Barriers to Self-Management in African American Adolescents with Asthma

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ABSTRACT

Objective: To review the literature on barriers to asthma self-management among African American adolescents.

Methods: Review of the literature.

Results: Asthma self-management barriers experienced by African American adolescents are often related to developmental needs, lack of knowledge, and personal perspectives and experiences. Adolescents find managing their symptoms and adhering to prescriptive therapies a burden and desire to be more like healthy peers. As they struggle to identify with peers, they may engage in risky behaviors such as ignoring symptoms and delaying treatment, thus leading to poorer asthma control and health outcomes. African American adolescents struggle with perceptions of racial biases from health care providers and teachers that interfere with self-management behaviors. They also describe the influence of culturally based practices learned from caregivers that contribute to their misconceptions and inadequate skills in effectively managing their asthma.

Conclusion: Researchers should seek to develop interventions to address the unique contextual and culturally based needs of African American adolescents that support the development of effective asthma self-management behaviors. This may include making use of family members (especially mothers) and extended support for self-management during this period of rapid growth and transition. Health care providers should consider a team-based approach to the adolescent patient. Such an approach should be grounded in recommendations from national guidelines that suggest a patient-centered approach to care that includes a partnership between the patient and the provider to address unique barriers to effective self-management.

Keywords: youth; caregiver; drug-therapy; self-efficacy; disease-management; patient-centered care.

Effective asthma self-management by urban African American adolescents is a critical aspect of care that should be addressed with vigilance due to the persistent disparities in disease prevalence, morbidity, and mortality compared to Caucasians.[1-3] The overarching goal of asthma self-management is to achieve symptom control, maintain normal activity levels, and minimize future risk of exacerbations and medication side effects.[4,5] Best practices for asthma self-management begin with a partnership between health care providers and clients (including parent/caregiver). This relationship should help affected individuals gain asthma control based on knowledge of their disease and treatment options, confidence and skills in trigger avoidance, medication administration, and management of acute exacerbations.[4,5]

Among youth aged 18 years and younger, African Americans have the highest asthma prevalence rates of all racial and ethnic groups, and between 2001 and 2009 asthma prevalence rates rose by 50% among African American youth.[6] As of 2015, prevalence rates for asthma among African American youth were 13.4%, as compared to 7.4% for white youth.[7] African American youth have been found to have more frequent asthma exacerbations and related school absences than white youth.[8] Furthermore, African American youth younger than 18 years are more likely to be admitted to the hospital for asthma and are 10 times more likely to die from asthma compared to non-Hispanic white children.[6]

Urban African American adolescents with asthma are particularly vulnerable to poor asthma self-management due to the complexity of the disease in this population.[3] African American youth must deal with multiple adverse environmental conditions, lack of knowledge or disbelief

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concerning effective disease self-management strategies, variable access and quality of care, and the psychosocial dynamics of being young while having a chronic disease.[2,3,9-11] It is important to understand and address barriers to successful asthma self-management during adolescence, as behaviors developed during this stage of life often persist into adulthood.[9] In this article, we review the literature on barriers to asthma self-management among African American adolescents and offer suggestions on clinical strategies for improving self-management in this vulnerable population.

Methods

The initial search strategy was developed in collaboration with an experienced librarian. Keywords, MeSH terms, and potential databases were identified. Keywords included *urban*, *African American*, *adolescent*, *asthma*, *self-management*, and *barriers*. These terms were expanded based on search results and a review of abstracts that fit the intent of our review. The search was limited to U.S. studies published between 2005 and 2017. Excluded from the search were conference abstracts, doctoral dissertations, master's theses, meta-analyses, systematic reviews, and studies conducted outside of the United States. Additional articles for the review were identified during the review process from the reference lists of the publications.

Abstracts were reviewed for articles that reported a study population inclusive of African American adolescents with asthma and that were related to self-management. Studies that used qualitative and other descriptive methods and cohort and randomized control trials were reviewed. Due to the limited number of articles found that exclusively focused on African Americans, the authors set a threshold for African American participants at 40% or greater for inclusion in this review.

Full papers were retrieved that met the inclusion criteria for a full review. Each author initially independently reviewed a selected number of papers and abstracted the study purpose, sample, study design, results, conclusions, and limitations. Subsequently, both authors reviewed in tandem and then discussed each selected manuscript to assure the appropriateness for inclusion. The subject matter was considered the priority for inclusion in the review. Study methods, sample size, and noted limitations were categorized but were not considered as a basis for exclusion. Thematic analysis was used to identify common themes across studies.

Results

We identified 23 papers that met our criteria (**Table**). Five common themes were found that related to barriers in disease self-management for African American adolescents: (a) knowledge and skills, (b) beliefs and attitudes, (c) personal/emotional factors, (d) caregivers, and (e) schools.

