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Asthma Across Childhood: Improving Adherence to Asthma Management from Early Childhood
to Adolescence

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Abbreviations:

ADAPT: Adolescent Adherence Patient Tool

CDC: Centers for Disease Control and Prevention's

ED: emergency department

ICS: inhaled corticosteroids

mHealth: mobile health

SABA: short-acting beta agonists

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Abstract

Asthma affects nearly 6 million US children. Throughout childhood, children undergo a series of biological, developmental, and psychosocial changes. Thus, factors influencing a child's asthma management differ across three essential stages—early childhood (0-5 years), school-aged years (5-12 years), and adolescence (12-18 years)—and require varied intervention by parents, school personnel, clinicians, and the children themselves. Since asthma care in children is characterized by fluctuations in severity and coordination among many stakeholders, optimal asthma control is difficult to achieve in this young population. Challenges in childhood asthma management are reflected in the low rates of children's adherence to medication regimes. While pharmacological and biological factors addressing age in physicians' treatment choices are well-outlined, age-specific approaches to patient-provider communication and asthma-related interventions are also important in improving quality of life for pediatric asthma patients.

Introduction

Asthma is the most common chronic pediatric disease, affecting nearly 6 million children in the United States.¹⁻⁵ Gaining control of asthma can be especially difficult during childhood as children undergo a variety of biological, developmental, and psychosocial changes. Asthma severity and approaches to treatment often change between early childhood (0-5 years), school-aged years (5-12 years), and adolescence (12-18 years). To achieve control and reduce future risk, standard asthma management include a pharmacological step-wise approach using inhaled bronchodilators and anti-inflammatory drugs, namely inhaled corticosteroids (ICS).⁶ However, adherence to treatment in children remains as low as 50%.⁶⁻⁷ Lack of adherence to asthma management leads to high rates of school absenteeism, low quality of life, activity limitations, high rates of urgent care events, and large financial burdens on families.^{4,8,9} Due to these challenges, it is essential that providers and interventions consider the role of a child's age group in promoting proper asthma management across childhood. In this paper, we will analyze challenges and methods to control asthma in three age groups—early childhood, school-aged years, and adolescence—specifically focusing on issues related to adherence, patient-provider communication, and interventions.

EARLY CHILDHOOD

Adherence

For children aged 0-5 years, asthma management is especially difficult because younger children may not be able to verbally express their concerns.¹⁰ At this age, asthma control is heavily dependent on caregivers who carry the responsibility of evaluating symptoms, following asthma management plans, obtaining medication, and administering treatment.¹¹

Beliefs and attitudes towards health behaviors are known to have a strong influence on health behavior decision-making. Similarly, caregivers' beliefs toward their child's asthma therapy heavily influence children's adherence to treatment.¹² Common concerns caregivers have towards asthma medications include the safety and long-term side effects of (e.g.: use of ICS and growth suppression) and dependence on medication.¹³⁻¹⁴ These concerns can inhibit caregivers from adhering consistently to asthma treatment plans. On the other hand, caregivers with a high perception of medication necessity and low concern of side-effects have been associated with greater medication adherence for their children.^{12,15,16}

Another caregiver-level factor that impacts children's treatment adherence is health literacy level. Caregivers with low health literacy levels have scored lower on assessments of asthma knowledge, report higher usage of rescue inhalers, and are less likely to report proper inhaler technique.¹ As a result, children whose caregivers have lower health literacy report more severe asthma symptoms and are more likely to visit the emergency department (ED). This is especially concerning as these children also have higher school absenteeism which can perpetuate poor educational outcomes and learning disparities.¹

Caregiver-Provider Communication

Given the importance of caregiver attitudes in asthma management adherence, clinicians could develop a deeper understanding of caregiver medication beliefs and use this knowledge to

counsel parents more effectively during appointments. Since parents fully carry the day-to-day responsibility for treatment during an asthmatic child's early years, it is important for clinicians to ensure that parents are equipped with the necessary skills and knowledge to manage their child's condition. Some research has found that parents tend to use reliever medications (e.g.: short acting beta agonists) much more than controller medications (e.g.: ICS)¹⁰, suggesting the need for greater understanding of preventative asthma treatment strategies.

