliciting and acknowledging parental beliefs is an important component of improving disease management.

Key words: childhood asthma, parental illness representation, health disparities

September 12, 2006
Molly C. Dougherty, RN, PhD

Dear Dr. Dougherty,

Enclosed please find the manuscript "Pathways to an Inadequate Medication Regimen in Childhood Asthma" for consideration for publication in *Nursing Research*.

The authors transfer all copyright ownership of the manuscript "Pathways to an Inadequate Medication Regimen in Childhood Asthma" to *Nursing Research* in the event the work is published. The undersigned authors warrant that the article is original, does not infringe upon any copyright or other proprietary right of any third party, is not under consideration by another journal, and has not been previously published. The authors confirm that they have reviewed and approved the final version of the manuscript.

Looking forward to the reviewer comments.

Sincerely,

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Charles Henderson, MA

Ann McMullen, MS, CPNP

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9/11/06

PATHWAYS TO AN INADEQUATE MEDICATION REGIMEN IN CHILDHOOD ASTHMA

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1 **ABSTRACT**

2 *Background:* Despite significant advances in treatment modalities, morbidity due to
3 childhood asthma has continued to increase, particularly for poor and minority children.

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5 asthma in juxtaposition to the “professional model” of asthma and to evaluate the impact
6 of that illness representation on asthma management outcomes.

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8 using a semi-structured interview. The impact of background characteristics, parental
9 beliefs, and the child’s symptom interpretation on asthma management was evaluated.

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12 factors ($p .005$), parental educational level ($p <.0001$), the child’s symptom
13 understanding ($p .02$) and the parent/health care provider relationship ($p <.0001$) had a
14 direct effect on the parental illness representation. The parental illness representation
15 ($p .05$), demographic risk factors ($p .006$), and formal ($p .02$) and informal ($p .0003$)
16 sources of asthma information had a direct effect on asthma outcomes. The parental
17 illness representation mediated the impact of demographic risk factors ($p .10$), parental
18 educational level ($p .07$) and the parent/health care provider relationship ($p .06$) on
19 disease management outcomes.

20 *Discussion:* Parents and health care providers may come to the clinical encounter with
21 markedly different illness representations. Establishing a partnership with parents by
22 eliciting and acknowledging parental beliefs is an important component of improving
23 disease management.

1 *Key words:* childhood asthma, parental illness representation, health disparities

1 The past two decades have witnessed significant advances both in the
2 understanding of the pathophysiology of asthma as well as new treatment modalities.
3 Nevertheless, morbidity due to childhood asthma has continued to increase during the
4 same time frame (Stempel, 2006). Asthma currently affects about 6.2 million children in
5 the United States and has an adverse impact on children and families, health care
6 institutions, health care finances, educational institutions, industry, and the economy
7 (ALA, 2006; Wang, Zhong, & Wheeler, 2005).

8 Disproportionate rates of disability, hospitalization, and death from asthma occur
9 in specific socioeconomic and ethnic groups in the U.S. (Akinbami, LaFleur, &
10 Schoendorf, 2002; ALA, 2006; Mannino et al., 2002). The reasons for these disparities
11 are not completely understood, and it is likely that multiple factors play a contributing
12 role (IOM, 2002). Available studies document lower anti-inflammatory medication use,
13 less access to and continuity of care, and more frequent emergency department
14 utilization for poor and minority children with asthma (Diaz et al., 2000; Finkelstein et al.,
15 2002; Rand et al., 2000). The National Cooperative Inner-City Asthma Study has made
16 an additional contribution to understanding health disparities by evaluating the impact of
17 family and community resources on morbidity outcomes in these children (Wade et al.,
18 1997). However, there is limited information available regarding parental perspectives
19 on barriers to optimal asthma management from families of diverse backgrounds.
20 Mansour and colleagues (2000) found that many of the urban minority parents they
21 interviewed in focus groups modified the asthma management plan prescribed by their
22 child's health care provider based on personal beliefs about the disease and the safety
23 and long-term complications of medications.

1 The National Heart, Lung, and Blood Institute’s National Asthma Education and
2 Prevention Program (NAEPP) Expert Panel 2 has issued definitive guidelines for health
3 care providers treating asthma and has articulated treatment goals for patients that are
4 considered attainable by the professional community (NAEPP, 1997, 2002). Because
5 anti-inflammatory medications for asthma have proven efficacy in clinical trials as well
6 as effectiveness in real-world practice settings, these medications are a central
7 component of asthma management (NAEPP, 2002). The guidelines recommend a
8 stepwise approach to therapy in which the dose, type of medications, and frequency of
9 administration are adjusted according to the level of symptoms in order to achieve
10 control. This document represents the “*professional model*” for asthma management.