Knowledge and Skills

Adequate knowledge of the elements of asthma self-management is critical for achieving control of this condition. Asthma knowledge includes a basic understanding of the disease process and treatment strategies, an awareness of early signs and symptoms of worsening asthma, and an understanding of how to manage environmental triggers.[4,5] Sin and colleagues conducted one of the earlier studies to examine the influence of asthma knowledge on asthma self-management in African American adolescents and found a significant positive association between knowledge and asthma self-management behaviors.[12]

Adherence to an asthma medication, especially inhaled corticosteroids (ICS), is one of the cornerstones to successful self-management of asthma.[13,14] Consistent use of ICS therapy to control asthma symptoms and disease progression is often suboptimal in African American adolescents and tends to worsen as they age;[15] studies have found lower adherence levels were more prominent in older African American adolescents and males.[13,16] In a recent study of adolescents with persistent asthma who were prescribed daily ICS, youth with greater ICS knowledge as assessed using a standardized instrument demonstrated significantly higher adherence rates.[13] Proper technique in the use of an inhaler is also important in medication administration. Asthma ICS medication delivery devices vary significantly and require different techniques for medication administration. However, inhaler device skills have been found to be very inadequate in high-risk African American adolescents.[17] Thus, knowledge related to ICS therapy and proper skills in the

Table. **Summary of Studies Reviewed**

Study/Purpose	*Study Design/ Sample Characteristics*	*Results*	*Conclusions/Limitations*
Ayala et al (2006)[23] Described factors that influence asthma management among 6th-8th graders and identified developmental differences	Descriptive study Sample: adolescents in 6th-8th grade (n = 50); 48% African American	4 major themes were identified: barriers and contextual influences, developmental issues, illness representation, and appealing to youth. Within each, similarities and differences were described based on grade level . All students held negative beliefs about asthma medications and reported greater autonomy in asthma management with less parental oversight after starting middle school.	Adolescents believe asthma is annoying and disrupts their daily lives and find asthma self-management challenging. Self-management barriers differ as youth age. Normal development milestones should guide asthma self-management programs. Adolescence is a transitional period and youth require support as they take on additional responsibilities in their care. Limitations: During focus group discussions youth were unable to distinguish between controller and rescue medications; therefore, references to medication use and dislikes are unclear.
Blaakman et al (2014)[25] Described medication management by urban teens in general and in response to a "directly observed medication" intervention	Qualitative, descriptive Sample: urban adolescents aged 12-16 years (n = 28); 54% African American	A common theme evolved around teens' lack of planning and forgetfulness. Teens reported challenges with juggling multiple priorities in school and socially, and reported that a benefit of taking their medication was feeling more autonomous. Benefits of the intervention were fewer asthma symptoms; negative perceptions related to structural issues of the intervention.	Teens prefer to be autonomous with taking medications but still need support in the form of reminders. Early adolescents have not yet learned to juggle competing priorities, which may contribute to poor adherence. Support from school nurses with "directly observed medication" therapy and motivational interviewing may help improve adherence to controller medications.
Bruzzese et al (2014)[26] Examined the utility of Self-Determination Theory to explain medication adherence in African American adolescents with poorly controlled asthma	Cross-sectional study using baseline data from a larger RCT Sample: urban adolescents aged 12-17 years (n = 168); 100% African American	Family routines were the only significant predictive indicator of medication adherence. Better asthma medication adherence was reported in families who shared greater integration of asthma care within the family unit.	Incorporating asthma care within the daily routine of the family improves medication adherence. The concept of a "shared family experience" appears to have a positive impact on the teen and may help promote asthma self-management competence. Limitations: Unable to predict any directionality of results due to study design limitations; data collected solely from self-report measures
Bruzzese et al (2012)[15] Characterized prevention and management behaviors of urban Hispanic and African American early adolescents with asthma	Cross-sectional study using baseline data from a larger RCT Sample: urban Hispanic and African American adolescents aged 11-14 years, with uncontrolled persistent asthma (n = 317); 41% African American	Only 36% who were prescribed controller medication took it daily; 31% reported not taking it at all; 92% reported using medications when symptomatic but 26% failed to ask for help when symptomatic; ~50% adhered to recommended preventive measures. African American adolescents reported lower odds of taking prescribed medication in cold weather compared to Hispanic youth.	Many African American and Hispanic early adolescents with uncontrolled persistent asthma have suboptimal prevention and management behaviors. Early adolescents perceived caregivers as having more responsibility for managing their asthma than themselves.
Cotton et al (2011)[28] Described the use of CAM, perceived efficacy, and disclosure of CAM use to HCPs by teens	Cross-sectional study of teens enrolled in a larger longitudinal study. Sample: adolescents aged 12-19 years of age (n = 151); 85% African American	Teens reported using various CAM strategies, with relaxation and prayer being the most common for asthma symptom management; 87% who used relaxation/prayer perceived these strategies as helpful. Teens were most likely to disclose the use of yoga and dietary changes to HCPs.	Use of CAM was common in this sample, but they were selective about sharing this information with HCPs. HCPs should assess CAM use among teens and help them understand when and if they should incorporate these strategies with evidence-based asthma management strategies.

