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Descriptors and Perception of Dyspnea in African-American Asthmatics

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Abstract

Objective—This study explores self-reported perception of asthma symptoms in African-Americans.

Methods—Qualitative methodology was used to analyze the responses from African-Americans within focus groups from Nashville, Tennessee.

Results—Common symptoms were chest tightness, “breathing problems,” and wheeze. Less commonly reported symptoms included cough, chest pain, dizziness, sweating, and “short of breath.” A single participant reported nocturnal wheezing.

Conclusions—This study provides insight into the descriptors and perception of asthma symptoms in African-Americans. Understanding the descriptors of symptoms and disease severity in African-American patients may lead to more accurate diagnosis, treatment, and reduced mortality within this high-risk population.

Keywords

dyspnea; African-Americans; asthma; perception; disparities

Introduction

African-Americans with asthma have greater morbidity and mortality than do Caucasians (1,2), possibly partly caused by their misperception or usage of different descriptors of dyspnea during an asthma attack. Self-reporting of symptoms and descriptors in African-Americans with asthma has not previously been studied. Understanding how African-American patients perceive and describe their symptoms will allow physicians to improve treatment and diagnosis of asthma and tailor patient education programs to improve self-management.

Although small studies have investigated symptom perception of induced bronchospasm (3), none has explored naturally occurring symptoms of asthma in African-Americans. Inaccurate classification of asthma severity based on symptoms leads to under-prescribing of medication for inner-city African-American pediatric patients (4). Physicians and African-American patients must be able to communicate asthma descriptors in a language that both

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parties understand for optimal care to be delivered (5). This study explores the description and perception of asthma symptoms and severity by African-Americans.

Methods

Our data represent the interim analysis of a study to create and validate a culturally sensitive perceived asthma severity questionnaire.

The study design used focus group methodology as a way to uncover the beliefs, attitudes, expressions, and descriptors of asthma symptoms and severity in African-American asthmatics. Focus group methodology allows for the determination of themes related to the perception of severity of an asthma exacerbation. Using these themes, a culturally sensitive dyspnea perception scale can be created for assessing African-American asthmatics.

Qualitative methods were chosen to allow in-depth descriptions of language used to characterize asthma symptoms and feelings about asthma that might not be fully uncovered in a structured interview or survey.

African-Americans 18 years of age and older were recruited in Nashville, Tennessee, from June 2003 to July 2004 via flyers posted at local minority universities, local tertiary care centers, community health clinics, and public health department clinics. Also, physicians at the County Hospital (staffed by medical college faculty and residents) referred patients to the study.

Inclusion criteria were patients with a diagnosis of asthma of at least 1 year's duration, requiring at least as-needed use of a bronchodilator within the previous year. All subjects were self-identified African-Americans born in the continental United States and who were living or going to school in Nashville. Asthma was diagnosed as a history of recurrent cough, wheeze, dyspnea, chest tightness, or unexpected visits to their physician or the emergency department for any of these symptoms during the preceding 12 months (6) (Table 1). All participants were being treated for asthma by their primary care physician or pulmonologist. Subjects had to speak fluent English; writing was only required to sign the consent form, which was read aloud to all participants before each focus group. Patients with exercise-induced asthma were allowed to participate in the study

Exclusion criteria were patients with a history of chronic bronchitis or chronic obstructive pulmonary disease (COPD), gastroesophageal reflux, angina, congestive heart failure, and arrhythmias. Patients with a daily productive cough were excluded from the study even if they were undergoing treatment for asthma. Subjects with other comorbid illnesses such as diabetes, hypertension, or smoking (less than 10 pack-years) were not excluded.

The Institutional Review Board at Meharry Medical College approved this study. Participants signed a consent form and completed a 1.5- to 2-hour focus group session. They received a light dinner and reimbursement for time and travel. Each focus group session was audio recorded. Participants were instructed not to identify themselves or use names in their responses. The same moderator led each focus group to sustain consistency and familiarity with the moderator guide. Participants were assessed with probes created to explore in-depth the constructs related to perception of asthma symptoms and severity. Each focus group had a Board-Certified pulmonologist (DST) present to ensure that the participants had asthma by the National Asthma Education and Prevention Program (NAEPP) criteria described above (6, Table 1) and to debrief the participants at the end of each session. A separate team member took observer notes to document interactions and focus group dynamics. An external consultant transcribed the recorded sessions verbatim.

Spirometry can be a time-consuming process, therefore, we decided not to perform spirometry during the focus group sessions. Our emphasis was on perceived symptoms during the subjects' course of their asthma, not symptoms at the time the focus groups were conducted. Additionally, asthma is a fluctuating disease and many of the asthmatics were well-controlled at the time of the focus groups. Conducting spirometry on our participants may have resulted in nondiagnostic spirometry thereby reporting asthmatics as falsely ineligible for our study.

