Enhancing Medication Adherence Among Inner-City Children with Asthma: Results from Pilot Studies

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ABSTRACT

Despite the availability of effective treatments that aid in controlling asthma symptoms, inner-city children with asthma have high rates of morbidity and are frequent users of emergency department services. The goal of these studies was to pilot test an intervention that used social learning strategies (e.g., goal-setting, monitoring, feedback, reinforcement, and enhanced self-efficacy) and targeted known barriers to individualize a family-based asthma action plan. Participants were 15 children with asthma, aged 7–12 years, who had been prescribed at least one daily inhaled steroid. The children and their mothers lived in inner-city Baltimore and all were African-American. Participants received up to five visits in their home by a nurse. Electronic monitors were installed on the children’s MDI to provide immediate feedback on medication adherence to the families and validate medication use. At baseline, only 28.6% of the children were using their medications as prescribed. Within four weeks, the number of children who were using their medications appropriately doubled from 28.6% at baseline to 54.1% (90% increase; \( p = 0.004 \)), while underutilization decreased from 51.2% to 25.4% (100% decrease; \( p = 0.02 \)). The number of children with no medication use at all dropped from 28.3% at baseline to 15.1% by week 5 (87% decrease; \( p = 0.009 \)). Thus, within four weeks, more than half the children were using their
inhaled steroids appropriately. In addition, the rate of underutilization decreased and that of nonutilization was cut in half. Our initial data suggest that an individualized, home-based intervention can significantly enhance adherence to the daily use of inhaled steroids in inner-city children with asthma. Nevertheless, adherence to daily inhaled steroid therapy remains a significant problem in this group.

Key Words: Medication adherence; Inner-city children; Childhood asthma; Self-efficacy; Child-parent relations

Among inner-city children with asthma, asthma morbidity and mortality is high (1–3). Asthma management is suboptimal; routine asthma care is uncommon and the Emergency Department (ED) is often used as the primary source of asthma care (4–9). Poor adherence to asthma therapy has been implicated as an important contributing factor in excess asthma morbidity (3,10). Rates of medication use commonly average 50% of prescribed doses (11–15), and up to 90% of patients will not consistently follow their therapy plan (16).

Medication adherence may be even more problematic among inner-city children seen frequently in the ED. Among preschoolers presenting to an inner-city pediatric ED for asthma, Farber and colleagues reported that only 11% used daily inhaled antiinflammatory medication, despite the fact that most (i.e., 72%) had functional severity scores in the moderate to severe range (7). Of this group, 51% had 10 or more prior ER visits (7). Thus, adherence to asthma therapy is at a critical juncture at which to intervene in trying to decrease asthma-related morbidity and emergency room visits.

There are many reasons why adherence to asthma therapy is suboptimal. First, therapy is demanding and often requires consistent use of medications, even when patients appear asymptomatic (17). Second, multiple barriers to adherence exist among inner-city families, including concerns about medication side effects and efficacy, forgetting, and use of ineffective action plans (18). Third, psychosocial problems are more prevalent among inner-city families, including disorganization, diminished quality of life, poorer problem-solving skills, and increased prevalence of depression among caretakers—each of which may compromise the family’s ability to manage asthma effectively (19–21). Fourth, roles for managing asthma may not be clearly defined. Caretakers may not adequately assess or monitor the child’s asthma management abilities (22,23) or negotiate developmentally appropriate responsibilities for asthma management tasks among caregivers and children (24,25).

Despite the critical role that adherence to therapy plays, no studies we are aware of have specifically targeted and objectively monitored medication adherence as a strategy to improve clinical outcomes among inner-city children. We hypothesized that a family-based intervention that was individualized by a nurse and delivered in the home would improve adherence among inner-city children with asthma. These studies were approved by the Joint Committee on Clinical Investigation of the Johns Hopkins University School of Medicine.