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Table. **Summary of Studies Reviewed (continued)**

Study/Purpose	*Study Design/ Sample Characteristics*	*Results*	*Conclusions/Limitations*
Crowder et al (2015)[19] Examined factors associated with asthma self-management in African American adolescents	Descriptive cross-sectional correlational study Sample: adolescents aged 14-16 years with asthma who received asthma treatment within the past year (n = 133); 100% African American	Formal asthma education was associated with higher self-management scores. Participants achieved moderately high Illness representation scores on several sub-scales indicating positive beliefs about their understanding of asthma and its controllability. Better self-management was associated with higher perceived illness consequences.	Formal asthma education may have lasting benefits towards asthma self-management during early adolescence. Program design and the need for refresher courses should be further examined. Illness representations may provide another avenue for improving asthma self-management. Limitations: Findings may differ in middle/ older adolescents or other racial groups. Standardized categories of the Asthma Control Test were collapsed, which may affect the findings on this measure.
Ellis et al (2016)[18] Determined if MST-HC improves asthma knowledge and controller device usage skills in adolescents and if improvements in these areas mediates changes in illness management	RCT Sample: adolescents with asthma aged 12-16 years and their caregiver (n = 167); 100% African American	MST-HC was associated with an increase in asthma knowledge and controller device usage skill. Control group participant's asthma knowledge and skills were either unchanged or declined over the study period. The effect of MST-HC on controller medication adherence was mediated by asthma knowledge and controller device use skills.	MST-HC is a community-based intervention that improves asthma self-management targeting medication adherence. Limitations: Controller medication adherence was not objectively measured. The difference in the effect of improvements in asthma knowledge vs. device use skills could not be determined. The intervention dose vs. the control group dose for treatment differed and therefore differences in outcomes could not be directly compared.
Ellis et al (2014)[27] Determined if MST was more effective than a comparison intervention, family support for changing beliefs about asthma-related positive parenting in caregivers of African American adolescents	RCT Sample adolescents aged 12-6 years and their primary caregiver (n = 167); 100% African American	Intervention caregivers significantly increased their rating of the importance of engaging in positive parenting behaviors related to their child's asthma care and their confidence to carry out the related behaviors compared to control group caregivers. Higher parent ratings on the importance of asthma-related positive parenting and parental confidence were related to higher levels of adherence to controller medication by youth.	Caregiver beliefs and confidence in positive asthma-related parenting behavior may improve controller medication adherence. Limitations: Adherence to a controller medication was the only asthma self-management behavior assessed. Possible inequities in dose of the control group may in part contribute to the findings of the study.
Evans-Agnew (2016)[9] Described and compared the discourse of asthma management disparities in adolescents in Seattle to existing youth-related asthma policies in Washington state	Qualitative study using focus groups and photovoice Sample: teens attending high school in 1 of 2 neighborhoods with the highest youth hospitalization rates for asthma (n = 20); 100% African American	State Asthma Plan and Adolescent Focus Group transcriptions and photo texts were compared on determinants of asthma management disparities in the areas of sociocultural systems, community system, health care system, and individual and family. African American youth were able to describe personal asthma management disparities they experienced that went beyond those discussed in the State plan, which were more general.	African American adolescents with asthma revealed that policies concerning school nursing and health care services for asthma are limited due to lack of input from youth affected by the disease. They report disparities in daily experiences within their community and schools that negatively affect their asthma control. Limitations: Small sample size and potential researcher bias in data collection and interpretation