The ideal size for an effective focus group is 6 to 12 participants (7,8). We used non-probability, purposive sampling techniques to recruit asthmatics for the focus groups. The issue of sample size in qualitative research is not set a priori; however, it is attained when data saturation is reached.

On completion of a focus group, audiotapes were transcribed and analyzed. Grounded Theory methodology is a well-established way to conduct the focus groups and analyze the data (9). Grounded theory methodology is a qualitative technique in which emergent theory is grounded in the focus group data to develop core themes. Grounded theory is a technique that minimizes the chance that the moderator will impose the hypothesis on the focus group participants. It generates theory derived by data systematically gathered and analyzed throughout the research process (9).

Data were collected by analyzing transcripts from each focus group. Each transcript was analyzed separately; all transcripts were then compiled and analyzed together. The process of labeling concepts (reviewing textual data to reduce them into larger themes) is known as coding. The research team reviewed the transcripts multiple times to confirm coding and themes. An independent consultant who was unfamiliar with the research question and asthma corroborated the coding. Each transcript was then analyzed using NVivo© qualitative coding and data analysis software, which allows for the prospective analysis of textual data. The NVivo© coding software package assisted in linking themes and concepts from seven transcripts by color coding themes and grouping them together into core categories. NVivo© is not a conventional statistical program; it is a qualitative software program that transforms textual data into quantitative data. Theoretical saturation of themes (the point at which no new themes arise) was reached at the 6th focus group. A 7th group was conducted to confirm saturation. The data collection process and the quality of the data were confirmed by methods suggested by Strauss and Corbin (9) and LeCompt and Goetz (10).

Results

Our focus groups identified that African-Americans perceive dyspnea during an asthma attack differently from the symptoms typically used by physicians to manage the disease.

Demographics of the sample population show that of the 35 participants, 69% were female (Table 2). The mean age for all the participants was 38. More than half of the participants had a college degree or higher as these participants were, by chance, recruited from local minority institutions of higher learning (67%). All participants had insurance coverage (Medicaid, Medicare, or private). Over a third of participants were diagnosed with asthma before the age of 18. Most participants were using medications, with 85% regularly using as-needed beta-agonists; some used inhaled corticosteroids and/or leukotriene modifiers as well. In the previous 12 months, 29% of the participants required an emergency department visit or hospitalization (Table 2).

Using Grounded Theory methodology to analyze transcripts, six core categories emerged regarding the perception of asthma symptoms and severity. Concepts that emerged were

knowledge/literacy, triggers, asthma management and control, psychological effects, symptom tolerance, perceived severity, and physical symptoms.

Participant responses indicate a dichotomy regarding asthma literacy. Some asthmatics became more concerned with their asthma and felt that its severity increased as they became more educated about their condition. Others became less concerned and felt their condition was less serious once they understood their disease. Symptom perception was not influenced by a dichotomy in asthma literacy.

Many of the participants were aware of their asthma triggers and attempted to eliminate interaction with identifiable triggers such as dust, seasonal change, household cleaning items, physical activity, exposing their skin to cold weather, and certain foods (e.g., shell fish, monosodium glutamate, and peanuts). Some attacks were unrelated to identifiable triggers and the participants' usual symptoms. Few subjects reported sinus congestion or rhinorrhea associated with their asthma symptoms, and these participants tended to be on an antihistamine or nasal steroid.

A dichotomy was present regarding the use of medications to manage asthma. Some African-American asthmatics indicated that they could manage their asthma by taking medications, whereas others perceived that not taking medications meant they had greater control over their asthma. Few of the participants felt that they were dependent on their medication; however, when asked how they manage their asthma, almost all participants replied that their primary relief came from their medication.

Participants, describing their symptoms and feelings related to their asthma, indicated a psychosocial aspect to their physical symptoms. Most of the respondents felt helpless or embarrassed during an asthma exacerbation. Many African-American asthmatics felt social pressure to hide their symptoms as well as a lack of community support to cope with their illness.

When queried about symptoms of an asthma attack, some of the participants did not know that change in their symptoms was indicative of an exacerbation of their asthma. Nevertheless, 85% of our participants used a short-acting rescue medication for the symptoms reported in Table 3. Many participants had grown accustomed over time to breathing poorly and indicated that judging the severity of their asthma was difficult. The analysis identified length of time having asthma, normalcy, and familiarity with triggers as the reasons why participants tolerated the symptoms described in Table 3. Few participants owned a peak flow meter. Many participants used rescue medications not for specific symptoms; rather they "just didn't feel normal." Some subjects could not perceive their own wheezing and had to be told by their family, friends, or coworkers that their symptoms were worsening.