11 An essential part of “*lay illness representations*” in a variety of theoretical models
12 is the person’s understanding of the nature and causes of the disease, perception and
13 interpretation of symptoms, beliefs about treatment, and the expected course and
14 timeline of the disease (Kleinman, 1988). According to Leventhal and colleagues,
15 individuals evaluate current symptoms against an implicit or “commonsense” cognitive
16 representation of the illness that may be based on the individual’s cultural context, prior
17 illness history, generic information about health and illness, information from the health
18 care provider, information from family and friends, or the wider media (Fortune et al.,
19 2004; Leventhal, Leventhal, & Cameron, 2001). There is a growing appreciation of the
20 need to explore the nature of the discrepancies between the professional model of
21 asthma and its treatment and the patient/family lay model in order to tailor interventions
22 to address specific barriers to optimal management. Recognizing the potential impact
23 of patient beliefs on treatment outcomes, the Institute of Medicine has identified patient

1 preferences and values and patient–clinician communication and partnership as critical
2 areas to be targeted for research addressing quality of care as well as health disparities
3 (IOM, 2002).

4 The research aims for this study were to:

- 5 1. Describe the illness representation of parents of children with asthma and identify
6 the discrepancies between the professional model of asthma and the
7 patient/family lay model,
- 8 2. Determine the impact of demographic and background characteristics on the
9 parental illness representation,
- 10 3. Examine the impact of demographic and background characteristics, the parental
11 illness representation, and the parent/health care provider relationship on asthma
12 management (the adequacy of the child’s medication regimen).

13 **METHODS**

14 **Study Design**

15 The study used a cross-sectional design with a one-time, semi-structured home
16 interview of parents of children with asthma as well as the children themselves, and a
17 retrospective one-year review of their medical records. Data reported here were
18 obtained from the child’s parent (or primary caregiver at home) and the child.

19 **Sample and Procedures**

20 The study population was recruited from six clinical practice sites in upstate New
21 York that included both pediatric clinics serving predominantly urban, minority families
22 and community pediatric practices serving primarily middle-class families. Parents and
23 children were invited to participate in the study if they met the following criteria: a) the

1 child was 5–12 years of age, b) the family was English-speaking, and c) the child
2 carried a diagnosis of asthma and had at least two asthma-related visits in the prior 12
3 months. School-aged children with the diagnosis of asthma were identified in each of
4 the clinical settings using the practices' computerized data sets to extract demographic
5 information, ICD 9 codes, and number of visits related to asthma. Eligible families were
6 informed of the study by a letter from the primary care providers in each of the settings
7 and could refuse further contact by notifying their health care provider. Potentially willing
8 participants were contacted by the research staff and offered enrollment.

9 The University of Rochester Institutional Review Board approved the study
10 protocol. After agreement to participate was obtained, a home visit was scheduled.
11 Formal consent processes took place at the home visit with written permission for both
12 the interview and medical record review obtained from the parent and assent obtained
13 from each child. Interviewers were experienced pediatric nurses trained in asthma care.
14 Interviews occurred over a 16-month period in both the clinic and private practice
15 populations in order to capture seasonal variations in asthma.

16 **Measures**

17 *Demographic Characteristics:* Race and ethnicity were determined using the National
18 Institute of Health classification system and later collapsed to white, black, Hispanic,
19 and “other” races. For race-related comparisons, black and Hispanic participants were
20 combined for “minority” status because the differences between these 2 groups were
21 not significant on the instruments measuring belief systems and the parent/health care
22 provider relationship. The “other” group was too small and diverse (n=3) for meaningful
23 contrasts and was deleted from analyses involving race. Poverty status was established

1 using Medicaid and State Children’s Health Insurance Program (SCHIP) eligibility since
2 these programs use federal poverty guidelines. Parental education reflected years of
3 formal education completed. We also constructed a summary demographic risk score,
4 with a value of 0 for families with neither poverty nor minority status (low risk) and a
5 value of 1 for families with either minority or poverty status (risk).