Table. **Summary of Studies Reviewed (continued)**

Study/Purpose	*Study Design/ Sample Characteristics*	*Results*	*Conclusions/Limitations*
Gibson-Scipio et al (2015)[24] Explored the asthma self-management goals, beliefs, and behaviors of urban African American adolescents prior to transitioning from pediatric to adult health care.	Qualitative study using focus group methods Sample: urban adolescents aged 14-18 years residing in Pontiac, MI (n = 13); 100% African American	4 core themes emerged: medication self-management, social support, independence vs. interdependence, and self-advocacy. Adolescent goals and beliefs often center on being normal like their peers. They take risks by not using asthma medications as prescribed and instead use non-evidence-based strategies in their response to symptoms. They value the support of their family, especially mothers. Few identified the importance of having a relationship with a health care provider for preventive care.	Most reported setting short- and long-term goals that were self-determined, but their goals often were not aligned with recommended asthma self-management guidelines. Youth could benefit from guided support in preparation for the added responsibilities they must assume in their asthma management. Support should focus on transition readiness skills and knowledge in areas of self-care, health care decision-making, and self-advocacy. Limitations: Only one focus group was used. Participants were recruited from a convenience sample, which could limit generalizability of findings.
Gibson-Scipio & Krouse (2013)[32] Identify asthma management goals, beliefs, and concerns of caregivers of teens with asthma	Qualitative study using focus groups Sample: primary caregivers of adolescents aged 14-18 years (n = 14); 57% African American	Caregivers' asthma management goals reflected their desire for adolescents to be more responsible for taking rescue medication, symptom recognition, and advocating for self. Caregivers reported culturally based beliefs and concerns about the potential harmful effects of asthma controller medications including fear of physical dependency and weight gain; concerns related to school-based asthma self-medication policies; and concerns related to school personnel's lack of knowledge about asthma and the potential risks for harm during an asthma attack.	Caregiver support and guidance is critical to successful transition of asthma care responsibilities and routines to the adolescent. Caregivers' beliefs and misconceptions about asthma management are often transmitted to the adolescent; thus, ongoing education is needed to improve understanding of the disease and its management. Limitations: Only 1 focus group was used. Participants were recruited from a convenience sample, which could limit generalizability of findings.
Guglani et al (2012)[31] Explored the effect of depression on the effectiveness of the Puff City asthma self-management program	RCT Sample: adolescents in 9th-11th grade from 6 Detroit public schools with a current diagnosis of asthma who screened positive for depression and their caregivers (n = 355 adolescents); 98% African American	For teens who screened positive for depression at baseline, overall QOL scores and scores in the symptom domain of QOL were higher for treatment group teens than controls, but the difference was not significant at 12 months. QOL scores for the emotional support domain were significantly different between intervention and control group teens at 12 months.	Depression did not mediate the intervention's effectiveness for treatment group teens. The intervention improved the emotional domain of QOL of students who were depressed at baseline. Limitations: Study investigators were unable to determine the mechanism by which depression modifies the relationship between the asthma management program and the emotional domain of QOL.
Houle et al (2011)[34] Assessed the extent of agreement between adolescents and caregivers on responses regarding the adolescent's asthma	Baseline survey data from a RCT Sample: 9th-11th grade students from 6 Detroit public schools (n = 314 adolescents and 215 caregivers); 91% African American	Congruence between the adolescent and caregiver responses varied across domains. Older age of the adolescent, having less severe asthma, fewer emergency department visits, less frequent use of rescue inhaler, higher household income, and less awareness of the adolescent's asthma by school personnel were associated with greater congruence for report of symptoms and functioning.	Reports of asthma symptoms and functional status differ, and this finding is most significant among caregivers and younger adolescents. HCPs and researchers may need to consider multiple sources to assess asthma symptoms and functional status in younger adolescents. Limitations: This study used cross- sectional data. Results may not reflect the congruence of reporting asthma symptoms and functional status during acute asthma episodes. The association of the findings with asthma self-management and clinical outcomes is not clear.

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Table. **Summary of Studies Reviewed (continued)**