To address gaps in caregiver health literacy, providers could explore methods and interventions (Figure 1) to ensure clear, understandable asthma communication. However, limitations in time and resources may render implementing certain educational interventions into the clinical visit difficult. Thus, discharge handouts with visual representations of asthma severity provide a simple and inexpensive means of improving communication. In one study, providers explaining the handouts to patients after ED visits resulted in improved rates of follow-up with primary care physicians.¹⁷

Interventions

Fragmented asthma care in early childhood and difficulty accessing providers are frequently cited barriers to asthma management. Within the clinical space alone, childhood asthma management requires ongoing coordination among many different healthcare professionals including ED staff, primary care physicians, and specialists, in turn requiring continuous management by caregivers. Continuity of care is an important factor in asthma control. However, achieving this is particularly difficult for families from lower socioeconomic (SES) backgrounds due to many existing barriers in receiving regular asthma care. For this reason, interventions focused on increasing opportunities for continuity are particularly important to ensure all children have equal, consistent access to asthma care.¹⁷ One approach to improving continuity of care for low-SES families includes offering vouchers for appointment transportation and telephone assistance for appointments.¹⁸ The increased rate of follow-up shown after

implementing these methods emphasizes the promise of resource availability to minimize access concerns.

Along with providing linkages to care, caregiver education is essential in achieving asthma control for younger children. Components of such education, highlighted in Table 1, may include (1) understanding the differences between controller and rescue medications, (2) recognizing signs of exacerbation in younger children, (3) preventative methods to avoid use of urgent care, (4) resources and informational sheets highlighting insurance programs, free clinics, and medication techniques, (5) creating action plans and reminders for monitoring appointments with providers, and (6) providing education on detecting and removing environmental triggers from the child's environment.¹⁹⁻²⁰ One effective method is to provide education through telephone coaching by call center nurses.⁸ This use of asthma coaches provides a convenient, cost-effective option for both patients and providers. In one study, coaches introduced behavior change strategies and tailored messages to support caregivers in providing care to their children, and by the end of the intervention, urgent care events (e.g.: ED visits, hospitalizations, unscheduled office visits, and after-hour calls) were halved.⁸

In addition to telephone calls with nurse coaches, peer coaches have also shown to be useful in chronic disease management education. After undergoing training by health professionals, peer coaches are useful because they can share relevant health information while also providing insight from their personal experiences with asthma treatment. One intervention focusing on educating caregivers of minority asthmatic children through monthly educational meetings, telephone calls, and biannual home visits with peer caregiver mentors resulted in reduced wheezing episodes, asthma exacerbations, emergency department visits, and caregiver missed work-days, and improved caregiver self-efficacy in controlling their child's asthma condition.²⁰ Caregiver coaching, from either nurses or peers, appears to improve children's asthma management.

SCHOOL-AGED CHILDREN

Adherence

Between the ages of 5-12 years, children are exposed to new triggers and additional stressors, such as, physical activity during recess, indoor environmental allergens, and food allergens. Additionally, asthma exacerbations increase with the calendar school-year with September being the month of peak exacerbation.²¹⁻²³ On top of this, children at these ages spend much more time in school and away from their caregivers. With these factors in mind, the school-aged group is particularly susceptible to asthma exacerbations, and indeed, children struggle with optimal asthma control in the classroom.²⁴ Therefore, because early habits to follow medication regimes are correlated with greater adherence later in life and because schools cannot reasonably be tasked with complete management of their asthmatic students' condition, development of self-efficacy should be emphasized.²⁵ Other important factors in adherence for school-aged children include: perceived control over asthma, belief in necessity of medication, and self-efficacy for asthma self-management.⁵⁻⁶ Programs that begin empowering children with the information and confidence to independently manage their asthma during school could be beneficial for this age group.

Patient-Provider Communication

For school-aged children, communication during doctor visits predominantly occurs just between providers and caregivers. In fact, an observational study found that children spoke significantly less than their caregivers, with an average of 20 child statements per visit compared to 156 caregiver statements.³¹ Another study found that children were involved in creating their own treatment plans during only 7.8% of visits.⁵ Greater input from children is necessary because caregivers may not be aware of critical information (such as certain triggers or symptoms) that impact treatment. To improve the quality of care, efforts to increase patient-centered conversations and shared decision-making with the child asthma patients are

important steps for physicians. In fact, one study found that the use of a patient-centered conversation style resulted in a five-fold increase in child participation as well as higher ratings for informativeness by caregivers.²⁶

Effective methods to improve communication with child patients include: visual aids, turn-taking in conversation to increase participation, and role modeling.²⁷ Visual aids during visits might include the use of coloring books, cue cards, or comic books that allow children to identify and explain environments that may trigger their condition (see Appendix A for examples of asthma resources appropriate for school-aged children).²⁷ Additionally, providers can ask patients and caregivers to describe treatment instructions in their own words to identify any miscommunication or misunderstandings between physician, patient, and caregiver. Providers could also teach caregivers how to disclose and explain medical information to their children in efforts to improve children's proper understanding of treatment.²⁷

