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Young African American adults with asthma: what matters to them?

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ABSTRACT

Background: Asthma is a common chronic condition that shows significant health disparities among minority populations. Little research has focused on the management needs and preferences of young African American adults with asthma, a population undergoing dramatic life changes as they transition from adolescence to adulthood.

Objective: To understand the experiences and perspectives of young African American adults managing their asthma.

Methods: Focus groups were conducted with African American adults (n = 34) 18 to 30 years old with a physician diagnosis of asthma. Focus group sessions were audiotaped, transcribed verbatim, and coded using constant comparative analysis.

Results: Six major domains were identified and some of the salient themes included changes in asthma management needs with the onset of adulthood, career limitations owing to asthma, childcare interference with asthma regimen adherence, and difficulties with medication cost owing to lapses in insurance coverage. Participants also reported feeling discouraged when interacting with physicians as it related to their asthma care; yet ageism and racism were not perceived. Despite poor medication regimen compliance, participants were overwhelmingly interested in participating in asthma self-management programs and had strong preferences that such programs be tailored specifically to young adults with special consideration of the cultural experience of young African Americans with asthma.

Conclusions: Young African American adults have specific barriers to optimal asthma care and distinctive ideas for self-management programs. It is important for the asthma care provider to identify and address these population- and age-specific barriers to improve asthma outcomes and decrease health care disparities.

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Introduction

Asthma is a common chronic condition characterized by airflow obstruction, bronchial hyper-responsiveness, and inflammation.¹ Studies have consistently demonstrated health care disparities in asthma. For example, African Americans have a much higher prevalence of asthma attacks, with nearly 3 times more emergency department visits, hospitalizations, and deaths from asthma than whites.² Recent prevalence rates for asthma in the United States have shown that 7.3% of the population has asthma, with a slightly higher rate of 8.1% in African Americans,³ yet the severity and control measures are significantly worse.

Health disparities in asthma are due to environmental and underlying genetic factors. Urban areas, which often have a

predominance of African American patients, may have factors associated with asthma, such as exposure to air pollution,⁴ cockroaches,⁵ dust mites,⁶ poor diet,⁷ poverty,⁸ stress,⁹ and violence.¹⁰ Nevertheless, studies that have controlled for these factors have found that African Americans have significantly worse asthma outcomes, decreased visits with asthma specialists, and decreased use of an inhaled corticosteroid for persistent asthma compared with whites.^{8,11–13} In consequence, understanding and removing barriers to optimal asthma care is important for decreasing asthma disparities in African Americans.

To date, little research has focused on optimal interventions in young African American adults with asthma. Young adulthood marks profound change and importance because many are faced with being responsible for their own health care, finances, education, and employment. In addition, many pediatricians discontinue care for patients at 18 years of age and not all adult medical providers are fully trained to handle the challenges and personalities of young adults emerging from adolescence.¹⁴

To understand the unique experiences of this population, focus groups were chosen to capture a detailed description of concerns,

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fears, and challenges related to asthma to generate concepts for improved management and research.^{15,16} Qualitative research provides useful methods to understand the complexity of patients' attitudes and beliefs regarding their health.¹⁶ Qualitative research also can be used to generate hypotheses for subsequent quantitative research. The authors conducted focus groups with young African American adults with asthma to better understand the barriers to optimal asthma management, identify strategies to improve asthma management, and explore preferences for participating in an asthma self-management program.

Methods

Participants

Focus groups were conducted with 34 African American adults 18 to 30 years old with a physician diagnosis of persistent asthma. All participants were self-identified as African American. Persistent asthma was defined as currently using a controller medication (inhaled corticosteroids, inhaled corticosteroids plus long-acting β agonist, or a leukotriene modifier) on a daily basis, using a rescue medication at least 3 times per week, or having been to the emergency department in the past year because of asthma. Participants were ineligible if they had any other significant cardiopulmonary disease, had a greater than 20-pack-year smoking history (because this level has been associated with the development of chronic obstructive pulmonary disease)¹⁷; were not fluent in English, or had a significant cognitive impairment that would make participation in a focus group impossible.

Participants were recruited from the University of Michigan asthma registry and 2 community clinics. Most patients who were recruited using the University of Michigan asthma registry had some type of insurance. One of the community clinics is a federally qualified health center, which provides care for individuals without insurance. The other recruitment site is a community outreach clinic, which serves adolescents and young adults exclusively, often without insurance. Demographic information and responses to the Asthma Control Test¹⁸ were collected by a self-administered questionnaire. The University of Michigan institutional review board approved the study, and all participants provided written consent.