6 *Background characteristics.* Illness representation theory would suggest that
7 information from diverse sources impacts parental beliefs as well as disease
8 management strategies. We evaluated both formal and informal sources of asthma
9 information. Formal asthma education received from the health care provider was
10 assessed using a structured interview reflecting essential educational content specified
11 by the NAEPP Expert Panel, such as teaching about the pathophysiology of asthma,
12 symptom assessment, medication use, device demonstration, environmental control
13 measures, and treatment goals (McMullen et al., in press). Informal sources were
14 assessed by asking about parental advice-seeking related to asthma management
15 outside the health care system. We also hypothesized that the child’s own symptom
16 evaluation and report as well as experience with asthma (other family members with
17 asthma, and the child’s illness duration) would have an impact on the parental illness
18 representation. The child’s symptom evaluation included the proportion of standard
19 asthma symptoms that the child agreed were consistent with asthma as well as the
20 proportion of standard asthma symptoms that they stated they would report to an adult if
21 they occurred.

22 *Parental Beliefs.* The Asthma Illness Representation Scale[®] (AIRS) is a 39 item
23 instrument consisting of 5 subscales that represent the different domains of parental

1 beliefs about asthma. The instrument was designed to capture both the professional
2 and lay representation of asthma. The process for instrument development through
3 parent focus groups, clinical expert review, cognitive testing, and statistical testing of
4 hypothesized relationships has been described elsewhere (Yoos, Kitzman, & McMullen,
5 2003). Construct validity, evaluated using principal components factor analysis with
6 varimax rotation, was supported for each of the subscales and the total instrument in
7 this study population. The AIRS assesses the following domains: 1) facts about asthma,
8 2) nature of symptoms, 3) attitudes toward anti-inflammatory medications, 4) emotional
9 aspects of medication use, and 5) treatment expectations. Parents responded to items
10 on a 5-point Likert scale (Strongly Agree to Strongly Disagree). Items were scored (and
11 sometimes reverse scored) so that a higher score indicated closer agreement with the
12 professional model of asthma and its management as articulated in the national
13 guidelines put forward by the NAEPP Expert Panel 2. The subscales, as well as sample
14 questions and Cronbach's alphas, are presented in Table 1.

15 *Parent/Health Care Provider Relationship.* Existing literature would suggest that the
16 parent/health care provider relationship has an important impact on both parental beliefs
17 and asthma management strategies (IOM, 2002; Yoos, Kitzman, & McMullen, 2003).
18 The Parent/Health Care Provider Relationship instrument consisted of 10 items
19 reflecting provider availability, sensitivity, and communication skills. Cronbach's alphas
20 and sample questions are also presented in Table 1.

21 ***Dependent Variable***

22 *Adequacy of the Medication Regimen.* In clinical practice, the choice of medications,
23 the frequency of visits, and decisions to refer to a specialist are all based on the

1 assessed asthma severity. The medication regimen variable we developed consists of
2 two components: 1) an assessment of current clinical status and 2) an evaluation of the
3 adequacy of the medication regimen in relationship to clinical status (Yoos et al., 2006).
4 To assess clinical status, we used a structured assessment of asthma severity/control
5 reflecting NAEPP criteria for severity classification [assessing daytime and nocturnal
6 symptoms, activity limitations, exacerbations, and beta₂ agonist use] (NAEPP, 1997).
7 Others have empirically established that the same dimensions also appropriately
8 assess control for the child already on medications and provide a clinically useful tool
9 that relates to asthma morbidity (Vollmer, 2004). Lung function tests were not obtained;
10 however, they are also rarely available in the general pediatric setting.

11 Parents were asked to report all medications that their child was currently using.
12 Medications were then categorized into “anti-inflammatory medications,” “rescue
13 medications,” and “other” medications. NAEPP guidelines that recommend anti-
14 inflammatory medication use for children with persistent symptoms were used to
15 evaluate the adequacy of the regimen (NAEPP, 1997, 2002). Regimen categories were
16 ordered in such a way that a higher number indicated a less adequate regimen. The
17 classification system for the regimen is summarized in Figure 1.

18 Children who had no or mild intermittent symptoms during the three months prior
19 to the interview and were not taking anti-inflammatory medications were classified as
20 currently having “*Mild Asthma*” and were removed from further analyses related to the
21 adequacy of the medication regimen. Children who had no or mild intermittent
22 symptoms and whose parents reported their using anti-inflammatory medications were
23 classified as being under good control and having an “*Optimal Regimen.*” Children who

1 had persistent symptoms despite reported anti-inflammatory medication use were
2 classified as having a “*Suboptimal Regimen.*” Children who had persistent symptoms
3 and the parent reported no anti-inflammatory medications were classified as being on
4 an “*Inadequate Regimen.*”

5 Additional background characteristics hypothesized potentially to modify a
6 relationship between background characteristics, parental beliefs, and the adequacy of
7 the medication regimen were evaluated for inclusion in the model for analysis. These
8 variables included household triggers and beliefs about when to contact the health care
9 provider. See Figure 2 for the study’s conceptual model.

