



# To Assess Self-reported Adherence, Management Behavior, and Barriers to Care after Hospital Visit and Study the Impact of Patient Education on Children with Asthma

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## Abstract:

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. Adherence was one of the key areas of interest for the 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. To assess the Self-reported Adherence, Management Behaviours, and Barriers and impact of patient education. Patients presenting during an acute attack of asthma at were recruited for this study. The medical record of the encounter was abstracted and compared with information that was obtained during a baseline interview 3 to 5 weeks later. There were 986 children 4 to 15 years of age living in city census tracts in the study. The parental report of medications prescribed and the information on the abstracted report agreed 95.15% of the time for the  $\beta$ -Agonists, 86.24% for steroids, and 7.71% for cromolyn. 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, by an estimated 60.0% of those who were told specifically to call for an appointment. Only one third of parents report that they were able to keep the child away from known asthma triggers nearly all of the time. After the follow up the significant changes are seen. 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. The patient education to improving the patient-physician partnership and also improve adherence.

**Keywords:** Adherence, Asthma, Pediatric, Communication, management, patient education

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## INTRODUCTION:

Asthma morbidity and mortality have asthmas who live within an city environment.<sup>1-5</sup> The specific reason(s) for this situation is unknown. To better understand and address this issue, The tasks of this effort increased disproportionately among children with are associated with asthma morbidity in children, and to address these factors. Non-adherence to a prescribed to asthma morbidity and I) to determine what factors 2) to develop an intervention therapeutic program is one of the purported factors contributing mortality in population's<sup>4-6</sup> and is likely to contribute to asthma morbidity in children with asthma. Therefore, one of the key areas of investigation in the compliance or adherence to an asthma management plan by patients and families. It sought not only to 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 adherence process puts more burden on the clinician to encourage behaviours that increase compliance and enhance the therapeutic effect of the treatment program. 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 the disease and to reinforce all these concepts of asthma management. The 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 non-invasive, inexpensive, and well established. The self-report of e may have problems with validity. This problem has been described regarding well established self-report instruments used to measure adherence.<sup>4</sup> Speculations on the reasons for adherence problems have included major areas such as 1) nature of the illness itself, 2) physician therapeutic settings and the continuity of care, 4) complexity of the s of the patient. Reasons that adults have given for not prescribed treatment program include forgetting (48%), inconvenience (11%), side effects (6%), and medication taste (1%).<sup>9</sup> Other reasons given for non adherence have included fear of dependency and depression.<sup>4</sup> Similar issues may pose barriers to adherence for children with asthma.

## METHODS:

The study 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. Participants were interviewed about these topics during a baseline interview and contacted regarding asthmas symptoms and health care baseline interview. To obtain a sample with a broad range of characteristics that might be

related to asthma morbidity, children with asthma and their parents were recruited from community clinics Erode and Namakkal Districts, in Tamilnadu, India. The children had to be between 5 and 15 years of age group. 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 have been described elsewhere<sup>4</sup> this study of self-reported adherence, management behavior, and barriers to care focuses on 986 children enrolled an acute asthma exacerbation. The medical record of the 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 visit follow up study was carried out after giving patient education.

**Measures:** The adherence portion of the baseline interview was modeled on and contained questions from the Asthma Self-Management Questionnaire, which focused on health care behaviours 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 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.

**Analysis:** Descriptive statistics were used to provide frequencies on various characteristics the population.  $\chi^2$  Tests were used to test the significance of the differences between groups on categorical variables. Significance was set at  $P < 0.05$