Focus Group Design and Data Collection

A research team composed of 2 asthma and allergy physician specialists and 2 behavioral research scientists with experience conducting asthma focus groups developed a series of open-ended questions and prompts to guide discussions. The questions were based on a review of the asthma literature about the intended target population and addressed topics, such as initial asthma diagnosis, interference with quality of life, challenges to optimal asthma management, medication compliance, changes in asthma over time, physician discussions regarding asthma, motivation to participate in an asthma self-management program, and their preferences for asthma education programs. Participants also were invited to share views or any other aspect of asthma management they wished to discuss.

Focus groups were conducted from November to December 2012. As recommended in previous research on the structure of focus groups, each group was designed to consist of 6 to 10 participants.^{19,20} Each focus group lasted approximately 1.5 to 2 hours and was led by 2 facilitators. The 2 facilitators were African American and experienced focus group leaders who had previously worked with African American and asthmatic populations. A physician also was present at the beginning of the focus group to answer questions posed by the participants. Once the question-and-answer period ended, the physician left the discussion area

Table 1

Characteristics of participants (n = 34)

Age (y), mean $\pm$ SD	24.7 $\pm$ 3.3
Sex, n (%)	
Male	11 (32)
Female	23 (68)
Currently in school, n (%)	8 (24)
Currently working, n (%)	20 (59)
Hours worked per week (for those currently working), mean $\pm$ SD	40.7 $\pm$ 12.6
Level of education, n (%)	
High school or less	20 (59)
Trade school/some college	9 (26)
College degree or higher	5 (15)
Medical problems (in addition to asthma), n (%)	
0	16 (47)
1	10 (29)
2	5 (18)
3	3 (9)
Age at asthma diagnosis (y), mean $\pm$ SD	7.6 $\pm$ 7.4
Asthma medications, n (%)	
None	2 (6)
SABA only	7 (21)
Daily ICS	13 (38)
Daily ICS + LABA combination	5 (15)
ICS/ICS + LABA and Singulair ^a	7 (21)
Any ED visits in previous year due to asthma, n (%)	
Yes	20 (59)
No	14 (41)
Any hospitalizations in previous year due to asthma, n (%)	
Yes	7 (21)
No	27 (76)
Unknown	1 (3)
Any ICU admissions/intubation in lifetime due to asthma, n (%)	
Yes	11 (32)
No	22 (65)
Unknown	1 (3)
ACT score, mean $\pm$ SD	16.3 $\pm$ 4.1

Abbreviations: ACT, Asthma Control Test; ED, emergency department; ICS, inhaled corticosteroid; ICU, intensive care unit; LABA, long-acting β_2 agonist; SABA, short-acting β_2 agonist.

^aMontelukast sodium (Merck, Whitehouse Station, New Jersey).

to generate unbiased conversation. The groups were conducted in a manner to ensure confidentiality and encourage spontaneous discussion. The moderators encouraged further discussion, obtained information from less vocal members of the focus groups, and clarified and summarized comments as needed. Each session was recorded and transcribed verbatim by an independent professional transcription service. Participants received a monetary incentive after completion of the focus group.

Analysis

The analysis of the focus group data began with a review of the transcript from the first focus group session. Consistent with recommendations for multiple coding of qualitative research data,^{21,22} 3 coders from the study team reviewed the first transcript: 2 physicians from the study team who had not been present for the focus group discussions and 1 of the focus group facilitators. Working independently, the coders read the text of the first transcript and identified categories of responses that emerged for each line of text. Then, coders discussed their individual coding of categories and themes. Differences in coding were resolved with repeated review and discussion of the transcript data. When agreement of consensus was established, a final coding scheme was constructed. This grid of codes was applied to the remaining interview data. Each remaining transcript was reviewed. When new categories or responses were identified, they were added to the grid of codes after consensus was established for the new findings. New categories of responses were added only after all coders had reached agreement.²³ After all transcripts were coded, themes and categories of responses were clustered into major domains. Data are presented as mean $\pm$ SD where appropriate.