Study/Purpose	***Study Design/ Sample Characteristics***	***Results***	***Conclusions/Limitations***
Laster et al (2009)[22] Explored and described potential barriers to effective asthma management among low-income urban families as perceived by both youth with asthma and their caregivers	Qualitative descriptive study using focus group methodology Sample: youth aged 8-17 years and their caregivers (n = 28); 92% African American	Youth described a lack of concern about taking controller medications and saw few benefits of reducing asthma episodes. Caregivers described youth paying little attention to asthma signs, symptoms, and triggers. Most caregivers reported adequate asthma management knowledge yet many described controller medication regimens that differed from prescribed regimens. Caregivers identified insurance-related barriers to asthma management such as gaps in coverage, high co-pays or no coverage of medications. Caregivers and children reported asthma management barriers related to lack of asthma knowledge among school personnel.	Barriers to asthma self-management exist for youth and their caregivers. Barriers may be personal, familial, or extend to the community (ie, schools). Interventions are needed that provide a comprehensive and holistic approach to asthma management. Limitations. Inherent limitations related to the use of focus groups.
Mosnaim et al (2014)[13] Identified factors associated with lower levels of adherence to ICS in minority adolescents with asthma	Cross-sectional baseline sampling of participants before randomization for a controlled trial Sample: adolescents aged 11-16 years with an active ICS prescription (n = 93); 88% African American	Those with low adherence (32%) differed from those with high adherence (40%) on 3 characteristics: age (older age associated with low adherence), gender (males disproportionately represented in low adherence group), and knowledge (low adherence group had less knowledge about ICS as measured by ICS questionnaire). Depression and ICS self-efficacy were not associated with adherence.	Youth ICS adherence decreases with age, a finding that may represent developmentally related risk taking behavior, autonomy, and/ or the desire to self-identify as normal. Asthma controller medication knowledge is an important aspect of care and adherence. Limitations: The study was cross-sectional, occurred over a 3-week period, and may not reflect behavior over a longer, more representative period.
Naar-King, et al (2013)[17] Described the asthma medication device skills of African American adolescents with asthma	Baseline data from a RCT that compared 2 home-based interventions Sample: high-risk adolescents ages 12-16 years (n = 170); 100% African American	Trained research assistants directly observed and coded each adolescent using his/her quick-relief and controller medication devices; only 5% showed all correct skills in using controller medication; none showed all correct skills in using quick-relief inhaler; 5% showed 90%-95% of correct skills in using devices.	High-risk African American teens with asthma demonstrated low skill levels in using their asthma medication devices correctly. This may have implications for poor medication adherence. HCPs need to be attentive to this need when working with this high-risk population. Limitations: Sample had a restricted range of asthma severity, which could also affect medication adherence.
Naimi et al (2009)[16] Explored older adolescents' beliefs about medication adherence to a controller medication and aligned them with the constructs of the Health Belief Model	Observational cohort study using quantitative and qualitative methods Sample: adolescents aged 15-21 years who were prescribed a controller medication (n = 40); 75% African American	Overall adherence was low (43%). Adherence was better for younger vs. older participants. Adolescents did not perceive preventive medications as a way of minimizing asthma-related health risks and perceived few benefits from taking a controller medication. Over half reported barriers to controller medication use. Teens made suggestions to increase their use of controller medications but most felt they would have difficulty overcoming the barriers without external support.	Teens have limited self-efficacy for taking daily controller medications due in part to perceived benefits and barriers. Teens may benefit from external support from family members for medication adherence. Limitations: Adherence rates may have been overestimated because adolescents were aware of medication use monitoring.

Table. **Summary of Studies Reviewed (continued)**

Study/Purpose	*Study Design/ Sample Characteristics*	*Results*	*Conclusions/Limitations*
Rhee et al (2007)[11] Explored psychosocial experiences and coping strategies of adolescents with asthma	Retrospective, descriptive approach using focus groups Sample: adolescents aged 12-18 years (n = 19); 47% African American	General perceptions: asthma limited their everyday lives; perceptions of loss and unfairness. Emotional reactions: embarrassment reported by older adolescents; inferiority in physical performance; negative emotions of loneliness and sadness. Perceptions and attitudes of others: misperceptions and minimizing physical limitations; asthma not perceived seriously enough by others. Coping strategies: toughening up themselves; guardedness; modifying lifestyle.	Interventions should promote positive interpersonal relationships between adolescents and important others, specifically improving communication and understanding various coping styles. Conflicts between developmental need for normalcy and everyday demands of the disease can affect self-management behaviors. Limitations: There was no follow up over time, and focus groups were of varying sizes, some very small.
Riekert et al (2011)[14] Assessed feasibility of a motivational interviewing (MI) based asthma self-management program for inner city African American adolescents	Non-randomized pilot study; pre-post evaluation of MI intervention Sample: adolescents aged 10-15 years seen in ER for asthma (n = 37); 100% African American	Adolescents reported feeling more motivated and ready to adhere to treatment, but no statistically significant difference in medication adherence was found between pre-post evaluations.	MI was feasible and acceptable to African American adolescents with asthma and might be efficacious to treatment adherence. Limitations: Absence of a control group
Sin et al (2005)[12] Examined the relationship among asthma knowledge, self-management, and social support in African American adolescents with asthma	Correlational descriptive study using a convenience sample Sample: students aged 15-17 years from 3 high schools in Alabama (n = 53); 100% African American	Asthma knowledge positively correlated with asthma self-management behaviors ($r = 0.33$, $P = 0.01$); social support positively correlated with asthma self-management ($r = 0.34$, $P = 0.008$). Asthma knowledge and social support accounted for 14% of variance of asthma self-management behaviors ($F = 4.05$, $P = 0.024$).	Knowledge about asthma may help adolescents feel more confident in managing their disease. Higher social support from family, friends, and school along with asthma knowledge may also enhance self-management behaviors in African American adolescents. Limitations: Small convenience sample, use of questionnaires with low reliability and limited validity
Valerio et al (2016)[31] Assessed the association between health literacy and asthma management among urban African American adolescents	Secondary data analysis from control group of RCT Sample: students aged 15-19 years with physician-diagnosed asthma in grades 9-12 from 6 Detroit high schools (n = 181); 100% African American	~ 44% of students had BMI ≥ 85th percentile. Overall health literacy was 11.70 ± 2.98 (range, 3-15). Multivariate analysis revealed inadequate health literacy score associated with younger students (9th grade), more hospitalizations, and lower QOL scores. Students with lower confidence in filling out medical forms were generally younger, had less educated mothers, BMI > 85th percentile, and were without rescue medication.	African American adolescents, especially younger teens, with inadequate health literacy were more likely to be obese and have hospitalizations for their asthma, which puts them at greater risk for poor asthma outcomes than their white or Hispanic counterparts. Limitations: This was an exploratory study, so findings do not reflect causality; 3-item health literacy assessment was not previously validated on adolescents.