OVERVIEW OF THE MEDICATION ADHERENCE INTERVENTION

We incorporated principles of Social Learning Theory (26) (e.g., increasing behavioral skills, clarifying expectations and roles, goal-setting, enhancing self-efficacy for asthma control, behavioral contracting and reinforcement) into an adherence intervention tailored to the needs of each family. The intervention specifically targeted known barriers to medication use, taught problem-solving strategies and opportunities, enhanced self-efficacy in parents and children for medication adherence, and provided ongoing feedback to link medication use with asthma control and goals. Emphasis was placed on nurturing the family’s medication self-efficacy over the course of the intervention.

A nurse visited families in their homes weekly 4–5 times to deliver the intervention. A common theme throughout all visits was to involve both the
child and the mother in creating an environment that would foster the regular use of preventive asthma medications. The nurse verified that family members had the knowledge and skills to help the child use medication appropriately. Expectations (both positive and negative) about the consequences of daily medication use were explored. Parents were taught how to shape adherence over time. The nurse modeled how to assess adherence, provide feedback, respond appropriately to

Table 1

Theoretical Basis, Teaching Strategies, and Evaluative Methods of the Intervention

<table>
<thead>
<tr>
<th>Goal</th>
<th>Teaching Strategies</th>
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<tbody>
<tr>
<td>Improve asthma management practices</td>
<td>Identify and address PCP and barriers to care</td>
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<tr>
<td>Improve access to care</td>
<td>Review asthma self-management principles during home visit and provide written materials</td>
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<tr>
<td>Provide state-of-the-art asthma education messages to motivate the family to make effective asthma management decisions</td>
<td>Develop and review an Asthma Action Plan for emergencies</td>
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<td>Demonstrate use of peak flow monitoring and diaries</td>
<td>Provide follow-up of access/utilization patterns</td>
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<tr>
<td>Provide feedback on MDI technique</td>
<td>• Behavioral Skills:</td>
</tr>
<tr>
<td>Clarify families’ understanding of asthma management plan and use of medications</td>
<td>• Teach medication skills for each type of asthma medication (i.e., inhaler use, nebulizers)</td>
</tr>
<tr>
<td>Enhance behavioral skills such as medication self-monitoring, problem-solving</td>
<td>• Teach medication-monitoring skills</td>
</tr>
<tr>
<td>Establish appropriate medication and self-management expectations</td>
<td>• Teach medication adherence strategies such as cueing, diaries, reinforcement, and tailoring</td>
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<tr>
<td>Negotiate asthma management goals with families</td>
<td>• Teach family how to evaluate prescribed vs. actual use to identify adherence difficulties</td>
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<tr>
<td>Use feedback to monitor and shape optimal asthma management behaviors</td>
<td>• Teach effective problem-solving strategies to address adherence problems</td>
</tr>
<tr>
<td>Enhance asthma management self-efficacy of families</td>
<td>• Expectations:</td>
</tr>
<tr>
<td></td>
<td>• Provide family with realistic expectations about the effectiveness of asthma self-management</td>
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<td></td>
<td>• Discuss common barriers to adherence (i.e., fears, timing, etc.)</td>
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<td></td>
<td>• Self-Efficacy:</td>
</tr>
<tr>
<td></td>
<td>• Set age-appropriate medication adherence goals</td>
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<td></td>
<td>• Use reinforcement strategies to reward appropriate medication adherence behaviors</td>
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<td></td>
<td>• Demonstrate how self-monitoring facilitates behavior change</td>
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<tr>
<td>Identify PCP and evaluate contact pattern and barriers to utilizing PCP</td>
<td>• Behavioral Skills:</td>
</tr>
<tr>
<td>Evaluate routine and acute asthma management knowledge</td>
<td>• Assess inhaler skills</td>
</tr>
<tr>
<td>Evaluate medication use knowledge</td>
<td>• Assess use of effective medication monitoring skills</td>
</tr>
<tr>
<td>Evaluate asthma prevention knowledge</td>
<td>• Assess use of medication adherence strategies (i.e., cueing, diaries, reinforcement, and tailoring)</td>
</tr>
<tr>
<td>Evaluate use of community and medical resources</td>
<td>• Assess ability to identify adherence difficulties</td>
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<tr>
<td></td>
<td>• Assess ability to utilize problem-solving techniques to improve adherence</td>
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<tr>
<td></td>
<td>• Expectations:</td>
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<tr>
<td></td>
<td>• Assess expectations regarding efficacy of asthma management</td>
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<tr>
<td></td>
<td>• Self-Efficacy:</td>
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<td></td>
<td>• Assess asthma self-efficacy for acute, routine, and preventive care</td>
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nonadherence, and offer reinforcement for the mothers during each visit. Clear roles for family members were established and weekly goals were negotiated between the parent and the child with the assistance of the nurse. A unique aspect of this intervention was the utilization of electronic metered dose inhaler monitors (Dosers™) to provide immediate feedback on medication use to families and to record adherence objectively. Components of the intervention are shown in Table 1.