10 **Statistical Analysis**

11 Descriptive statistics were calculated for the AIRS instrument and each of the
12 subscales as well as the Parent/Health Care Provider Relationship instrument.
13 Preliminary analyses were carried out to inform the development of the primary models.
14 These analyses included the examination of differences among group means based on
15 race/ethnicity, poverty, and parental education as well as examination of the predictors
16 of parental beliefs and an adequate medication regimen using standard regression
17 models. Theory and these exploratory analyses of relationships informed decisions
18 regarding variables for possible inclusion in the final structural model.

19 To examine the relationships among the variables in the model fully, including
20 possible causal relations, we estimated and tested jointly two simultaneous equations.
21 The first equation for regimen included parental beliefs as an endogenous variable
22 predicting regimen as well as a set of exogenous predictors determined as described
23 above and from examination in the structural model. The second equation for parental

1 beliefs included as predictors a second set of exogenous variables. Figure 2 and the
2 tables in the results section show the variables included in the final model. Risk was
3 included in both equations in the primary model using the constructed variable involving
4 both race and poverty status after an examination of various alternative specifications of
5 these variables.

6 We obtained estimates by ordinary least squares (OLS) and full information
7 maximum likelihood (FIML) as well as other methods such as three stage least squares
8 (3SLS). Tests of indirect effects were obtained by both the delta (Henderson & Ceci,
9 1992) and bootstrapping methods. Tests based on the delta method are presented in
10 the results section. Rather than estimating predictors of illness beliefs and an adequate
11 medication regimen separately, structural equation modeling considers the model as a
12 system of equations and estimates parameters jointly. The estimates do not differ
13 greatly by method of estimation, and the simpler OLS estimates are shown in the
14 results.

15 We also examined a model in which race and poverty status and their interaction
16 were included in the regimen equation and the regressions of parental beliefs on
17 regimen were specified for the 4 race-by-poverty groups.

18 RESULTS

19 *Participants*

20 Of the 277 potentially eligible children based on the practices' datasets and able
21 to be contacted, 49 (18%) families refused, for a final study population of 228 families.
22 Demographic characteristics of the sample are presented in Table 2. The sample was
23 diverse in race, age of the child, socioeconomic status, and educational level of the

1 parent. Approximately half of the participants were from minority populations, primarily
2 African American. Younger and older school-aged children were equally represented,
3 as were poor and non-poor families. More than half of the parents had greater than a
4 high school education, and approximately 14% had less than a high school education.
5 All levels of asthma symptom severity were represented.

6 ***Parental Illness Representation and the “Professional” Model of Asthma***

7 Descriptive information for the total AIRS instrument and its subscales is
8 presented in Table 3. Possible scores ranged from 1 to 5, with a higher score indicating
9 greater agreement with the professional model of asthma as articulated by the NAEPP
10 Expert Panel 2 guidelines.

11 Discrepancies between the lay and professional models of asthma are apparent
12 in a number of the subscales. The lowest level of agreement was in the subscale
13 related to the nature of symptoms. The professional model is that asthma is generally a
14 chronic illness and the disease is present even when symptoms are controlled and
15 currently not apparent. Parents described asthma as episodic, acute, and/or
16 uncontrollable symptoms. While NAEPP Expert Panel 2 guidelines stress the
17 importance of treating even mild or moderate symptoms if they are persistent, parents
18 primarily focused on acute exacerbations and more severe symptoms in their symptom
19 evaluation. Half would not call the health care provider for cough, and 42% would not
20 call for wheezing. Another lower- scoring domain was attitudes toward anti-inflammatory
21 medications, with parents expressing negative attitudes toward these medications and
22 concern about side effects. Twenty-seven percent of parents thought medications
23 should be a last resort in treatment, 33% believed that one should try to get children off

1 these medications as quickly as possible, and 71% worried about side effects. Parents
2 also had lower treatment expectations than the professional community. Nearly half of
3 the parents expected that asthma would affect their child's school attendance, and 50%
4 worried that something terrible would happen to their child if they were not present. It is
5 interesting to note that the highest score (indicating the closest match to the
6 professional model) was in the subscale related to "facts about asthma." Parents had
7 fairly accurate factual knowledge about pathophysiology, pharmacology, and triggers.
8 The Parent/Health Care Provider relationship was rated as quite positive and beliefs
9 about when to contact the health care provider were relatively consistent with the
10 professional model. Nevertheless, 39% of the parents reported that they would not
11 contact the health care provider for night-time symptoms occurring more than twice a
12 month or if the child needed rescue medication more than twice a week (37%). Expert
13 Panel guidelines state that both of these symptoms indicate the need for a corrective
14 action in terms of the medical regimen.

