

# Self-reported Adherence, Management Behavior, and Barriers to Care After an Emergency Department Visit by Inner City Children With Asthma

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**ABSTRACT.** *Objective.* The inability to adhere to a prescribed therapeutic program for the treatment of a chronic disease may be responsible in part for continued disease activity. This problem may be more of an issue in the treatment of asthma, a common, potentially lethal chronic condition in which the lack of symptoms may be interpreted as remission. Adherence was one of the key areas of interest for the National Cooperative Inner-City Asthma Study. The focus of this study was to identify those issues reported by families that could adversely affect their adherence to an asthma care program. The identification of barriers to adherence could then form the basis of a successful intervention program. This study describes barriers to adherence, asthma management behavior, and self-reported adherence.

*Methods.* Patients presenting during an acute attack of asthma at an emergency department (ED) were recruited for this study. The medical record of the ED encounter was abstracted and compared with information that was obtained during a baseline interview 3 to 5 weeks later. During the baseline interview, parents were asked about health care behaviors related to adherence.

*Results.* There were 344 children 4 to 9 years of age living in inner city census tracts in the study. Four areas of adherence (medicine use, appointment-keeping, emergency actions, and asthma attack prevention) were investigated. The parental report of medications prescribed at the ED and the information on the abstracted ED report agreed 94.9% of the time for the  $\beta$ -agonists, 86.8% for steroids, and 69.4% for cromolyn. Among respondents, 85.4% of parents reported that they are able to follow the ED recommendations almost all of the time; side effects of medicines were a concern for 81.1% of caretakers who were adherent and for 89.5% of caretakers who were nonadherent. Doubts regarding the usefulness of medications occurred in 34.4% of those considered adherent and 54.2% who admitted nonadherence. Medications were forgotten some of the time by 45.2% of the children, and 52.8% tried to get out of taking medicine. Appointments for follow-up care were kept by 69% of those given an appointment in the ED, by an estimated 60.0% of those who were told specifically to call for an appoint-

ment, and by an estimated 25.2% of those who were neither given an appointment nor told specifically to make one. Only one third of parents report that they were able to keep the child away from known asthma triggers nearly all of the time. Approximately half avoided allergens; however, only 37.5% reported avoidance of cigarette smoke. The use of preventive medicines occurred in 23.5%. Using a medicine and taking the child to a physician were reported as the first or second action during an acute attack of asthma by 72.1% of respondents.

*Conclusions.* Adherence to an asthma-management program involves a number of areas: medication, appointment-keeping, prevention, and applying an emergency plan of action. Barriers to adherence may exist in one or all four of these areas, leading to ineffective control of asthma. Recommendations are made for improving the patient-physician partnership to improve adherence. *Pediatrics* 1998;101(5). URL: <http://www.pediatrics.org/cgi/content/full/101/5/e8>; *asthma, adherence, inner city children.*

ABBREVIATIONS. NCICAS, National Cooperative Inner-City Asthma Study; ED, emergency department.

Asthma morbidity and mortality have increased disproportionately among children with asthma who live within an inner city environment.<sup>1-5</sup> The specific reason(s) for this situation is unknown. To better understand and address this issue, the National Cooperative Inner-City Asthma Study (NCICAS) was established. The tasks of this effort were twofold: 1) to determine what factors are associated with asthma morbidity in inner city children, and 2) to develop an intervention to address these factors. Nonadherence to a prescribed therapeutic program is one of the purported factors contributing to asthma morbidity and mortality in all populations<sup>6</sup> and is likely to contribute to asthma morbidity in inner city children with asthma. Therefore, one of the key areas of investigation in the NCICAS was compliance or adherence to an asthma management plan by patients and families.