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Table. **Summary of Studies Reviewed (continued)**

Study/Purpose	*Study Design/ Sample Characteristics*	*Results*	*Conclusions/Limitations*
Wagner & Steefel (2017)[33] Explored the beliefs regarding asthma management and Asthma Action Plans of African American caregivers residing in 3 New Jersey public housing communities	Qualitative study using semi-structured interviews Sample: caregivers of children aged 3-15 years (n = 9); 100% African American	Self-determination was common among the themes and subthemes identified. 3 major themes emerged: Challenges in the Urban Environment (subthemes included insurance instability, food insecurity, legacy of intergenerational asthma, involuntary reactions to each challenge) Preferences for Familial Methods (subtheme described the use of non-medical interventions to control progression of asthma, use of vigilant observation and non-traditional preventive strategies vs. an Asthma Action Plan) Access to Medical Care (subthemes included lack of knowledge regarding Asthma Action Plans, decision-making and preferences regarding the need to seek emergency care, and the importance of "attentive attitudes" of health care providers)	African American caregiver knowledge and beliefs about asthma and asthma care can potentially influence adolescents with asthma. Limitations: This study had a small sample size. The caregivers' influence on child-related asthma management and beliefs over time cannot be determined from this study. The association between caregiver beliefs and asthma management was not assessed.

HCP, health care provider; MST-HC, Multisystemic Therapy-Health Care; QOL, quality of life; RCT, randomized controlled trial.

use of inhaler devices is an important aspect of asthma self-management that have been found to be inadequate in African American Adolescents.

Interventions and programs geared to improving education may lead to improved self-management. Multisystemic Therapy-Health Care (MST-HC) is a tailored home-based intervention that includes knowledge and skill-building components. In a study of African American youth with poorly controlled asthma, the program was found to improve illness management.[18] In addition, adolescents who complete formal asthma education programs demonstrate significantly higher scores in self-management than those youth who do not participate in these programs.[13,19] Unfortunately, few African American teens report participation in an asthma education program.[19] In a study of a motivational interviewing intervention to improve controller medication adherence for African American adolescents,[14] youth reported gaining more knowledge about their asthma medications and were significantly more motivated to take their controller medications after participating in the intervention; however, while adherence to controller medications was greater than baseline, it was not significantly different.[14] This study demonstrated the value of asthma education and the feasibility of a motivational intervention to support controller medication adherence. However, this study also demonstrated the complexity of medication adherence in that neither knowledge or motivation led to significant changes in medication adherence among African American adolescents.

Low health literacy can also act as a barrier to asthma self-management. Health literacy requires skills and knowledge that enable an individual to communicate, process, and understand basic health information that informs health decisions.[20] Health literacy was found to be associated with indicators of poor disease self-management among urban African American adolescents in grades 9 through 12.[21] In this study, health literacy was established using questions about confidence in filling out medical forms, self-reported problems with learning about the youth's medical condition, and the need for assistance in reading hospital materials. Adolescents with poor health literacy scores were more likely to reside in a household with the following characteristics: mother with less than a high school education, Medicaid health insur-

ance, family members with a body mass index exceeding the 85th percentile, and lack of rescue medication. Poor health literacy was most common among younger adolescents (ie, ninth graders). Some youth with poor health literacy also reported more emergency department visits, hospitalizations, and lower overall quality of life.[21]