Table 2

Major domains identified in focus groups with young African American adults with asthma

Domain	Descriptors
I. Impaired quality of life due to asthma	Unable to pursue desired career choice or had to switch jobs because of asthma symptoms Limited ability to play with their children
II. Life responsibilities interfering asthma management	Parenthood or other care-taking roles take precedence over managing their asthma
III. Difficulty with asthma medication compliance and medication concerns	Belief that if they are not having symptoms, the medication is not needed Desire not to be different from their peers Inconvenient to carry medications Costs and lack of insurance are significant barriers
IV. Asthma management has changed as reached young adulthood	Overall increased awareness of their triggers and better informed on how to manage their asthma, even if not necessarily compliant
V. Belief that their physician does not understand their asthma management issues	Believing that their physician was just prescribing medications instead of having a discussion with them Believing that physicians were not helpful in assisting with obtaining medications
VI. Motivation to participate in an asthma self-management program	Convenient and tailored messages are important Online programs are desirable Programs that utilize smart phones and text messages are also popular

Results

Thirty-four young adults with asthma participated in the focus groups. All participants were self-identified as African American. The average age of the participants was 24.7 ± 3.3 years, and the average age at which asthma was diagnosed was 7.6 ± 7.4 years. Sixty-eight percent of participants were women and 59% of participants had a high school education or less. Poor asthma control was evidenced by the fact that the mean number of emergency department visits over the past year was 1.5 ± 1.6 , and the mean score on the Asthma Control Test was 16.3 ± 4.1 (range 7–23), which are consistent with “uncontrolled” asthma by the National Asthma Education and Prevention Program¹ guidelines (Table 1). There were no significant differences in the demographic information or asthma measures among participants from the 3 recruitment sites (data not shown).

Six distinct domains emerged from the focus group discussions, which are summarized in Table 2. Direct quotations from the focus group members are included under each theme to illustrate the richness of the qualitative data.

Domain I: Impaired Quality of Life Due to Asthma

Participants described impairments in quality of life specific to young adulthood. A frequently mentioned frustration was the need to alter career choices and work activities because of asthma. Others noted they were not able to play with their children or take part in household chores to their desire.

I was afraid to join the marines.
Car exhaust at the dealership bothered me, so I had to change jobs.
I can't go as fast stocking shelves at work.
I can't play with my son the way I want to.
My daughter wants to play, but I can't because my asthma starts acting up.

It's my responsibility around the house to help my mother, help cut the grass and stuff like that and I can't.

Domain II: Life Responsibilities Interfere with Asthma Management

Participants acknowledged a plethora of responsibilities, with childcare duties playing a significant role in interfering with optimal asthma management. Other responsibilities included working, attending school, having a significant other, taking care of other family members, and household chores.

I work and I have a little child, so the busyness of it all makes it hard to remember to take care of my asthma.
When you're a parent or have responsibilities for other people, you tend to forget about yourself, especially as women. Men are different, it's in their nature to think about themselves first, but women, we just automatically put everyone else ahead.
I have extended family that live with me, and have to help my nieces and nephews out with their medical problems too.
...[Asthma] is not always the first thing on my mind with my other responsibilities.

Domain III: Difficulty with Asthma Medication Compliance and Medication Concerns

The participants reported many barriers to asthma medication compliance. Terminating therapy when symptoms abated was common.

After you feel better, you be like “okay maybe I'm healed” and then a week later you're like “Nah, I need my inhaler back.”

Many participants also expressed a desire to fit in with their peers and not stand out by taking asthma medications. In addition, participants often reported not using a spacer or peak flow meter because of the inconvenience.

I hate feeling like I'm different. I have a problem when it comes to that and I hold off on my medicine.
As you get older, you care what people think more. So I try to hold [asthma medication] off and be cool.
I don't use a spacer and there's no way I'm carrying that around.
I can't carry my medications in the summer, in winter I can put it in my coat, but I don't like carrying it in my pants.

Other barriers that affected many of the participants were the cost or difficulty obtaining their medications. This was often due to insurance coverage lapses. For example, some participants described their issues with cost when probed by the facilitators.

I was on my mom's insurance, but then when I was 25, I had to get my own insurance that didn't cover the medications I was on.
I try to spread [fluticasone and salmeterol; Advair, Glaxo-SmithKline, Philadelphia, Pennsylvania] out. I'm paying 65–70 dollars at a time for it.
I've had health insurance lapses, so sometimes I have the inhaler and I'm okay and then it goes out, but then I don't have insurance.