NCICAS sought not only to discover if there was adherence, but also to identify what factors affected adherence. The successful management of any disease state must include the essential component of adherence to the therapeutic program. The term adherence has evolved from the older problem of compliance, which is simply the extent to which a patient takes medication or follows recommendations. How-

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ever, adherence is a more dynamic process that evolves from a process of collaboration between the patient and/or caregiver and the health care provider. Through this process, the physician and patient establish and implement a medical program that is mutually agreed on and achievable. Thus, the adherence process puts more burden on the clinician to encourage behaviors that increase compliance and enhance the therapeutic effect of the treatment program.

Adherence may be more problematic in asthma because of the variable nature of the disease. Asthma is a chronic condition with episodic acute exacerbations. Exacerbations may occur only when patient-specific triggers are encountered. Long periods may pass without any disease activity. However, the potential for an acute, severe exacerbation is always present. The nature of the disease requires a therapeutic program that involves a number of potentially difficult issues. Patients with asthma need to know how to prevent asthma attacks and what to do when an attack occurs, and have an understanding of the medications used for asthma. They also need interval visits to their health care providers to monitor the disease and to reinforce all these concepts of asthma management. Few medical conditions require such a degree of vigilance. Therefore, it is easy to understand why adherence may be difficult.

When theophylline levels are used as a measure of adherence in asthma, 30% to 73% of patients in the studies are found to be within a therapeutic range, indicating that the drug has been taken as prescribed.<sup>7-9</sup> Newer technologies using microprocessors have shown similar results, with estimates of adherence ranging from 3% to 80%.<sup>10-14</sup>

There also does not seem to be a difference in adherence levels with respect to the population studied; overall estimates for adherence in both the pediatric and the adult asthma populations are ~50%.<sup>15-23</sup>

The measurement of adherence to a medical program has a number of problems. Current trends in drug therapy involve agents that are not easily measured. Newer electronic devices tend to be expensive and untested in a number of populations. However, one commonly used measure of adherence, self-reported adherence, is not affected by the type of medication used, simple to administer, relatively noninvasive, inexpensive, and well established. The self-report of adherence may have problems with validity. This problem has been described regarding well established self-report instruments used to measure adherence.<sup>24,25</sup>

Given the fact that the vast majority of individuals are nonadherent at some time, it becomes important to discover the reasons for nonadherence. When questions are presented in a nonthreatening manner, parents may begin to report concerns they have about medical management programs. Knowledge of what makes it more difficult for inner city families to adhere to a therapeutic regimen can guide the development of interventions. Speculations on the reasons for adherence problems have included major areas such as 1) nature of the illness itself, 2) physi-

cian behavior and attitudes, 3) therapeutic settings and the continuity of care, 4) complexity of the medication program, and 5) characteristics of the patient. Reasons that adults have given for not following a prescribed treatment program include forgetting (48%), inconvenience (11%), side effects (6%), and medication taste (1%).<sup>26</sup> Other reasons given for nonadherence have included lack of time, denial of illness, the occurrence of side effects, fear of dependency, and depression.<sup>27</sup>

Similar issues may pose barriers to adherence for inner city children with asthma. Children may be required to take numerous medications at difficult intervals. Parents may experience concerns about potential side effects and even doubt about the efficacy of the medication. Children may refuse to take medication or try to avoid its use. Parents also may have difficulty making follow-up appointments for continued care because of scheduling barriers, impediments in the patient-physician relationship, and financial barriers. Finally, parents may fail to carry out appropriate asthma management and preventive strategies because of inadequate knowledge or inaccurate beliefs.<sup>28</sup>

The purpose of this study was to address the issue of adherence in a comprehensive manner in a population at elevated risk for asthma morbidity and mortality. The perspective here is that of the parents and patients and not of the physicians seeing these children in an acute care setting. Parental perceptions of problems in the areas of medication-taking, asthma attack management, asthma prevention, and appointment-keeping were assessed in a population of children who were recruited for the NCICAS in an emergency department (ED) during an episode of acute asthma. Adherence may be enhanced if physicians are aware of the issues that families have regarding programs prescribed for them.

