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Respiratory Medicine

journal homepage: www.elsevier.com/locate/rmed



Caregiver and pediatric provider perspectives on symptom-based inhaled corticosteroid therapy in asthma



Tiffany Dy^a, Ericka M. Lewis^b, Vithya Murugan^c, Sarah Gehlert^d, Juanita Taylor^a, Jane Garbutt^a, Leonard B. Bacharier^a, Mario Castro^a, Kaharu Sumino^{a,*}

- ^a Washington University School of Medicine, Saint Louis, MO, USA
- ^b University of Maryland School of Social Work, Baltimore, MD, USA
- ^c Saint Louis University School of Public Health and Social Justice, Saint Louis, MO, USA
- ^d University of South Carolina College of Social Work, Columbia, SC, USA

ARTICLE INFO

Keywords: Intermittent therapy Patient centered treatment Adherence Qualitative study

ABSTRACT

Objectives: Guidelines recommend that healthcare providers adjust the dose of inhaled corticosteroids (ICS) in asthma patients based on the degree of symptom severity and control. Symptom-based, intermittent ICS therapy (use of ICS together with short acting bronchodilators- symptom-based adjustment: SBA) has been demonstrated to be comparable to guideline-based management by providers in controlled clinical trials. We sought input from African American caregivers and pediatricians on the acceptability and barriers for this alternative management strategy.

Methods: Focus group interviews of caregivers and individual interviews with community providers of African-American children ages 6–17 years with mild-moderate persistent asthma were conducted by trained facilitators to assess perceptions of how asthma affects children and their caregivers, and of SBA as a management strategy. Interview data were transcribed and analyzed using inductive thematic based coding.

Results: Twenty-six parents participated in six focus groups. Fourteen pediatricians were interviewed. Caregivers reported facing financial burden and difficulty with tracking medications. Caregivers and pediatricians were favorable about SBA, citing its potential for decreased use of medications and cost and similarity to actual care provided. Some caregivers voiced concern that SBA would not be as effective as daily ICS. Caregivers suggested that education on symptom recognition and close communication between physician and patient would facilitate the implementation of SBA.

Conclusions: SBA was generally viewed favorably by caregivers and providers of African American children. However, concerns regarding effectiveness of SBA were voiced by both caregivers and providers. Patient education and provider-patient communication is important in implementing this alternative asthma management strategy.

1. Background

African American children with asthma have more symptoms and higher rates of exacerbation, healthcare utilization and mortality than white children with asthma, even after adjusting for factors such as income, education, and asthma severity [1,2]. African American children also report lower quality of life compared to their white peers. One commonly cited explanation for this disparity is lack of adherence to clinical visits and daily use of controller medication [3,4].

Symptom-based adjustment (SBA) is a strategy whereby inhaled corticosteroids (ICS) are administered concurrently with short acting

bronchodilators when symptoms occur. SBA allows the patient or caregiver to adjust their ICS dose use without requiring clinic visits, in contrast to the current guideline-based strategy in which the patient takes fixed daily doses of ICS with dose adjustment during provider clinical visits. Several prior studies have demonstrated that symptom guided, intermittent inhaled corticosteroid therapy is as effective as daily use of ICS in controlling mild to moderate persistent asthma and preventing exacerbations [5–7]. Therefore, SBA could be a simpler, patient-centered, alternative strategy with adjustment of the ICS dose based on patients' asthma symptoms rather than providers' orders, especially in those African American patients who have difficulty

Abbreviations: ICS, inhaled corticosteroids; SBA, symptom based adjustment; LTRA, leukotriene receptor antagonist; LABA, long acting beta agonist *Corresponding author. Washington University School of Medicine, 660 Euclid Avenue, Campus box 8052, Saint Louis, MO, 63110, USA. E-mail address: ksumino@wustl.edu (K. Sumino).

adhering to clinical visits and daily use of controller medications. However, SBA is not commonly used by providers in current routine practice [8].

We conducted a focus group study of African American caregivers and structured interviews with pediatric primary care providers to better understand their perceptions SBA, and identify what they would consider as barriers and facilitators to implementation in the community.