Domain IV: Asthma Management Has Changed with Age

Although participants frequently reported not taking their medications as prescribed owing to the aforementioned reasons, many participants reported an improved understanding of how to manage their asthma as they have reached young adulthood. Some stated that they had a better awareness of their asthma triggers and an increased understanding of how to prevent attacks.

I didn't care about triggers as an adolescent, but now I do.
I have better control 'cause I know the signs when I'm starting to get sick and I can take the medication by myself.

Participants also acknowledged that when they were younger, many had someone to remind them to take their medications, whereas, in young adulthood, this is not the case.

My mom always reminded me to take it [asthma medication], but now I have to remember on my own and I forget.

Domain V: Belief That Their Physician Does Not Understand Asthma Management Issues

Many participants expressed frustration with their physicians, particularly a feeling that their physician was not taking the time to explain asthma management and was just prescribing medications. Others felt rushed during their appointments and believed that they did not have an adequate asthma management plan.

When I go to my appointment, they try to rush, get you in there, rush you out, get you some stuff, take this, do this.

The doctor was just kind of oblivious, she would just say “Oh here, take this” and we never actually sat down and made a plan. I’ve talked to my doctor before. When [my asthma] has gotten bad, they seem to always revert to steroid medication, and I don’t like the way it makes me feel.

Despite these frustrations, when asked if they felt it was difficult to speak to their physician because of personal factors or insinuated racism, the overwhelming response was “no.”

Domain VI: Motivation to Participate in a Self-Management Program

The vast majority of participants expressed interest when asked if they would be willing to participate in an asthma self-management program. Many expressed the desire to learn more about their asthma and improve control.

I would do it to figure out how to best manage my asthma, so I can get more active and get healthier.

The participants also had specific ideas about the features of the program. Overall, convenience was a large factor in determining whether they would participate. Most participants used the Internet and E-mail daily and had smart phones with free text messaging. Many participants stated that an online program would be helpful and expressed that receiving messages by E-mail and text would be desirable. They also expressed a need that any messages delivered through an asthma management program be tailored specifically to African Americans. Moreover, participants expressed a keen interest to learn preventative information through such a program.

If you market it towards African Americans, it may [help them] understand.

I think the African American population has different issues with [asthma].

I would like to know if the weather is changing or if there’s supposed to be a high pollen count, information like that to let me know ahead of time that my asthma might be acting up.

Discussion

Racial and ethnic minorities in the United States have significantly worse health outcomes.¹⁶ The present focus groups reinforced these findings as evidenced by the percentage of those with yearly emergency department visits (59%), yearly hospitalizations (21%), and lifetime intensive care unit admissions or intubations (11%). Therefore, research is critical to understanding the specific challenges and preferences in minority populations to improve health management.

The purpose of this study was to fully understand the important issues for asthma control in young African American adults. Major

domains that emerged from the analysis included career alterations or limitations because of asthma, childcare interfering with asthma regimen adherence, difficulties with medication cost owing to an insurance lapse, increased responsibility over time, and feeling disheartened regarding interactions with physicians specific to their asthma care. Despite poor medication regimen compliance, participants were overwhelmingly interested in participating in an asthma self-management program geared to the communication style and concerns of young African American adults. These programs may be most effective through the use of culturally appropriate syntax, inclusion of models of color in educational materials and self-management programs, and by addressing the domains listed in Table 2.

The young adults in the present study expressed that caregiving roles interfere with optimal asthma self-management. Young women in particular often reported that caring for their family and children had precedence over their own asthma care. Many parents tend to hold traditional views when it comes to the division of childcare and breadwinner responsibilities, with mothers being primarily responsible for childcare and fathers being the breadwinners.²⁴ In addition, mothers are noted to be engaged in interactions with their children more frequently than fathers.²⁵ Therefore, it is not surprising that many of the young women in the focus groups were more concerned with taking care of their families than with their own health care. In addition, many participants, men and women, expressed frustration regarding limitations in playing with their children because of their asthma symptoms. It is important for asthma care providers to recognize these obstacles and use them as motivation, particularly for young African American women, when counseling them on the importance of asthma care.