## METHODS

### Procedures

The NCICAS was undertaken in response to the pressing public health problem of increasing asthma morbidity among children in the inner city. NCICAS focused on four broad areas—allergens and airway irritants in the home environment, access to medical care, adherence, and psychosocial factors—that were seen as potential contributors to asthma morbidity in the inner city. Participants were interviewed about these topics during a 2½-hour baseline interview and contacted by telephone regarding asthma symptoms and health care use at 3, 6, and 9 months after the baseline interview.

To obtain a sample with a broad range of characteristics that might be related to asthma morbidity, 1528 children with asthma and their parents were recruited from EDs and community clinics in eight major metropolitan inner city areas. The children had to be between 4 and 9 years of age, from English- or Spanish-speaking families living in a census tract in which at least 20% of the households had incomes below the federal government's poverty line for 1990. To meet the study definition of asthma, the child had to have physician-diagnosed asthma and asthma symptoms lasting >3 days within the past 12 months or cough, wheeze, or shortness of breath that lasted >6 weeks during the past 12 months. A detailed discussion of the design and methods for the first phase of NCICAS have been described elsewhere.<sup>29</sup>

This study of self-reported adherence, management behavior, and barriers to care focuses on 344 of the 378 children enrolled in NCICAS while they were in the ED for an acute asthma exacerbation. Eighteen children were excluded because they had not

been told by a physician that they had asthma, and 16 did not complete the adherence data form. After study eligibility was determined by an on-site interviewer, parental consent and child assent were obtained. The medical record of the ED visit was abstracted for information about the history of the attack, the treatments given, and the medications prescribed for home use, and whether a follow-up appointment was given or suggested. An appointment was made for the child and parent to complete a baseline interview 3 to 5 weeks after the ED visit.

The parent baseline interview asked about demographic characteristics and the health of the child, asthma responsibility and knowledge, health care access, psychological adjustment, and adherence. The parent was asked to recall the child's health service utilization for asthma over the previous 3 months and asthma symptoms and difficulties with sleep and play during the previous 2 weeks. In a separate interview from the parent, the child was asked questions about asthma knowledge, responsibility for asthma management, self-competence, adherence, medication use, and cognitive competence.

## Measures

The adherence portion of the baseline interview was modeled on and contained questions from the Asthma Self-Management Questionnaire,<sup>30</sup> which focused on health care behaviors and barriers to adherence. The selected questions covered three areas: 1) the use of medications prescribed, 2) the use of an emergency plan of action for an acute attack, and 3) the application of avoidance measures for asthma triggers. Questions also were asked about appointment-keeping, what therapy had been recommended at the ED visit, problems with the child taking medications, attitudes toward giving medications, and whether the respondent had concerns about side effects or the efficacy of the medications prescribed. Respondents also were asked to describe what they did to prevent the child from having an attack. The answers to these open-ended questions were volunteered by the respondent and recorded by the interviewer. Questions also were asked about follow-up from the ED, whether a visit had been scheduled or the parent had been told to make a follow-up visit, and barriers to making and keeping the follow-up appointment. This approach did not measure adherence per se. To do this would have required full knowledge of the physician side of the interaction. This study examines only the patient side of the clinical encounter and factors that may interfere with effective asthma management. This approach investigates asthma management behaviors through the tool of self-report in four major areas that were considered to be key components to successful asthma management. In each of these areas of asthma management—medication use, appointment-keeping, avoidance of asthma triggers, and emergency actions—patient and family perspectives and behaviors were examined. Potential barriers that patients and families have that prevent them from following through with recommendations were identified.

## Analysis

Descriptive statistics were used to provide frequencies on various characteristics of the population.  $\chi^2$  Tests were used to test the significance of the differences between groups on categorical variables. Significance was set at  $P < .05$ .