15 **Structural Model Evaluation**

16 In the examination of the relationships among the variables influencing parental
17 illness representations and asthma management practices (appropriate medication
18 regimen) we hypothesized that demographic characteristics, formal and informal
19 asthma education, and the parent/health care provider relationship would affect asthma
20 management both directly and indirectly through AIRS. Experience with asthma and the
21 child's symptom evaluation and report were hypothesized to impact parental beliefs
22 directly and asthma management only indirectly through their effect on the parental
23 illness representation. (See Figure 2)

1 Table 4 shows the OLS estimates for the final structural model. Variables
2 included in the model accounted for 41% of the variance in parental beliefs and 18% of
3 the variance in the child's medication regimen. Fit indices indicated that the
4 hypothesized model fit the empirical data well: $\chi^2=3.13$, $p = .79$, CFI =1.00, TLI =1.09,
5 RMSEA=0, SRMR=.01. The demographic risk variable accounting for minority race and
6 poverty ($p .005$) and parental education ($p <.0001$) had direct effects on the parental
7 illness representation, with those at greatest risk having illness representations most
8 discordant with the professional view. The child's understanding of symptoms that
9 represented asthma ($p .02$) as well as the parent/health care provider relationship
10 ($p<.0001$) also had a direct effect on the illness representation. Although asthma
11 education provided by the health care provider was a significant predictor of parental
12 beliefs in a simple preliminary model including only demographic characteristics and the
13 child's symptom severity, formal asthma education and informal sources of information
14 such as advice from others and experience with asthma did not have an effect on the
15 parental illness representation in the full model analysis.

16 The parental illness representation had a significant direct effect on the
17 medication regimen ($p .05$). Demographic risk also had a direct effect on the
18 medication regimen, with those at greatest risk having less adequate regimens ($p .006$).
19 Formal asthma education had a positive effect on the medication regimen ($p .02$), while
20 informal advice seeking was associated with a less adequate medication regimen
21 ($p .0003$). While the parent/health care provider relationship did not have a direct effect
22 on regimen, there was a trend for its impact ($p .06$) as there was for the impact of

1 demographic risk (p .10) and the parental educational level (p .07) to be mediated by
2 the parental illness representation (Table 4).

3 In the model with regressions of AIRS on regimen specified separately by the 4
4 race-by-poverty groups, there was an indication that the primary effect of AIRS on
5 regimen was for the low risk group.

6 **Discussion**

7 Results from this study indicate that clinicians and families may think about
8 asthma and its treatment quite differently. Areas of greatest divergence were around
9 the nature and interpretations of symptoms, treatment expectations, and attitudes
10 toward anti-inflammatory medications. A key element for optimal disease management
11 as articulated by the Expert Panel 2 is accurate symptom assessment and ongoing
12 monitoring (NAEPP, 1997). The concept of chronicity is critical to patient understanding
13 of the need for daily preventive medications (Halm, Mora, & Leventhal, 2006;
14 Handelman, Rich, Bridgemohan, & Schneider, 2004). Parents, in this sample, viewed
15 asthma as episodic, unpredictable, and not readily controlled. Persistent, but somewhat
16 less dramatic symptoms such as nighttime cough, or symptoms that could be managed
17 with the use of short-term bronchodilators (even if frequent use was required) were not
18 viewed as poor control or requiring a contact with the health care provider (Yoos et al.,
19 2005). Worries about daily anti-inflammatory medications were also abundant.
20 Although the 2002 Expert Panel Updates again indicate that strong evidence
21 establishes the efficacy and relative safety of these agents, a significant proportion of
22 our families felt that these medications should only be used as a last resort and that one
23 should try to discontinue these medications as soon as possible.

1 The key process for optimal disease management in the Expert Panel guidelines
2 is an interactive partnership between the patient (parent) and the health care provider.
3 In order for this partnership to work, the participants need to have a common
4 understanding of the nature of asthma, its symptoms, achievable treatment goals, the
5 role of medications, and self-management practices. Realistically, patients are largely
6 responsible for the day-to-day management of their chronic illnesses. To improve the
7 quality of that management, clinicians need to help to prepare them for this task and
8 work to create a more patient responsive health care system (Frist, 2005). It is clear
9 from this research that patients and health care providers may start with marked
10 differences in their basic assumptions about the disease and its treatment. Decades of
11 educational research in diverse other domains shows that simply superimposing an
12 educational program, without identifying and acknowledging existing beliefs, is likely to
13 be ineffective (Carey, 1986). In this study population, the asthma education that was
14 provided did not impact the parental belief system, although it did positively impact the
15 regimen. Our prior analysis of the content of the formal asthma education reported by
16 the caregivers indicated that much was focused on practical skill acquisition such as
17 inhaler use and that the least discussed areas were those related to beliefs such as
18 treatment goals (McMullen et al., in press).