Financial difficulty in obtaining the prescribed medications owing to a lack of insurance was a commonly noted barrier to medication adherence. Much of this difficulty stemmed from insurance policy practices in which young adults are no longer covered on the parents’ insurance. In addition, many reported subsequent lapses in obtaining their own insurance. For some patients, young adulthood represents the first time they are responsible for their own health care, which can be a daunting task in the current medical system. Likewise, during a busy clinic, physicians may not always be thinking of their patients’ daily hassles as a barrier to addressing their health care needs. Nevertheless, insurance coverage must be anticipated by providers to ensure that the correct steps are undertaken before lapses or other issues occur. Some corrective measures could include directing the patient to appropriate resources, such as Web sites to assist with medication cost or county-based health coverage, and using trained social workers to assist patients in the health coverage process to prevent insurance lapses. Provider education regarding resources for insurance coverage is critical in this population.

Participants overwhelmingly believed they had a better understanding of their asthma triggers as they reached young adulthood and a better understanding of how their asthma was supposed to be managed, although actual compliance was poor overall. Specifically, participants often reported terminating therapy when their symptoms abated. This phenomenon has been described previously as the “no-symptoms, no-asthma” syndrome and refers to the belief that asthma is perceived as an acute, episodic condition rather than a chronic illness.^{26,27} In previous research, the no-symptoms, no-asthma syndrome has been associated with poor asthma outcomes, including less acknowledgment of lung inflammation, lower rates of self-reported adherence to inhaled corticosteroids, and a lower likelihood of participating in self-management tasks, such as routine physician visits when asymptomatic, use of peak flow measurements, and self-adjustment of medications.²⁷ This acute, episodic view of asthma was prevalent in these participants and may be more consistent with an adolescent thought process.²⁸

The young adults expressed other adolescent values and assessments,²⁹ specifically regarding perceived peer evaluation. Participants expressed feeling uncomfortable with taking their medication in public settings because some believed that they were “standing out” by taking asthma medication. Others discussed their annoyance with the inconvenience of carrying a spacer and the need to still rely on friends and family to remind them to take their medications. Knowledge of these concerns can help providers develop tailored management plans for this age group, such as inhaler techniques that do not require the use of a spacer and medication reminders (electronically or by association with another daily activity). It is therefore important for the asthma care provider to recognize that although the patient is chronologically an adult, the patient’s thought process regarding the management of chronic disease may be more similar to that of an adolescent.

The discrepancy between understanding asthma management and patient-reported compliance with the prescribed treatment also may stem from a sense of disconnect between themselves and their asthma care providers. Interestingly, patients expressed the impression that their asthma care providers were more likely to prescribe medication than have a conversation with them regarding asthma management. However, none of the focus group participants felt that age or race played a role in communication difficulties with their health care providers. Poor communication between patient and provider seems to play a major role in medication nonadherence in this population. This emphasizes the importance of communication between the physician and the patient, with the most effective counseling being tailored specifically to the concerns of young African American patients, to convey the importance of following an asthma treatment plan and the consequences of nonadherence. Given that education may be given by other providers in the clinical setting, including nurses, respiratory therapists, and medical assistants, it is important that all patient care providers understand and implement the principles of effective counseling in young African American adults with asthma.

Another goal of this study was to ask participants about their opinions for participating in asthma self-management programs. Overall, participants were very interested in self-management programs as a tool to improve asthma control. They expressed particular interest in electronic media (E-mail, text messaging) for convenience, which is unlikely to be true for other age groups.³⁰ They endorsed the benefits of an asthma education program tailored specifically to African Americans and the need for providers or health care systems to develop culturally sensitive materials. Discussions between patients and asthma care providers that empower patients to take control of their own asthma care, such as symptom monitoring using a peak flow meter, asthma action plans, and educational materials that are tailored specifically to African Americans, will likely be of greater motivational merit to ensure compliance and ultimately decrease asthma-related health care disparities.

Young African American adults represent a population at risk for poor health outcomes because of their minority status and the potentially difficult transition from adolescence to adulthood. The present focus group analysis showed specific quality-of-life limitations because of asthma and barriers to asthma care. The analysis also showed displeasure in physician counseling of asthma in this group. Culturally appropriate discussions between the physician and the patient related to the treatment of chronic disease should increase patients’ understanding of their disease and in turn may improve outcomes. In addition, conversations that display the physician’s sensitivity to the patient’s specific needs are likely to be more motivational to the patient than generic, nontailored discussions. In asthma care, it is crucial to understand the specific barriers of a population to provide the most appropriate and effective care.

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