## RESULTS

### Sample Characteristics

Table 1 shows the demographic data on the 344 children recruited from the EDs. Also included is health care utilization in the 3 months before the baseline interview and recent disease activity. The average age of the children enrolled was 6.3 years, and 61.6% were boys. Within the study sample, 66.2% were African-American and 25.0% were Hispanic. There was a family history of asthma in 55.7%, family income was  $< \$15\,000$  in 56.5%, and 28.4% of the primary care providers/respondents were married. The mother of the child was the respondent in

**TABLE 1.** Sample Characteristics ( $N = 344$ )

Demographics	
Age, mean ( $\pm$ SD)	6.3 ( $\pm$ 1.7)
Age $< 6$ , %	36.0
Male, %	61.6
African American, %	66.2
Hispanic, %	25.0
At least one smoker in household, %	54.7
Family history of asthma, %	55.7
Income $< \$15\,000$ , %	56.5
Caretaker married, %	28.4
Respondents	
mother %	86.6
father %	4.7
Health service utilization for asthma in the previous 3 months	
Hospitalizations (mean $\pm$ SD)	0.26 $\pm$ 0.52
Unscheduled visits, (mean $\pm$ SD)	1.36 $\pm$ 1.05
At least one hospitalization, %	22.4
More than one unscheduled visit, %	34.3
Wheezing in the previous 2 weeks days (mean $\pm$ SD)	3.23 $\pm$ 3.86

86.6% of the baseline interviews and the father in 4.7%.

Asthma severity in this population ranged from moderate to severe. Table 1 also provides morbidity information as characterized by two measures of disease activity, health service utilization and recent wheezing. During the 3 months before the baseline interview, hospitalizations occurred in 22.4% of the children. Unscheduled visits attributable to asthma occurred more than once in 34.3%. Wheezing was an active problem in the 2 weeks before the baseline visit, with an average of 3.23 days of symptoms during this interval.

### Adherence to Medications

The description of medication adherence involved several assessments. The first was the concordance between discharge instructions as noted on the ED chart and the parents report at the baseline interview of medication prescribed at the ED visit. The second area was the parent's self-report of adherence. The third area involved the identification of factors that may contribute to nonadherence.

Table 2 shows the concordance between the baseline visit and the ED report of medication use. ED

**TABLE 2.** Comparison of Parents Report of Medication Prescribed and Medications Recorded on the ED Chart

Prescribed at ED based on chart review ( $N = 292$ )	Patients (%)
$\beta$ -Agonists	74.3
Xanthines	5.1
Steroids	46.6
Oral steroids	43.8
Inhaled steroids	4.1
Cromolyn	16.8
Percent of those prescribed at ER who reported the medicine at baseline	
$\beta$ -Agonists ( $n = 217$ )	94.9
Xanthines ( $n = 15$ )	93.3
Steroids ( $n = 136$ )*	86.8
Oral steroids ( $n = 128$ )	84.4
Inhaled steroids ( $n = 12$ )	91.7
Cromolyn ( $n = 49$ )	69.4

\* There were four children on both inhaled and oral steroids.

**TABLE 3.** Self-assessment of Adherence to Medications

	Adherent N = 227	Nonadherent N = 86	
Age of child (y)	6.3	6.4	p = .84
Average number of medicines	2.4	2.3	p = .55
Taking three or more medicines	42.3%	38.4%	p = .53
Using oral, inhaled, and nebulized medicines	37.9%	51.2%	p = .04
Have some concerns about side effects	81.1%	89.5%	p = .08
Have some doubts about usefulness	34.4%	54.2%	p = .002
Sometimes worries that the child is getting too much medicine	37.6%	47.7%	p = .11
Sometimes feels that they are not getting enough medicine	13.7%	14.0%	p = .96

charts were available for only 292 of the 344 children recruited from the ED. The ED charts noted  $\beta$ -agonists 74.3% of the time. At the baseline interview, 94.9% of those prescribed  $\beta$ -agonists reported using them. Methylxanthines were discharge medications for 15 children. Again, almost all of those parents (93.3%) also reported using this medication at the time of the baseline interview. The agreement between the self-report of medication use and the ED chart audit was less for the antiinflammatory agents. Steroid use (oral and inhaled) was in agreement 86.8% of the time and cromolyn use 69.4% of the time.