Interventions

Since school-aged children spend a large portion of time at school, multi-component, school-based interventions are appealing in their ability to reach students and faculty, and they address multiple factors involved in optimal asthma control. Common components of school-based interventions are (1) case detection, (2) staff education, (3) referrals to resources, (4) direct treatment administration, and (5) student and caregiver self-management education.^{2,28} While validated questionnaires to identify cases of undiagnosed asthma exist, school-wide screening has been shown to have limited cost-effectiveness.²⁹⁻³⁰ However, school-based programs can still bring benefits by identifying individuals with prior diagnoses and/or poorly controlled asthma. This school identification of children with asthma is a key first step to preventing exacerbation and absenteeism for students.³⁰

Additionally, school staff can be trained as asthma champions by learning to recognize asthma symptoms, identifying children with poorly controlled asthma, assisting students with asthma

management, and responding to asthma exacerbations.^{2,31} A Cochrane review on asthma education of school staff identified that schools with tailored programs write and adhere to more school asthma policies, have better prepared staff, and take more measures to avert or control asthma attacks caused by common triggers such as exercise.³² School programs that provide linkages to clinical care and community resources have shown to bring a positive influence in asthma outcomes for children.³³ Given that not all schools have the capacity to enact school-based asthma education programs, families may need to be directed to community resources, clinical care, and local organizations that may be able to provide support instead.^{2,31}

School nurses can provide an additional layer of asthma management improvement. Multiple studies have found that when school nurses directly and daily administer inhaled corticosteroids, this decreases days of activity limitation, uses of rescue medication, and unnecessary healthcare utilization.³⁴⁻³⁷ Direct observed therapy programs also provide opportunities to ensure that children are using proper treatment techniques. However, in 2015 only 50% of schools had access to a full-time registered nurse, with 18% having no nurse at all.^{29, 30} Therefore, direct administration may not be feasible for all schools or it may burden schools with limited nursing personnel available to administer a student's treatment.³⁹

School-based models have shown to be highly effective but are difficult to implement and scale as access to resources is not uniform across schools. Schools may have fully staffed health centers, full-time nurses, or no personnel at all.² Unfortunately, the schools with a greater burden of students with asthma and which would benefit the most from these programs tend to have limited resources.²⁹ The Centers for Disease Control and Prevention's (CDC) National Asthma Control Program suggests that state-coordinated programs can help build capacity to implement school-based asthma control programs in schools with limited funds.³² State asthma programs can help implement school asthma programming by connecting schools with stakeholders (e.g.: community organizations and health departments) as well as promoting

administrative support within school systems. Additionally, state-level programs can provide technical assistance through provision of evidence-based informational material, collection of evaluation data to determine an intervention's effectiveness, and creation of policies to promote school asthma programs.³²

Outside of school, self-management education programs can be effective. Self-management programs have been demonstrated to reduce asthma symptoms and emergency department visits, as well as improve school performance.⁴³⁻⁴⁵ Given that students have varied triggers and symptoms, these programs are especially useful for imparting skills tailored to manage one's individual needs. Involving caregivers in these programs has also resulted in positive influences on asthma outcomes for children. One asthma education program required children and their caregivers to complete self-management homework together, and showed improved self-management skills, self-efficacy, and communication with caregivers.⁴²

Given the wide range of stakeholders involved in interventions for school-aged children, greater coordination between clinics, schools, and homes is needed. Future studies concerning this age group can focus on which components of school-based asthma programs are most impactful, which methods to scale school-based interventions will be important in promoting greater asthma control for school-aged children, and how to incorporate school-based programs with home self-management.

ADOLESCENTS

Adherence

Compared to younger age groups, adolescents consistently have the lowest rates of asthma medication adherence.^{4,43} These rates can be attributed to the many developmental, psychosocial, and environmental changes that occur across early (ages 12-14 years old) and later (ages 15-18 years old) adolescence.²⁸ In early adolescence, cognitive functioning shifts

from concrete to abstract thinking, transitioning an adolescent child's simplified perception of asthma into a more complex understanding of their condition,^{28,44} potentially overwhelming children with asthma and in turn, leading them to eschew the condition all together, including its treatment. This period is also marked by an increased focus on peer acceptance and desire for autonomy from caretakers.^{9,28,44} Consequently, in efforts to avoid embarrassment or seeming different from their peers, adolescents may hide their symptoms and not take their medication.⁴⁵

In later adolescence, social influence becomes less of a barrier to adherence.²⁸ Instead, common self-reported reasons for nonadherence include: forgetfulness, misunderstanding of medication regimes, and low perceived need for asthma medications.⁴⁵⁻⁴⁷ A common misconception among this age group is mistaking improvement of symptoms with "outgrowing asthma."⁷ For this reason, the patient-doctor relationship is an essential intervention point to ensure a clear understanding of condition severity and medication benefits.