Perception of an asthma exacerbation in these African-American participants varied from minor breathing difficulty to gasping for air and requiring emergency care. Common symptoms were "breathing problems," chest tightness or pain, dizziness, sweating, and wheezing. Less commonly reported were body pain, cough, throat pain, "short of breath," phlegm, and inability to walk (Table 3). The phrases "breathing problems" and "short of breath" were probed, but no further definition of these phrases could be elicited, and the participants reported that they felt either one or the other symptom, but not both. Participants denied the sensation that they could not "get air in.". Only a single African-American participant reported nocturnal wheezing due to asthma, even when the focus group participants were directly asked if their asthma ever bothered them at night or interfered with their sleep. No participants reported waking up to use their bronchodilator. Thus, African-Americans perceive asthma symptoms, but perceive them using descriptors often

not typically defined as asthma. This may also explain the delay in many of our subjects from getting bronchodilators or steroids upon acute presentation to health care providers.

Discussion

We found that African-Americans misperceive their symptoms during an asthma attack; this is important because understanding how African-Americans perceive their symptoms is necessary information for helping to eliminate the disparities in asthma morbidity and death. This misperception may be due to a misunderstanding of the symptom descriptors of asthma, both in African-American patients and their healthcare providers. Cross-cultural differences in communication can effect the perception of illness among races (2). Exploring perceptions of asthma symptoms in African-Americans may provide information that will improve treatment outcomes in this group (11).

Themes emerged regarding feelings of embarrassment, shame, and emotional discomfort related to their asthma symptoms (12). Psychological symptoms are not generally thought of as descriptors of asthma and are not included in NAEPP guidelines (6). Social support networks and methods to improve self-efficacy may prove to be useful ways of combating feelings of shame and embarrassment. Providing tools for African-Americans with asthma to address these issues may improve their overall ability to cope with the disease.

Our study supports previous work that demonstrates a lack of correlation between symptom perception and asthma severity (13,14). African-American participants' comments indicated passivity regarding symptoms due to acclimatization to an inability to inhale, chest tightness, weakness, or dyspnea. It is believed that patients with more severe asthma underestimate the severity of their disease because of a blunted perception of dyspnea (15–17), and many African-Americans in our focus groups were unable to detect or describe when their asthma was worsening. This is particularly worrisome given the highly educated nature of our participants, suggesting that many patients with asthma are not properly taught by their physician about the nature and symptoms of their disease. It is expected that patients with less education would be even less articulate in describing their symptoms.

The typical symptoms of asthma (cough, phlegm, and wheezing) (18) in African-Americans did not emerge as an important theme in our focus groups (either with baseline symptoms or during an exacerbation requiring physician intervention). Although wheezing is the best discriminator of asthma (18), African-American participants indicated difficulty perceiving wheezing and relied on family and friends to tell them when their wheezing was worsening. Inability to perceive wheezing negatively affects the ability of patients to manage their disease, especially in terms of when to call their physician or use rescue medication (19). Few of the participants had access to objective measures of asthma severity such as a home peak flow meter or serial pulmonary function testing at their physician's office (15,20).

Of particular importance is the absence of concern and recognition of nocturnal symptoms by African-Americans with asthma, despite being specifically asked. Nocturnal symptoms are a key feature in the diagnosis (6,21,22) and treatment of asthma (23). The lack of self-reported nocturnal symptoms does not serve as a measure of asthma severity or appear to play a role in the diagnosis of asthma within this population; rather it displays a lack of dyspnea perception or description. Qualitative techniques suggest that African-Americans do not reliably report nocturnal symptoms of asthma. Thus, it may be necessary to modify asthma classification and therapy guidelines in this minority population.

Anterior chest discomfort was the sole symptom of an asthma exacerbation for some of our focus group participants. Several of these participants reported that they were often triaged to the cardiac care part of the emergency department. They frequently had to wait hours

before receiving a nebulizer treatment or steroids for their asthma, as the treating physicians believed these participants had acute coronary syndrome. Chest pain has been recognized as a symptom of asthma, especially in the elderly (24) and those with gastroesophageal reflux (25). Chest pain needs to be considered as a symptom of asthma in African-Americans based on our focus groups. African-Americans with asthma may therefore have difficulty differentiating an exacerbation of their disease from other chest pathology, such as acute coronary syndrome.

Our study did not support the findings of Hardie, et al. in terms of descriptors of asthma in African-Americans (3). In the Hardie study, based on subjects in the San Francisco area, African-Americans almost exclusively used upper airway descriptors of their asthma symptoms (such as a tight or itchy throat), whereas our focus group participants were much more likely to use lower airway descriptors of their symptoms. Three differences in the study designs may account for this difference: (a) geographic factors (the Southeastern location of our study rather than Western location of the Hardie study may reflect regional speech patterns); (b) using focus groups with open-ended probes in our study rather than fixed answer questionnaires; or (c) the fact that we relied on self-reporting of historical symptoms rather than using bronchoprovocation (26). More work is needed to determine if African-Americans truly perceive and describe their asthma differently than Caucasians.