The self-assessment of adherence to medications revealed that 85.8% had been able to follow all of the treatments prescribed by the doctor in the ED almost all of the time, 81.4% used all medicines as prescribed, and 78.5% of the caretakers of children who took regularly scheduled medicines had no problems ensuring that the child took the medicine at the correct time. Ninety-four percent had medicines at home to use in the event of an attack, and only 6.7% admitted to not filling a prescription.

Caretakers were considered to be adherent if they said they followed the treatments prescribed almost all the time and used all medicines as prescribed. There were 227 caretakers who met this definition (72.5% of the 313 who answered both questions). A comparison of these 227 caretakers with the 86 who admitted a problem is shown in Table 3. The nonadherent group differed significantly in having a more complicated medical program and in the occurrence of doubts regarding the usefulness of the medicine.

Children 6 to 9 years of age ( $n = 217$ ) reported their medication practices and adherence (Table 4). In this group, 178 (81.6%) reported that they were taking medicine for their asthma at the time of the interview. Chronic preventive therapy was reported by 49.4% of these.

Among the children who took medicine, 49.2% reported that they take medication on their own some or most of the time (Table 4). The children in this sample acknowledged more readily problems with adherence than did their parents. Forty-five percent indicated that they forgot to take their medication at least some of the time. The child's self-report on forgetting to take medicine did not correspond to parental reports regarding the child receiving medication on time. Almost half of the children admitted trying to avoid taking medicines. However, 73.1% of the children reported failure in

their efforts to avoid taking medicine, indicating that potential child nonadherence is mitigated by adult supervision. The children's reasons for not wanting to take medicine varied and included issues of bad taste, the need to change activities, difficulty in taking the medicine, and side effects.

**Appointment-keeping**

At baseline, parents were asked whether they were given a follow-up appointment before they left the ED or were told to call to make an appointment. If they had not been given an appointment, then they were asked whether they tried to make one and, if so, whether they were successful. If the appointment made, or given, was before the date of the baseline visit, then they were asked whether they kept the appointment. Because data on the keeping of appointments were not available for all parents, the probability of keeping an appointment was estimated by multiplying the probability making an appointment by the probability of keeping an appointment if the appointment was scheduled before baseline.

Ninety-eight parents (29.4%) reported that they were given an appointment at the time of the ED visit (Table 5). Sixty-nine percent of these 71 patients whose appointment was scheduled before the date of the baseline visit kept the appointment. One hun-

**TABLE 4.** The Children's Self-report of Adherence\* ( $N = 217$ )

	%
Takes any medicine for asthma now?	81.6
If taking any medicine now ( $N = 178$ )	
Takes asthma medicines every day even if no symptoms	49.4
Takes medicines when asthma symptoms begin	95.5
Forgets to take medicines some or lot of the time	45.2
Tries to avoid taking medicines some of the time	52.8
Took medicine within 7 days	84.9
Takes medicine on his/her own (some or a lot of the time)	49.2
Someone watches them take medicine (some or a lot of the time)	68.9
If tries to avoid taking medicine some of the time ( $N = 93$ )	
Ends up having to take it anyway (some or a lot of the time)	73.1
Why patient tries to avoid taking it?	
Makes patient feel funny	28.0
Tastes bad	46.2
Hard to take	31.2
Is a bother	52.7
Other	17.4

\* Questions were given to those 6 to 9 years of age.