Patient-Provider Communication

Adolescent patient-provider rapport plays a critical role in facilitating asthma control for adolescents. Studies show that poor relationships with providers can cause adolescents to withhold information or attempt to minimize visit time, increasing the communication gap between providers and patients.⁷⁻⁹ Meanwhile, strong, long-term provider relationships are correlated with improved adherence to medications and improved quality of life.⁹

Providers also play a critical role in facilitating the transition of responsibility for asthma management from caregivers to patients. To assist in this transfer of care, providers could consider initially meeting with adolescents without the presence of their caregiver. This method allows for more time to directly communicate with the adolescent, answer questions, and build patient provider trust. These visits should also designate time to involve the adolescent in goal-

setting, developing an asthma action plan according to their lifestyle, and discussing risk-taking behaviors that they may be hesitant to disclose, such as smoking.^{28,48}

With the rise of e-cigarette or vaping use in this population, health-risk behaviors, specifically smoking, are important to discuss with adolescents.^{28,49} Studies on provider attitudes towards e-cigarette counseling cite there may be barriers to discussions with adolescents, including providers' lack of knowledge on e-cigarettes, unfamiliarity with adolescents' motivation and slang, lack of time to counsel during appointments, and clarity of screening tools.⁴⁹ Currently, screening often includes physicians asking if patients smoke or use tobacco products. Since adolescents may not necessarily conceptualize e-cigarette usage under these categories, this could lead to missed opportunities for discussion. Thus, clinicians should consider asking specifically about e-cigarettes or vaping.⁴⁹ Cessation counseling, education on the impact of smoking on their chronic condition, and risk-reduction resources are important to prevent smoking-induced exacerbation of adolescent asthma.^{28,45} Given the strong correlation between family support and greater adherence, caregivers could join later in the appointment to review their adolescent's asthma management plan and identify approaches to support their regimen.⁹

Interventions

With the unique challenges adolescents face in asthma management, novel approaches to increase their understanding of asthma and medication adherence should be explored. Considering that 73% of adolescents in the United States have access to smartphones, mobile health (mHealth) applications—smart phone apps—could be a useful intervention for self-management.⁴⁸⁻⁴⁹ One mHealth application, the Adolescent Adherence Patient Tool (ADAPT), is equipped with features such as a symptom monitor, medication alarm, educational videos, peer chat, pharmacist chat, and adherence monitor. In one controlled study, patients with low baseline adherence rates who used this tool showed improvement in asthma medication

adherence.⁵⁰ This example is just one of many applications being developed or that already exist in the current market to aid in asthma self-management. However, many asthma mHealth applications are tailored to adults, and more studies are required to understand features that would be more appealing for adolescents specifically. Some research has identified adolescent-friendly features to include: trigger and symptom identification (75%), charts tracking changes in condition over time (69%), a diary feature (69%), and emergency plan (63%). Overall, a majority of these adolescent participants felt that they were more engaged in their self-management after using an asthma app tailored to adolescents.⁵¹ MHealth has great potential for helping adolescents with asthma self-care, and more studies and guidance are needed to help providers better understand which apps to recommend.⁵²⁻⁵⁴

Still, while many adolescents are using applications on their mobile phones, the uptake of mHealth applications for asthma self-management is slow to gain popularity. In one study, researchers conducted semi-structured interviews with a group of adolescents aged 13-18 years and discovered that nearly two-thirds of these teens had never used an mHealth application.⁵⁵ To encourage mHealth application uptake, greater promotion of mHealth applications on social media and inclusion of features tailored to the younger population were suggested. One method of tailoring includes the “gamification” of features by adding virtual badges, points, leaderboards, and challenges to improve engagement with mHealth applications.⁵⁵

This area of mHealth and adolescents is rife with research possibilities. Assessing mHealth application feature acceptability for adolescents is one area warranting further research. Future studies could also evaluate methods to discern the quality of mHealth programs. While standardized scales to measure mHealth application quality are in the process of being developed, no validated methods for users to discern the effectiveness of different mHealth

applications are yet available.^{56,57} Improvements need to be made to mHealth, but mHealth programs elucidate a promising avenue for addressing challenges that adolescents may face in self-managing their asthma.