19 Successful educational messages need to begin with eliciting the patient's
20 (parent's) current knowledge and beliefs, identifying differences between that model and
21 the professional model, and then clearly communicating a commitment to participatory
22 decision-making and collaboration in the treatment decisions (Epstein et al., 2004). This
23 research indicates that identifying the parental interpretation of symptoms, concerns

1 about medications, and expectation for treatment outcomes are particularly important
2 content areas for focused discussion for the busy clinician with limited available time.
3 Structured assessments of severity/control are indicated and the decision-making
4 process for assessment and subsequent treatment needs to be shared with families.
5 The child deserves to be a partner in these discussions, as their symptom
6 understanding significantly impacted parental beliefs. Both the actual content of asthma
7 education and the parent/health care provider relationship had an important impact on
8 outcomes.

9 Accesses to health care, insurance issues, the appropriateness of health care
10 delivered, and broader societal issues have all been recognized as important barriers to
11 optimal disease management. The recent report by the Institute of Medicine has
12 specifically identified interpersonal processes such as patient preference and patient–
13 clinician communication as other areas to be targeted for quality improvement and
14 research to address health disparities (IOM, 2002). This research highlights some
15 modifiable barriers and potential processes that may enhance patient-clinician
16 communication in the treatment of asthma.

17 **Limitations:**

18 Despite the important differences related to race and/or poverty identified, the
19 research described here may nevertheless represent a conservative bias. All of the
20 participant families had a medical home and nearly all had health insurance. Chronic
21 illness care is complex, and multiple factors affect an appropriate medication regimen
22 for the patient with asthma. It is important to note that patient-related factors only
23 accounted for 18% of the variance in the medication regimen outcome. These findings

1 certainly support the Chronic Care Model (Wagner et al., 2001) that proposes that true
2 quality improvement in chronic illness care requires a full range of interventions that
3 include health care provider and health care system change as well as patient change.
4 Provider decision-making and health care system issues were not measured in this
5 parental model.

6 **Summary:**

7 This report documents key areas of discrepancy between the professional and lay models
8 of asthma. We conclude that parental beliefs about what constitutes asthma symptoms,
9 management of symptoms, expectations for treatment outcomes, and medication attitudes are
10 important areas of focus for the busy clinician. Furthermore, the complex and chronic nature of
11 asthma calls for a restructuring of our current system of care delivery.

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Figure 1. Medication Regimen Classification System

Regimen Categories	Report of Persistent Symptoms*	Report of Anti-inflammatory Medications
Mild Asthma (n = 28)	NO	NO
Optimal Regimen (n = 27)	NO	YES
Suboptimal Regimen (n = 109)	YES	YES
Inadequate Regimen (n = 64)	YES	NO