Beliefs and Attitudes

Beliefs and attitudes towards taking asthma medications can act as barriers to adherence in the adolescent. African American adolescents often report the belief that ICS are not helpful or necessary.[16,22-25] These beliefs have been correlated with a lack of understanding of the inflammatory mechanisms of asthma, reports of asthma attacks despite use of controller medications, fear of addiction to medications, and a belief that nontraditional interventions (eg, exercise) will work better to get rid of asthma or abate symptoms.[16-19,22-24] African American adolescents also report beliefs that asthma will go away or get better as they age, and they are willing to forgo the use of controller medications based on these beliefs.[24]

African American adolescents often engage in asthma self-management independent of caregivers. These youth describe asthma self-management activities an annoyance and of low priority in part due to competing tasks and negative interactions with caregivers.[25] During early adolescence asthma self-management is often suboptimal, and as youth age they become less observant regarding their asthma and are less likely to seek help.[26] Adolescents' beliefs and low prioritization of asthma self-management may contribute to forgetfulness and loss of inhalers, which are common reasons reported for poor adherence to ICS.[16,23-26] Further, the role of caregivers during this period has often been overlooked. Caregivers of African American adolescents have been found to be stressed and overwhelmed with personal responsibilities and neighborhood conditions, leaving them little time to attend to the asthma self-management behavior of youth. Due to these contextual factors, interactions with chronically ill youth may be strained, resulting in negative interactions with youth related to asthma self-management. However, in an intervention study that used multisystemic therapy (an approach that targets the affected individual, family, and community), improvement in positive parenting behaviors related to asthma self-management contributed to improved ICS adherence by adolescents.[27]

Adolescents can perceive traditional asthma self-management as conflicting with their own personal and/or cultural beliefs. They may seek options beyond the use of medicine and have voiced preferences for behaviors that they believe will "strengthen their lungs" more naturally.[24] An appreciation of how youth might use complementary/alternative medicine (CAM) as an adjunctive therapy or in place of evidence-based asthma care is important to understanding the potential effect on morbidity and mortality. Behaviors and beliefs about the use of CAM have not been well studied among urban African American adolescents with asthma. Only one study was found that assessed the use of CAM among a primarily urban African American adolescent population. In that study, 71% of the population reported using some form of CAM during the past 30 days.[28] Prayer and relaxation were the most frequently used strategies in the management of asthma symptoms. Perceived efficacy of relaxation and prayer among teens who engaged in this form of CAM was 87% and 85%, respectively. Other CAM strategies included yoga, meditation, guided imagery, and biofeedback. When adolescents were asked if they shared their use of CAM in asthma management with a health care provider, most reported sharing the use of yoga and dietary changes but were least likely to share their use of prayer and guided imagery.[28]

Personal/Emotional Factors

African American adolescents have reported asthma as a limiting factor in terms of both physical and social activities. They perceive asthma as a burden to themselves and others (eg, peers, family, coaches).[9,25] The burden of asthma is further exemplified in the emotional response to the symptoms of the disease and the self-management responsibilities. The need to prevent and respond to asthma symptoms is associated with being embarrassed, frustrated, angry, annoyed, worried, lonely, and isolated.[9,11,25] Negative coping strategies by youth in response to psychosocial experiences include decisions to disregard or give minimal attention to asthma symptoms and to delay or not take prescribed medications.

Students report ignoring asthma symptom management while engaging in physical activities to maintain a sense of normalcy among peers and as a way of dealing with perceptions by coaches or teachers that they are weak or in need of being protected.[24,25]

Negative thoughts and experiences can result in depressive disorders and poor quality of life. Depression is a common finding among urban youth with asthma.[29,30] Youth diagnosed with asthma who have comorbid depression may benefit from interventions to improve self-management. In a secondary analysis from a Web-based asthma management intervention targeting African American adolescents, depression was found to have a modifying effect on the emotional domain of quality of life for youth in the intervention arm of the study. This finding indicates that participants who were depressed and who reported low levels of emotional quality of life benefited from the Web-based interventions that targeted self-management.[31]

Caregivers

Caregivers (especially moms) are a common source of support for the development and implementation of asthma self-management behaviors in adolescents.[32] Caregivers sometimes hold beliefs similar to those of youth and believe the urban environment can act as a barrier to asthma management.[9,25,32] They describe the complexity of asthma treatment plans, a lack of understanding of the disease process, and insensitivity of health care providers to their expressed needs along with the providers' limited cultural awareness in the development of self-management plans.[9,22,33] Caregivers describe how family finances, insurance gaps, access to care, and their own familial/cultural beliefs influence their decisions and ability to support their child's asthma management.[33] When faced with the cost of care they report instances of having to decide between necessities such as food and housing or co-pays for medications and office visits.[22,33] They also report concerns about visits with multiple providers due to an inability to access their primary care provider, which can lead to delays in their child being diagnosed with asthma.[22]