**METHOD**

**Study I**

Participants

Participants for the initial study were five African-American children, aged 7–12 years, from inner-city Baltimore, and their mothers. These children were selected at random from a sample of children who had completed an inner-city asthma education study. Participating families had received some form of asthma education and the children had been prescribed daily-inhaled steroids (ICS) by their primary care provider.

Procedure

The asthma medication plan was first verified with the primary care provider. A nurse met weekly with the family over four weeks. In the first visit, asthma knowledge was evaluated and updated, medications and their proper use were reviewed, adherence to medications was identified as a mutual goal to work toward, clear roles for the child and parent were established, and a monitoring chart and stars were left with the family to record medication use. Dosers were installed on the ICS metered dose inhaler. Families were taught how to read the Doser screen for immediate feedback on medication use.

During follow-up visits, adherence data were recorded, medication canisters were weighed, feedback was provided to the family about adherence patterns, reinforcement strategies were reviewed, and adherence goals were discussed with the child and parents. When adherence had improved, the nurse also provided small incentive toys to the child (e.g., stickers, pens). Problem-solving skills were taught to parents to address adherence barriers (including how to respond appropriately to nonadherence) and family roles for asthma medications were reviewed and revised as needed. Examples of the common scenarios which the nurse educator problem-solved with families included: (a) the use of medications when visiting a noncustodial parent on weekends; (b) medications not refilled before inhalers were empty; (c) using meals or other daily activities as a cue for taking medications; and (d) finding a place for the child to keep medications to ensure easy access at all times.

Results

At the end of the four weeks, the mean daily medication adherence was 79% (range 56–96%) based on Doser data. The nurse reported that the families responded very positively to the home visits. Four of the five children were enthusiastic about the medication-monitoring charts and displayed them prominently in their homes. All families reported that the Dosers were helpful and asked to keep them after the study.

**Study II**

Participants

The second study was designed to replicate and expand our initial findings. Participants were 10 inner-city African-American children with asthma, aged 7–12 years, who were prescribed a daily ICS, and recruited in the manner described above.

Procedure

Three elements were added to the study design. First, one to two weeks of baseline medication adherence was collected. During the initial visit, an overview of the study was provided and masked Dosers were placed on the child’s inhaler to monitor baseline medication use. (Dosers in “masked” mode have a blank screen and provide no feedback while recording inhaler use). Visits two through five followed the same sequence as outlined above in Study I. The Doser screen was unmasked to provide immediate feedback about inhaler use for the rest of the study. Second, the medication-monitoring chart was expanded to include both inhaler use and asthma symptoms. Third, an asthma goal sheet was used with the child to explore expectations about the benefits of asthma control. The nurse asked, “By taking your medicine, what might you be able
to do this week?” Children identified personally important events (e.g., play outside, ride bike) that could be potentially influenced by medication adherence.

Results

At baseline, most of the children (i.e., 71%) were not using their medications as prescribed. By week five, the number of children using their medications appropriately doubled from 29% to 54% ($p = 0.004$), while underutilization decreased from 51% to 25% ($p = 0.02$). Medication adherence patterns across the five weeks are shown in Fig. 1. The number of children who reported days with no medication use at all dropped from 28% at baseline to 15% by week 5 ($p = 0.009$). As in the previous study, the nurse reported a high level of enthusiasm and support for the intervention among both the children and their caretakers.