## RESULTS:

### **Sample Characteristics:**

The data of the 986 children recruited from the visit. Also included is health care utilization in the before the baseline interview and recent disease activity. The average age of the children enrolled was 11.7 years and 59.53 were boys. There was a family history of asthma in 55.7%, family income was Rs. 10,000 in 64.9%, and 72.6% of the primary care providers/respondents were married. The mother of the child was the respondent in 39.29% of the baseline interviews and the father 43.21%. 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 chart and the parents report at the baseline interview of medication prescribed at the 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 report of medication use. Charts were available for only 862 of the 986 children recruited from the hospital. The charts noted agonists 74.3% of the time. At the baseline interview 95.15% of those prescribed  $\beta$ -Agonists reported using them. Methyl xanthines were discharge medications for 15 children. Again, almost all of those parents (91.66%) also reported using s 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 anti-inflammatory agents. Steroid use (oral and inhaled) was in agreement 86.24% of the time and cromolyn use 7.71% 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 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 per cent had medicines at home to use in the event of an attack, and only 6.7% admitted to not filling a prescription. Care takers 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 5 to 15 years of age (986) reported their medication practices and adherence (Table-4). In this group, 806(81.6%) reported that they were taking medicine for their asthma at the time of the interview. Chronic prevention therapy was reported by 49.4% of these. Month the children who took medicine 49.2% reported that they take medication on their own some or most of the time in 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 did their parents. Forty five some of the time 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.

**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 5). Eighty-two per cent 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 22.7% 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 using home remedies, were reported, 12% of the time. Seventy-two per cent 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.

**Table. 1: Sample Characteristics (N=986).**

| Demographics   | %          |
|--|------------|
| Age, Mean  | 11.7(±1.7) |
| Male   | 59.53      |
| At least one smoker in household                               | 54.7       |
| Family history of asthma                                       | 55.7       |
| Income < Rs.10000  | 64.9       |
| Caretaker married  | 72.6       |
| Respondents  | 43.21      |
| Father   | 39.29      |
| Mother   |            |
| Health service utilization for asthma in the previous 3 months |            |
| Hospitalizations (mean ± SD)                                   | 0.26±0.52  |
| Hospitalizations (mean ± SD)                                   | 1.36±1.05  |
| At least one hospitalization,                                  | 22.4       |
| More than one unscheduled visit                                | 34.3       |
| Wheezing in the previous 2 weeks days                          | 3.23       |

**Table. 2: Comparison of Parents Report of Medication Prescribed and Medications Recorded.**

| Prescribed at ED based on chart review (N = 862)                        | Patients(%) |
|---|-------------|
| β-Agonists  | 74.3        |
| Xanthines   | 5.57        |
| Steroids  | 47.22       |
| Cromolyn  | 17.68       |
| Percent of those prescribed at ER who reported the medicine at baseline |             |
| β-Agonists(n=640)   | 95.15       |
| Xanthines(n=48)   | 91.66       |
| Steroids(n=407)   | 86.24       |
| Cromolyn(n=152)   | 7.71        |

**Table. 3: Self-assessment of Adherence to Medications.**

| Characters  | Adherent n(108) | Nonadherent n(878) | p-value |
|---|-----------------|--------------------|---------|
| Average number of medicines                                   | 2.4             | 2.3                | 0.55    |
| Taking three or more medicines                                | 42.3%           | 38.4%              | 0.53    |
| Using oral, inhaled, and nebulized medicines                  | 37.9%           | 51.25%             | 0.04    |
| Have some concerns about side effects                         | 81.2%           | 89.5%              | 0.08    |
| Have some doubts about usefulness                             | 34.4%           | 54.2%              | 0.002   |
| Sometimes worries that the child is getting too much medicine | 37.6%           | 47.7%              | 0.11    |
| Sometimes feels that they are not getting enough medicine     | 13.7%           | 14.0%              | 0.96    |

**Table. 4: The Children's Self-report of Adherence\* (n =986)**

|  | n(%)      |
|--|-----------|
| Takes any medicine for asthma now?                             | 804(81.6) |
| If taking any medicine now (N=804)                             |           |
| Takes asthma medicines every day even if no symptoms           | 397(49.4) |
| Takes medicines when asthma symptoms begin                     | 363(45.2) |
| Tries to avoid taking medicines some of the time               | 424(52.8) |
| Took medicine within 7 days                                    | 682(84.9) |
| Takes medicine on his/her own (some or a lot of the time)      | 395(49.2) |
| Someone watches them take medicine (some or a lot of the time) | 553(68.9) |
| If tries to avoid taking medicine some of the time (N = 237)   |           |
| Ends up having to take it anyway (some or a lot of the time)   | 173(73.1) |