Caregivers report a need to include culturally based practices, past experiences, and personal beliefs into the adolescents' asthma management plan.[22,32,33] In a small interview-based study of caregivers residing in 3 New Jersey public housing communities, caregivers reported preferring "familial" methods of controlling asthma (eg, restriction of activities; use of showers, steam, vaporizers, and nebulizers) over evidence-based recommendations. Many caregivers were confused or lacked knowledge about asthma action plans.[33] Caregivers have also been found to lack adequate or accurate knowledge related to asthma medications and factors that improved or worsened asthma. While caregivers report a desire to help educate their teens by passing on what they know, their lack of adequate asthma knowledge may hamper their efforts and potentially worsen the teens' asthma self-management.[32]

While African American caregivers often describe themselves as hypervigilant concerning their child's asthma, they may report different information than their adolescent when both are questioned about asthma symptom experiences and functional status.[34] Factors increasing the level of congruence between caregiver and teen asthma symptom reports were found to be related to the adolescents' age and asthma disease classification. Symptom questionnaire responses of older teens and those with mild intermittent asthma were more likely to be similar to caregiver reports. The researchers concluded that clinicians and researchers may obtain reliable asthma symptom and functional status reports by asking the adolescent directly.[34]

Schools

Caregivers and adolescents describe schools as a threat to self-management and the overall health of youth with asthma.[9,32] They perceive that a lack of knowledge by staff, teachers, and coaches contributes to inattentiveness or disbelief in the credibility of reported asthma symptoms by youth.[11,23] These misperceptions and the lack of attentiveness by adults in the school may pose safety and health issues for African American youth.[9,25,33,34] For example, adolescents report pressure from teacher, coaches, and peers in school settings to partake in sports and/or gym classes. Youth want to identify with healthy peers and thus often choose not to take asthma medications during such activities or opt to continue participating while being compromised by airway obstruction. Of great concern

were reports by caregivers and teens of not being allowed to call a parent for support or retrieve their medications when needed for asthma symptoms.[32]

Future Research and Practice Implications

In this review, we identified 5 common themes around barriers to asthma self-management for African American adolescents (knowledge and skills, beliefs and attitudes, personal/emotional factors, caregivers, and schools). Caregivers, especially mothers, play a pivotal role in the development of effective asthma self-management behaviors. Depsite good intentions, there is evidence of caregivers passing on ineffective experiential and culturally based beliefs and practices to their adolescents that can negatively influence self-care behaviors.[13,28,38] Studies are needed to further investigate these findings among caregivers as their beliefs and practices for asthma self-management have been found to coexist among adolescents. Studies that investigate how to incorporate caregiver asthma knowledge, cultural beliefs and behaviors in developing self-management interventions have the potential to positively influence asthma outcomes among African American adolescents.[27] The unique cultural beliefs, contextual environmental, and social disparities faced by African American caregivers should not be neglected.

African American adolescents, like adolescents in other racial or ethnic groups, desire to be autonomous in their asthma self-management. However, as adolescents age their adherence behaviors often decline. This may suggest a need for a longer transition period to self-management that extends into emerging adulthood (18-25 years). While youth want to feel supported, there appears to be a fine line between receiving needed support and what youth describe as "nagging" behaviors by adults. Additional investigations into how asthma responsibilities are transitioned from the parent to youth and how best to support the development and maintenance of related behaviors and skills are warranted. In addition, teens described problems related to communicating with health care providers, noting a lack of clarity in explanations received about how to manage their asthma. Some teens believed the communication challenges were based on beliefs and biases held by providers that African American youth had limited capacities for self-management.[9] There is a need to better understand interactions among African American adolescents, parents, and clinicians so that communication and transitioning asthma care to the youth will produce optimal health outcomes.

According to asthma guidelines, the patient-provider relationship is essential to effective asthma self-management.[4,5] However, there is little mention in the literature of team-based care. Clinicians such as physicians, physician assistants, and nurse practitioners provide direct care to adolescents in terms of disease management and the overall effectiveness of treatment plans. African American youth demonstrate a need for asthma education that is comprehensive and that is contextualized to their daily lives. A team-based approach to care that includes social workers and community health workers may help to extend the reach of clinicians. Follow-up times with families and youth between office visits can be used to support adolescents to develop asthma self-management and allow them a safe space to describe frustrations and other emotions that contribute to their desire to be disease-free.

Summary

Asthma is a chronic disease that is often more severe and difficult to manage in African American adolescents. While African American adolescents describe developmental needs like those of other youth, cultural beliefs and contextual experiences influence their self-care management in unique ways. Opportunities exist to better understand the needs of African American adolescents and to help them successfully gain the knowledge, skills, and behaviors needed to effectively engage in self-management of their asthma.

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