DISCUSSION

Results from these two preliminary studies suggest that a tailored medication adherence program delivered by a nurse in the family home can significantly increase the consistent use of inhaled steroids among inner-city children with asthma. A unique focus of both studies was the enhancement of adherence self-efficacy in both children and parents. In Study II, we also had families monitor both asthma symptoms and asthma medication (on the same star chart) to emphasize their interrelationship and show how self-management increases asthma control.

Why is medication adherence so problematic among children with asthma? One reason may be that adherence is commonly viewed as an “all or nothing” activity—either patients are adherent with medications or not (in contrast to the approach that adherence is a behavior that can be shaped over time). Electronic monitoring studies have shown that, in general, patients overreport their medication use to their health care providers (19,27–30). At the same time, health care providers fail to question medication adherence appropriately (31–33), thereby missing opportunities to discuss and improve adherence patterns. In addition, most inner-city children receive episodic care in the ED to manage acute attacks. A recent study of patient-provider communication during ED care of children with asthma revealed that communication with parents was lar-
gely biomedical and children had little involvement in the discussions (34). Thus, presently there is little opportunity for the type of discussions that are most likely to enhance medication adherence for many inner-city families of children with asthma.

An individualized intervention delivered by a nurse offers many important opportunities to enhance asthma management, including medication adherence. Home visits over time provided an optimal environment to establish a family dialogue among a health care provider, children, and the family to develop an individual asthma management plan. This type of therapeutic partnership among physician, family, and child has been cited as an important component of asthma medication adherence and improved outcomes in children (35).

Asthma action plans that are developed with the family, and outline which members will assume various responsibilities, have also been associated with improved asthma management in children (25).

We believe that another critical component of this approach was the ability of the nurse to model effective problem-solving skills and appropriate responses to nonadherence. By setting realistic expectations (e.g., normalizing some degree of nonadherence for most children is common initially) and enhancing problem-solving skills, we established medication adherence as a goal to work toward, rather than as a discrete event.

Our intervention appeared to be well received by both parents and the children. The nurse reported little difficulty contacting the families to set up an initial visit or scheduling follow-up visits. Both the family and the child appeared to value the asthma knowledge-and-adherence education and were eager to receive feedback on medication-use patterns and how to optimize adherence. Families rated the Dosers as being the most helpful of monitoring tools, followed by the monitoring charts. The broad range of skills taught to families were well accepted and motivated the children to utilize their medication as prescribed. Thus, an intervention that is tailored to the needs of the family and delivered in the home by a nurse shows real promise of increasing medication adherence among inner-city school age children with asthma.

A strength of this study was the use of objective monitoring, since self-reports have been shown to overestimate medication adherence (36,37). In children, measurement difficulties are compounded and parents appear to be less accurate than their children when reporting medication adherence (18). Limitations include the use of small convenience samples and the absence of a control group. Long-term outcomes were not assessed and it will be important to verify whether increased medication adherence results in decreased morbidity and ED visits.

These preliminary results provide encouraging support for the role of home visits by a nurse and objective monitoring and feedback to enhance medication adherence among inner-city children. Families were provided with opportunities to learn about asthma management and proper medication use in a relaxed setting where open discussion was encouraged. Realistic goals and opportunities to improve adherence was negotiated among the nurse, the parents, and the child. Self-confidence in managing asthma and adherence to medications was enhanced through education and problem-solving experiences with a nurse. Monitoring, feedback, and reinforcement were also used to increase self-efficacy and to link outcomes to medication adherence. Substantial risks and costs are associated with nonadherence to asthma therapy among inner-city children with asthma. This intervention may serve as a model to enhance asthma management through medication adherence among this high-risk group.

REFERENCES

Enhancing Medication Adherence Among Inner-City Children

33. Steele, D.J.; Jackson, T.C.; Gutman, M.C. Have You Been Taking Your Pill? The Adherence-


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