**TABLE 5.** Appointment-keeping Behavior: Scheduling, Keeping an Appointment, and Reported Barriers to Making and Keeping Appointments

	Given an Appointment N = 98 29.4%	Told to Make an Appointment N = 133 39.9%	Neither Told nor Given an Appointment N = 102 30.6%
Tried to make an appointment	Not Applicable	104 (78.2%)	32 (31.4%)
Tried and made an appointment	Not Applicable	84 (63.2%)	29 (28.4%)
Appointment scheduled before baseline interview	71	60	18
Kept appointment	49 (69%)	57 (95%)	16 (88.9%)
Estimated percent making and keeping appointment	69.0%	60.0%	25.2%

dred thirty-three parents (39.9%) were told to make an appointment; 78.2% of these tried to make one and 63.2% were successful. Ninety-five percent of appointments scheduled before baseline were kept, so the probability of making and keeping an appointment is estimated to be 60%. Only 28.4% of the 102 parents who were neither given nor told to make an appointment made a follow-up appointment. For these parents, 88.9% of the appointments scheduled before baseline were kept, resulting in an estimated rate of making and keeping an appointment of 25.2%.

Barriers to making an appointment for a follow-up visit, as reported by the parents, also are noted in Table 6. The most common reason reported for not making a follow-up appointment was that the child was well. Other reasons reported frequently included lack of available appointments, not knowing that an appointment was needed, not being given an appointment card, a busy phone, a busy parent, and cost.

**Asthma Prevention**

Fifteen percent of the families seen in the ED during an attack indicated that they did not know what triggered the child’s asthma. In a self-assessment of adherence, one third reported that they were able to keep the child away from asthma triggers nearly all of the time. When parents were asked about preventive strategies, nearly half of the sample reported that

they tried to keep the child away from allergens (48.3%) (Table 7). Beyond avoidance of asthma triggers, caretakers reported limited strategies for asthma prevention. Sixty-two percent reported refraining the child from overexertion. Cigarette smoke exposure occurred in 54.7% of the households (Table 1), and fewer (37.5%) reported avoidance of cigarette smoke. The use of preventive medicine occurred in 23.5%. The caretakers almost never relied on potentially problematic preventive strategies such as advice from friends or the use of home remedies. Fifteen percent reported that their child’s physician had recommended obtaining a peak flow meter. Fewer than half of those individuals (6% of the total sample) actually obtained a meter. Only 6% of families reported possessing and using a peak flow meter as a part of their asthma prevention program.

**Emergency Plan of Action**

Parents were asked what they do when the child has asthma signs or symptoms or actually has an asthma attack (Table 8). Eighty-two percent of the respondents reported using an asthma medicine, and 64.2% went to a clinic or emergency room. The child was told to lie down or rest by 48.0% of parents. In addition, 15.4% of the parents gave fluids by mouth, and 13.4% reported calling a physician as a part of their emergency plan of action. Other responses, such as calling a hospital, performing breathing or relaxing exercises, attempting postural drainage, and

**TABLE 6.** Barriers to Appointment-keeping

Barriers to Making an Appointment	Told to Make Appointment, but Did Not Try		Told to Make Appointment, Tried, but Unsuccessful		Not Told to Make Appointment, and Did Not Try	
	N	%	N	%	N	%
Visit not necessary, child well	16	55.2	1	5.0	24	34.3
Did not know they should	0	0.0	0	0.0	14	20.0
Told to make one only if child is not well	0	0.0	1	5.0	4	5.7
Child improved	0	0.0	0	0.0	5	7.1
Already had an appointment	0	0.0	0	0.0	4	5.7
Subsequent ED visit occurred	1	3.4	0	0.0	2	2.9
Did not receive an appointment card	1	3.4	3	15.0	2	2.9
Did not know where to go	0	0.0	0	0.0	1	1.4
Phone was busy	1	3.4	2	10.0	0	0.0
Staff was rude	0	0.0	1	5.0	2	2.9
No available appointment	0	0.0	9	45.0	0	0.0
Cost	3	10.3	2	10.0	1	1.4
Parent too busy	3	10.3	0	0.0	0	0.0
Parent forgot	0	0.0	0	0.0	3	4.3
Parent ill at the time	1	3.4	0	0.0	0	0.0
Child was sick	1	3.4	1	5.0	2	2.9
Unknown	2	6.9	0	0.0	6	8.6
Total	29	100.0	20	100.0	70	100.0