Limitations to our study include the small catchment area from which participants were recruited, making it difficult to generalize our findings to the African-American community outside of Nashville. As the participants were asked to describe their symptoms of prior attacks, the study is subject to recall bias; nonetheless, these are the descriptors these African-Americans report to their physicians. Spirometry was not performed; however, this study was designed to measure perceived symptoms throughout the course of a subject's illness, not at the time of the focus group. The time spent performing spirometry (approximately 2 to 3 hours per focus group if post-bronchodilator challenge was performed) would also have adversely affected the social dynamics of the focus groups (7,8). Furthermore, well-controlled asthmatics would be expected to have normal spirometry. Caucasian control groups and bronchoprovocation were not used, as the purpose of the focus groups was to identify self-reported symptoms in African-Americans with asthma. The majority of subjects were well educated, but this should have improved the self-reporting of symptoms.

In conclusion, the perception of symptoms is instrumental in the treatment of asthma. The usage of inhaled steroids is predominantly based on self-reported symptoms (21). Inadequate reporting of symptoms may lead to under treatment and the potential for greater morbidity and mortality (5,6,22). Furthermore, some patients with comorbid illness may not be able to differentiate the symptoms between their various disease processes, thus being unaware when their asthma was worsening. Understanding perceptions and descriptors of symptoms and disease severity in African-American patients with asthma may lead to more accurate diagnosis, treatment, and reduced mortality.

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Table 1

National Asthma Education and Prevention Program (NAEPP) Key Indicators for Considering a Diagnosis of Asthma (By History) (6).

- Wheezing
  - high pitched whistling sounds when breathing out–especially in children
  - Lack of wheezing and a normal chest examination do not exclude asthma
- History of any of the following:
  - Cough, worse particularly at night
  - Recurrent wheeze
  - Recurrent difficulty in breathing
  - Recurrent chest tightness
- Symptoms occur or worsen in the presence of:
  - Exercise
  - Viral infection
  - Animals with fur or feathers
  - House-dust mites (in mattresses, pillows, upholstered furniture, carpets)
  - Mold
  - Smoke (tobacco, wood)
  - Pollen
  - Changes in weather
  - Strong emotional expression (laughing or crying hard)
  - Airborne chemicals or dust
  - Menses
- Symptoms occur or worsen at night, awakening the patient

Table 2

Demographic information of focus group participants.

Variables	N	%
Age		
18–25	13	33%
26–45	10	26%
46–65	12	31%
≥65	4	10%
Gender		
Male	12	31%
Female	27	69%
Income		
≤ $10,000	13	33%
$11,000–$40,000	10	26%
$41,000–$75,000	3	8%
≥ $75,000	4	10%
Education		
≤11th grade	6	15%
12th grade	7	18%
4-year college	19	49%
≥4 years of college	7	18%
Age diagnosed with asthma		
<18	13	33%
19–25	9	23%
26–45	5	13%
≥45	12	31%
Currently taking medication		
Yes	33	85%
No	5	13%
Required an emergency department visit in the past year		
Yes	11	29%
No	28	71%

Percentages in some columns do not total to 100 owing to missing values as some participants were reluctant to answer these probes.

Table 3

Symptom descriptors in African-Americans with asthma.

***N* = 35**	**Male**	**Female**	**Total**
Symptom descriptors[†]			
Breathing problems[§]	4	19	23
Chest tightness	7	10	17
Chest pain	4	8	12
Light headed (dizzy)	1	8	9
Wheezing	2	6	8
Sweat	1	7	8
Body pain	1	6	7
Severe cough	0	5	5
Throat pain	2	3	5
Shortness of breath[§]	3	1	4
Cannot walk	1	1	2
Phlegm	0	2	2
Tired	0	2	2
Uncomfortable	0	2	2
Allergies	0	1	1
Like a cold	0	1	1
Pressure	1	0	1
Sleep elevation	0	1	1
Wake-up at night	0	1	1
Throwing up	0	1	1
Scared	0	1	1
Sample probes:			
1 When you have an asthma attack how do you feel?			
2 What does an asthma attack feel like?			
3 What are some of your asthma symptoms?			

[†]Participants were allowed to give more than one symptom descriptor. Descriptors are colloquial as they are the actual words used by the participants.

[§]"Breathing problems" and "shortness of breath" could not be further defined by the participants. Participants who reported one symptom denied that they had the other.