* based on NAEPP criteria for *persistent* asthma in the prior 3-month period

Figure 2. Conceptual Model

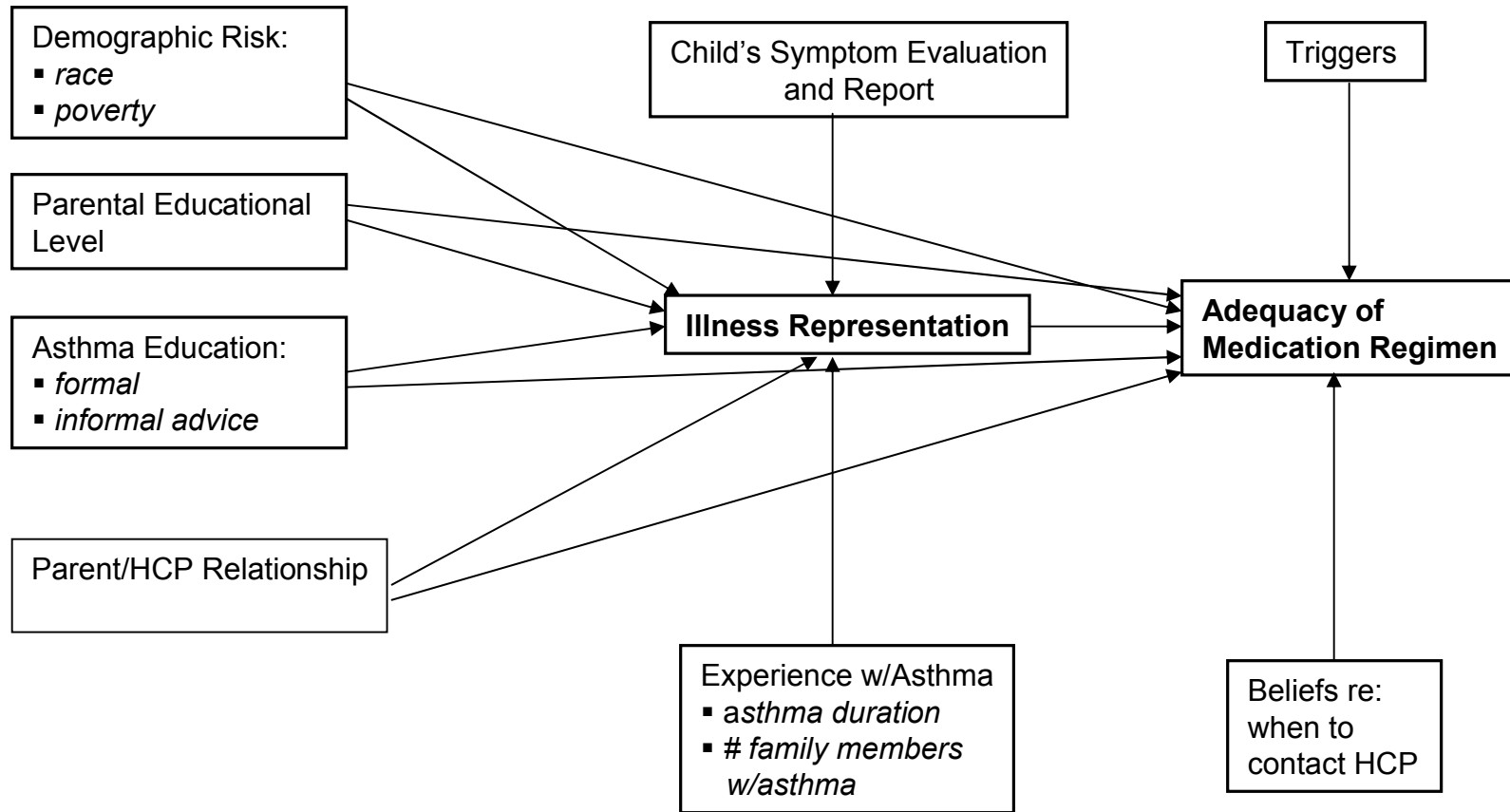


Table 1. Sample Items and Cronbach's alphas for the assessment of parental illness beliefs and the parent/health care provider relationship

SUBSCALE	ALPHA	SAMPLE ITEMS
Total Asthma Illness Representation Scale (AIRS[®])	.84	
AIRS Subscales		
<ul style="list-style-type: none"> ▪ Attitudes toward Anti-inflammatory Medications 		<p>Parents should try to get their children off inhaled steroids as soon as possible</p> <p>I worry about the side effects of inhaled steroids</p> <p>After a child has taken inhaled steroids for a while, they won't work when they are really needed</p> <p>Using inhaled steroids should be a last resort</p> <p>I'm worried my child could become addicted to inhaled steroids</p>
<ul style="list-style-type: none"> ▪ Treatment Expectations 		<p>I believe my child can be symptom-free most of the time (<i>r</i>)*</p> <p>I expect that asthma will not affect my child's school attendance (<i>r</i>)*</p> <p>Children with asthma can expect to have symptoms several times a week</p>
<ul style="list-style-type: none"> ▪ Facts about Asthma 		<p>Asthma is caused by weak lungs</p> <p>Inhaled steroids fight inflammation of the lungs (<i>r</i>)*</p> <p>Exposure to allergens can make an episode worse (<i>r</i>)*</p> <p>Asthma is caused by exposure to winds/drafts</p> <p>Treating with medication now may prevent complications later (<i>r</i>)*</p> <p>Children are more likely to outgrow asthma if they only take medications when they are in real trouble with their asthma</p>