**TABLE 7.** Parental Report of Prevention Strategies

What types of things do you do to prevent an asthma attack? ( <i>N</i> = 347)	%
Keep child from running or getting excited	62.5
Avoid known allergens	48.3
Avoid cigarette, pipe, and cigar smoke	37.5
Avoid bad weather; stay at home	36.9
Give asthma medicine	23.5
Give a lot to drink	8.7
Avoid strong odors (perfume, cleansers)	6.1
Keep away from sick children	3.5
Ask family or friends for help or advice	1.5
Use home remedies, herbs, teas	1.2
Peak flow recommendations	
Physician recommended	15.0
If recommended ( <i>n</i> = 52), obtained	42.3
If not obtained ( <i>n</i> = 30), was it because of cost?	33.3
If obtained ( <i>n</i> = 22), is it used?	90.9

**TABLE 8.** Parental Report of Management of Acute Asthma

What do you do when the child is having asthma signs or symptoms or is having an asthma attack? ( <i>N</i> = 344)	%
Give asthma medicine	81.7
Go to clinic or ED	64.2
Have child lie down or rest	48.0
Give fluids by mouth	15.4
Call physician	13.4
Call hospital	9.3
Have child do breathing or relaxing exercise	7.8
Do postural drainage	6.7
Put child in steam from sink, shower	3.2
Use home remedies, herbs, or teas	2.0
Ask family or friends for help or advice	2.0
Measure peak flow	1.2
Use medicines or call physician as first or second action	72.1

using home remedies, were reported <10% of the time. Seventy-two percent of the respondents used a medication or took the child to a physician as the first or second action in their response to an acute asthma event.

## DISCUSSION

Adherence in childhood asthma involves the collaboration of the parent, child, and physician in developing a mutually agreed on treatment plan that the parent and child are able manage and one that the physician knows will be effective. To understand this complex process, NCICAS developed a self-report questionnaire to assess adherence in the areas of medications, emergency plans, appointment-keeping, and asthma attack prevention. Our approach went beyond the traditional focus on medication use alone. We attempted to reveal the patient-related factors that affect adherence. The additional information gained regarding appointment-keeping, avoidance measures, and management of symptoms supports this multidimensional approach to the assessment of adherence. Thus, our approach holds promise for improving adherence and the quality of asthma care, more generally, by helping health care professionals to understand the patient's perspective.

In choosing to assess adherence via self-report, we confronted the problem of parents denying or minimizing nonadherence to present a more favorable

impression of themselves. Our data regarding medication adherence suggest that parents may have been susceptible to such social desirability biases. However, we gained a much more thorough understanding of this population than would have been obtained through biological assays or pill counts. From previous research, we know that parents and children with asthma are nonadherent, at least some of the time.<sup>21,23</sup> Characteristics of the disease, such as its episodic nature, make nonadherence with chronic medications more likely. Thus, the more interesting and important questions are how do families approach their management of the child's asthma and how do they think about adherence. Understanding the barriers, both personal and systemic, that contribute to nonadherence were critical to our approach, which culminated in the development of an intervention to reduce asthma morbidity in inner city children.

With respect to the specific findings, parents reported extremely high levels of adherence to asthma medication use. However, school children more readily acknowledged forgetting their medications or trying to avoid taking them. This pattern suggests that social desirability biases may make parents more reluctant to admit medication nonadherence. Conversely, parents believe children are more adherent than they truly are. Interestingly, children's self-reported nonadherence was reduced by close parental supervision. Specifically, among the children who reported trying to avoid taking their medications, nearly three fourths indicated that the adult caregiver(s) ultimately made them take it anyway.

As we had hypothesized in the development of our questionnaire, parents readily reported potential barriers to adherence. In particular, 40% were uncertain about the medication's usefulness, and >80% had concerns about side effects. In part, parent's concerns regarding medications may result from an incomplete understanding of the chronic nature of asthma and the need to take medications even in the absence of symptoms. Improved patient-physician communication with emphasis on the risks and benefits of asthma medications may diminish the saliency of these potential contributors to nonadherence.