Conclusion

Given the many different challenges and barriers to achieving optimal asthma control in children, it is important that providers and interventions address age-appropriate factors impacting the progression of their chronic disease. A major influence in optimizing care for asthmatic children is understanding who carries the primary responsibility for asthma management throughout childhood. In early childhood, caregivers manage nearly all of asthma control, and interventions could focus primarily on caregiver asthma education. During the school-aged years, children begin to form some level of autonomy over their asthma care, but they are reliant on adults for assistance; thus, school-based interventions that partner with caregivers may be helpful. By adolescence, children rely more on self-management, and asthma management could include more use of mHealth applications.

Figure 1. Asthma interventions across the ages

Table 1. Asthma educational program components across childhood

Common asthma educational program components across childhood

1. Understanding asthma and the importance of maintenance therapy
2. Differences between controller and rescue medications used in asthma control
3. Inhaler technique
4. Signs of asthma exacerbation
5. Resource Identification
 - a. For parents and schools: insurance programs, free clinics, community organizations that can provide assistance
 - b. For all: informational sheets on medication and inhaler technique
6. Creating action plans
7. Detecting and removing environmental triggers

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EARLY CHILDHOOD
(0 – 5 years)

- Visual asthma severity charts
- Appointment transportation vouchers
- Appointment telephone assistance
- Telephone coaching
- Peer parent coaches

SCHOOL-AGED
(5 – 12 years)

School-based interventions

- o Staff education
- o Resource referrals
- o Direct administration

Self-management education³³

ADOLESCENCE
(12 – 18 years)

Mobile health interventions

- o Symptom and medication monitors
- o Educational videos
- o Peer & pharmacist chat
- o Adherence monitor
- o Emergency plan

Appendix A**Online Resources for School-Aged Children**

Resource	Intended Audience	Description
Asthma Action Plan https://secure.aaafa.org/np/clients/aaafa/product.jsp?product=21&	School-aged children	The Asthma and Allergy Foundation of America (AAFA) created an asthma action plan that uses an analogy of a traffic light to outline what medication to use depending on a child's symptoms. Physicians may fill out and explain the action plan to patients as well as create copies for school staff.
Dr Al and the Sneeze n'Wheeze Busters https://www.aaaai.org/Aaaai/media/MediaLibrary/PDF/Documents/dr_allergist_coloring_book_w.pdf	School-aged children	The American Academy of Allergy, Asthma, & Immunology created a coloring book tailored to school-aged children to educate children about their condition and potential triggers.
Student Asthma Action Card https://secure.aaafa.org/np/clients/aaafa/product.jsp?product=11&	School staff (teachers, nurses, after-school staff)	This action card by the AAFA can be used to provide more specific directions for school staff on a particular student's asthma management.
Strategies for Addressing Asthma in Schools https://www.cdc.gov/asthma/pdfs/Strategies_for_Addressing_Asthma_in_Schools_508.pdf	School staff (Administration)	This is a guide created by the Centers for Disease Control and Prevention's (CDC) National Asthma Control Program. This is a compilation of information and resources for schools with an interest in creating more "asthma friendly" schools.
Asthma-Friendly Schools Initiative Toolkit https://www.lung.org/lung-health-and-diseases/lung-disease-lookup/asthma/asthma-education-advocacy/asthma-friendly-schools-initiative/toolkit/	School staff (Administration)	The American Lung Association created an asthma management toolkit to guide schools in providing opportunities to manage asthma during school.
Athletes and Asthma: The Community Coach's Role https://www.health.state.mn.us/diseases/asthma/communities/trainin	School staff (Coaches and physical education teachers)	The Minnesota Department of Health created a free course to educate coaches and physical education teachers on how to handle children's asthma

g.html		
Child Care Asthma/Allergy Action Card https://secure.aafa.org/np/clients/aafa/product.jsp?product=12&	Caregivers	This card is particularly useful for parents to keep track of their child's medication plan, as well as signs and symptoms.
Asthma Home Assessment Checklist https://www.cdc.gov/asthma/pdfs/home_assess_checklist_P.pdf	Caregivers	These checklists from the Centers for Disease Control and Prevention (CDC) can help home visitors and families find common asthma triggers in their home and remove these triggers from children's environments
Asthma Brochures in Spanish https://secure.aafa.org/np/clients/aafa/product.jsp?product=203&	Caregivers	These brochures provide basic information about asthma management for families.
Asthma Inhaler Instruction Videos https://www.cdc.gov/asthma/inhaler_video/default.htm	Caregivers and school-aged children	These videos by the CDC in both English and Spanish provide instructions on how to use inhalers.