<ul style="list-style-type: none"> ▪ Nature of Symptoms 	<p>Asthma symptoms are unpredictable</p> <p>Asthma symptoms come on suddenly</p> <p>Asthma cannot be controlled</p> <p>It's hard to figure out how bad an attack is</p>
<ul style="list-style-type: none"> ▪ Emotional Aspects of Medication Use 	<p>My child is reluctant to use an inhaler in front of other children</p> <p>My child thinks that taking daily medicine is a hassle</p> <p>Taking daily medication makes a child feel different from other children</p>
<p>Beliefs about when to contact the Health Care Provider</p>	<p>.76 If my child had asthma symptoms more than 2 times per week, I would contact my child's health care provider <i>(r)*</i></p> <p>If my child needed to use Albuterol more than 2 times per week, I would call my child's health care provider <i>(r)*</i></p> <p>If my child was limited in gym or physical activity, I would call my child's health care provider <i>(r)*</i></p>
<p>Parent/HCP Relationship</p>	<p>.82 When I call the doctor's office, they understand my concerns <i>(r)*</i></p> <p>My child's health care provider understands how my child's asthma affects our family's day-to-day life</p> <p>My health care provider's office hours are convenient for me <i>(r)*</i></p> <p>I see a different health care provider every time I go to the office</p> <p>I worry about "bothering" the doctor when I have questions or worries</p>

(r) = reverse scored*

Table 2. Demographic Characteristics of the Sample

Demographic Characteristic	N	%
Maternal Race		
Black	84	37
White	123	54
Hispanic	18	8
Other	3	1
Age of Child		
5–8 yrs.	98	43
9–12 yrs.	130	57
Poor / Non-Poor*		
Poor	103	45
Non-poor	124	54.5
Self-Pay (No Insurance)	1	0.5
Educational Level of Parent		
< High School	31	14
High School	68	30
>High School	129	56
Clinical Practice Setting		
Clinic	79	35
Private Practice	149	65
Geographic Location		
Urban	100	44
Suburban	115	50
Rural	13	6
Symptom Severity of Child**		
Mild Intermittent Symptoms (no medications)	28	12
Mild Intermittent Symptoms (on medications)	27	12
Mild Persistent	86	38
Moderate	55	24
Severe	32	14

* Based on Medicaid and SCHIP eligibility

**Based on NAEPP criteria

Table 3. Mean Scores for the Instruments for the total sample

Instrument	Mean (SD)
Total AIRS Instrument	3.43 (.37)
Parental Attitudes Toward Anti-Inflammatory Use	3.22 (.62)
Treatment Expectations	3.23 (.67)
Facts About Asthma	3.90 (.39)
Nature of Symptoms	3.01 (.64)
Emotional Aspects of Asthma	3.31 (.65)
Beliefs about when to contact the Health Care Provider	3.70 (.83)
Parent/Health Care Provider Relationship	4.10 (.50)

Table 4. Direct, Indirect, and Total Effects of variables on the Adequacy of the Medication Regimen

Variables and their effect	β	p-value	R ²	
Direct Effect on Illness				
Representation				
Demographic Risk (race, poverty)	-0.159	.005	.41	
Parental education	0.050	<.0001		
Formal Asthma Education	-0.003	.46		
Informal Asthma Education	-0.034	.46		
Parent/Provider Relationship	0.253	<.0001		
Experience with asthma				
➤ # of family members with asthma	-0.023	.39		
➤ asthma duration	0.0003	.61		
Child Factors				
➤ asthma symptoms for child	-0.313	.02		
➤ symptoms child would tell parent	0.091	.54		
Direct Effect on Regimen				
Demographic Risk (race, poverty)	0.315	.006	.18	
Parental education	0.001	.96		
Formal Asthma Education	-0.016	.02		
Informal Asthma Education	0.332	.0003		
Parent/Provider Relationship	0.04	.67		
Illness Representation	-0.285	.05		
Beliefs re: when to contact health care provider	0.075	.16		
Triggers	0.03	.41		
Indirect Effect of Illness				
Representation on Regimen				
Demographic Risk (race, poverty)	0.045	.10		
Parental education	-0.014	.07		
Formal Asthma Education	0.0007	.49		
Informal Asthma Education	0.01	.49		
Parent/Provider Relationship	-0.072	.06		
Experience with Asthma				
➤ # of family members with asthma	0.007	.43		
➤ asthma duration	-0.0001	.62		
Child Characteristics				
➤ asthma symptoms for child	0.089	.13		
➤ symptoms child would tell parent	-0.026	.56		

Total Effects

Risk (race, poverty)	0.36	.002
Parental education	-0.013	.55
Formal Asthma Education	-0.015	.02
Informal Asthma Education	0.342	.0002
Parent/Provider Relationship	-0.028	.77