Whether parents made or attended follow-up appointments after the ED visit was influenced strongly by whether the physician recommended that the parent schedule one. Fewer than one third of the parents who were not given or told to make an appointment subsequently scheduled one. Adherence with follow-up visits can be improved significantly by scheduling them at the time of the acute care visit. In addition, the child's lack of symptoms was the most commonly cited reason for not scheduling a visit. This finding suggests that parents may not understand the reason for continuing care or find these visits unnecessary in helping them manage their child's asthma. Although relatively uncommon, parents also noted institutional barriers to obtaining follow-up care such as the unavailability of appointments, difficulty getting through by phone, rude staff, and failure to receive an appointment card.

Thus, barriers to adherence exist both in the parent's understanding of optimal asthma care and in the system of health care available to these families.

In contrast to the high level of self-reported adherence with medications, parents reported greater difficulties avoiding triggers and allergens. Only 37.5% reported the avoidance of cigarette smoke, despite the fact that 55% had smokers in the household. In addition, fewer than one quarter of the parents indicated using medications preventatively. Other strategies, such as monitoring lung function via a peak flow meter, were almost never used. These findings suggest that health care providers could provide greater education regarding triggers and trigger avoidance and the preventive use of medications. Peak flow meters also could be prescribed much more widely as an adjunct to ongoing asthma management in inner city children.

With respect to the management of acute symptoms, most parents reported giving medication and seeking medical care as a part of their emergency plan. However, only 13.5% indicated calling a physician for advice, and only a small proportion noted behavioral strategies to control symptoms at home. This pattern of responses suggests that parents may overutilize emergent care because of an inadequate plan for dealing with the acute onset of symptoms.

The findings from the NCICAS assessment of adherence after an emergent visit are consistent with psychological models of adherence. In the Health Belief Model,<sup>28</sup> perceptions of the individual's susceptibility, severity of the condition, potential benefits of available treatments, and existing barriers contribute to adherence with a prescribed regimen. The current findings suggest that inner city families may be at risk for nonadherence as a result of inaccurate perceptions about the nature and severity of asthma and doubts about the efficacy of medications. In addition, parental responses indicate the possibility that the costs of following the medical recommendations (side effects of medications, inconvenience of bringing the child for continuing care) may outweigh the perceived benefits.

Viewing our data within the Health Belief Model framework suggests several avenues for intervention. Health care providers may have an impact by facilitating the parent's understanding of the illness, underscoring the benefit of ongoing treatment, and eliminating existing systemic barriers. Specifically, health care providers might place greater emphasis on the chronic nature of asthma through the prescription of antiinflammatory agents and the recommendation of scheduled visits, even when the child is asymptomatic. Changing the emphasis of asthma care to the prevention of symptoms and the treatment of chronic airway inflammation can be done in the context of expanded education regarding the benefits of ongoing care and prevention for children with asthma and their families. Many of the existing problematic health beliefs may be modified by providing families with a better understanding of asthma and the state-of-the-art practices for optimal management.<sup>31,32</sup>

This report describes only half of the adherence

interaction, the perspective of the child and adult caretaker. The intent of the first phase of NCICAS was to determine what factors may be responsible for the increased burden of asthma in the inner city child. There was no attempt at intervention. As shown here and in many other studies on adherence, very few caretakers will admit to nonadherence. However, this study has provided significant insight regarding issues that may affect their ability to carry out a prescribed program of asthma care. Physicians need to be aware of such self-management behaviors and potential barriers to their recommendations. If adherence is conceptualized as a partnership between the physician and the family, the behavior of both partners may need to be addressed to reduce morbidity among inner city children. Physician recommendations will carry greater authority in an atmosphere of mutual respect. Thus, the communication between parent and physician must be improved so that physicians are aware of the concerns and barriers that confront families.

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