**Table.5: 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? (N= 986) | %    |
|--|------|
| Give asthma medicine   | 81.7 |
| Go to clinic   | 64.2 |
| Have child lie down or rest  | 48.0 |
| Give fluids by mouth   | 15.4 |
| Call physician or Call hospital  | 22.7 |
| Use home remedies, herbs, or teas  | 12.0 |
| Ask family or friends for help or advice   | 12.0 |
| Use medicines or call physician as first or second action  | 73.4 |

**Table. 6: Strategies employed for health education and its impact on compliance**

| Health education strategies                                    | Total (%)<br>878 | Adherent<br>n (%) 634(72.2) | Non-Adherent<br>n (%) 244(27.8) |
|--|------------------|-----------------------------|---------------------------------|
| Written action plan  | 198(22.55)       | 144(22.71)                  | 54(22.13)                       |
| Distribution of paints leaflets about asthma in local language | 189(21.52)       | 132(20.83)                  | 57(23.36)                       |
| Asthma awareness camp  | 115(13.09)       | 103(16.24)                  | 12(04.91)                       |
| Verbal praise  | 115(13.09)       | 98(15.45)                   | 17(6.96)                        |
| Interactive communication skill                                | 104(11.84)       | 83(13.09)                   | 21(8.60)                        |
| Answering to family worries                                    | 89(10.14)        | 40(6.30)                    | 49(20.08)                       |
| Tailoring the medication to patients needs                     | 68(7.74)         | 34(5.36)                    | 34(13.93)                       |

**Health Education:**

Various strategies were employed with the help of a health educator after 12 week of therapy to improve the patient's compliance to the therapy, and these patients further duration of 12 weeks to evaluate the response to the intervention. We have tried to educate these bronchial asthma patients in different ways, so that it will help adherence to the therapy. These different ways included: Verbal praise communication skills 104(11.84), tailoring the medications to the patient's routine 68(7.74), conducting asthma awareness camps for the defaulted patients 115(13.09), distribution of literature regarding asthma and its consequences in local languages 189(21.52). Answering to the family's worry 89(10.14), and written self-action plan 198(22.55) (Table 6). After 12 weeks of therapy, it was observed that the compliance

improved in additional 634 patients (72.2%) who had defaulted earlier. The remaining 244(27.2%) patients were found to be still non-adherent to the therapy. It was also observed that direct interaction with the patients or with the parents of asthma patients improved the compliance to a significant level

**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 that the physician knows will be effective. To understand this complex process 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 medication use alone. We attempted to reveal the patient-related factors that affect adherence. In choosing to assess adherence via self-report, we confronted the problem of parents denying or minimizing non-adherence to present a more favourable impression of themselves [6]. 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 non-adherent, at least some of the time.[7,8] Characteristics of the disease, such as its episodic nature, make non-adherence 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 eliminated in the development of an intervention to reduce asthma morbidity in 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 non-adherence 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 ported potential barriers to adherence.

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 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 preventively. 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 on-going asthma management in children

With respect to the management of acute symptoms, most parents reported giving medication 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 behavioural strategies to control symptoms at home. This pattern of responses suggests that parents may over utilize emergent care because of an inadequate plan for dealing with the acute onset of symptoms. The findings from the assessment of adherence after an emergent visit are consistent with psychological models of adherence. In the Health Belief Model, 11 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 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. 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 on going 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.[4] The report describes only half of the adherence interaction. The perspective of the child and adult caretaker. The intent of the first phase was to determine what factors may be responsible for the increased burden of asthma in the child. There was no attempt at intervention. As shown here and in many other studies on adherence, very few caretakers will admit to nonadherenc

#### CONCLUSION:

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 partnership between the physician and the family, the behaviour of both partners may need to be addressed to reduce morbidity among children. Physician recommendations will carry greater authority in an atmospheres 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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