2. Methods

2.1. Study design and population

2.1.1. Caregivers

Our target population of caregivers of African-American children with asthma was recruited using flyers posted in public places in communities including health fairs, bulletin boards, and community pediatricians' offices. Six focus groups included a total of twenty-six African-American caregivers of children and adolescents with asthma, in groups of two to five caregivers. We included caregivers of African-American children ages 6–17 years with asthma who met the criteria of 1) self-reported, physician-diagnosed asthma, 2) prescribed treatment with low dose ICS, or leukotriene receptor antagonist [LTRA], or low-dose ICS plus LTRA, 3) symptoms less than 5 times a week per parent report, and 4) no severe asthma (not on high dose ICS or combination therapy or history of ICU admission). We determined these criteria based on a previous study in which SBA was found effective in mild-moderate persistent asthma [7].

Focus group interviews were facilitated by two external facilitators with special training in focus group methods. The facilitators' roles were to conduct the focus group and analyze the qualitative data. They had no role in clinical care, nor in conducting any aspect of research besides the focus group. The six group interviews, which ranged from 44 to 90 minutes in length, were held at community locations (public park recreation center, civic center, privately owned community center, and a church) to increase ease of participation. Caregivers were asked to complete a confidential (i.e., de-identified) questionnaire soliciting basic socio-demographic and clinical information. In group interviews, caregivers were initially asked a series of questions from an interview guide that focused on the impact of asthma on their children. Group members were then introduced to the concept of symptom-based adjustment strategy for treatment of asthma, and were asked a set of openended questions to determine their initial impressions and concerns regarding this strategy (Table 1).

2.1.2. Primary care pediatric providers

Primary care pediatric providers of African-American children and adolescents with asthma in the City of St. Louis were invited to participate. Face-to-face interviews were conducted with a sample of 14 primary care pediatric providers.

Pediatric providers were interviewed individually by the researcher (pulmonary physician: (K.S.)). The researcher was trained in qualitative interview methods and used a guide constructed for the interview

Table 1 Questions for caregivers.

- 1) How does asthma bother you and your child?
- 2) What is the most important goal for asthma care for you and your child?
- 3) How do you usually manage your child's asthma every day?
- 4) Do you do things differently when the child's asthma is doing well, and when the symptoms area worse?
- 5) (After describing what SBA is and how to do it) What comes to your mind first about the approach called "symptom based adjustment" for children?
- 6) What would stop you from trying the new symptom-based adjustment approach?
- 7) Are there any problems you can think of when doing the symptom-based adjustment?

(Table 2). Interview guide items addressed first the providers' perceived barriers to asthma management in their practice. Then, the concept of SBA was introduced, and the providers were asked about their perspectives of SBA and perceived barriers to its use.

This study was approved by the Institutional Review Board at Washington University in St. Louis.

2.2. Analysis

Focus groups and provider interviews were conducted until all points in the respective interview guides had been saturated and no new concepts were identified by interviewees. Because the purpose of focus groups is to allow some members to stimulate the thinking of others and thus generate unanticipated content, flexibility was allowed

Table 2
Ouestions for providers.

- 1) What do you think about the current asthma guidelines?
 - Do you think it is working for you?
 - What is the advantage of the current asthma guidelines?
 - · What are the problems of the current asthma guidelines?
 - Do you think it is easy for patients to follow?
 - Do you think it is difficult for patients to follow?
 What change would you like to see?
- 2) (After describing what SBA is and how to do it) Can you describe what first comes to mind about the symptom based approach to asthma management for children in your practice with mild to moderate asthma?
 - Do you see any barriers for implementing SBA?
 - Do you have any suggestions for implementation?

in interviews. All focus groups and provider interviews were audiotaped and transcribed verbatim by a professional transcriptionist experienced in transcribing group interviews. Two external facilitators who conducted the focus group sessions also conducted the qualitative analysis.

Dedoose, a cross-platform software, was used for qualitative data management and analysis. The qualitative analysts employed a mixed content analysis approach [9] that included: 1) development of a codebook and 2) identification of themes. First, preliminary codes were developed based on questions from the interview guide. One transcript was selected for double-coding, ensuring these preliminary codes adequately captured patterns that developed across the focus groups. This led to the development of an initial codebook. Upon agreement of the codebook, the remaining transcripts were double-coded for themes. Throughout the process, the analysts met regularly to discuss coded data and address coding disagreements to facilitate the identification of salient themes. Mixed content analysis, characterized by the use of inductive and deductive reasoning, is an appropriate method for analyzing qualitative data derived from semi-structured interviews. Its flexible structure enables data analysis according to an existing framework while at the same time allowing researchers to discern common threads that may have emerged outside the interview guide [9]. An identical strategy was employed to analyze physician interviews. Emergent themes from caregiver focus groups and individual provider interviews were compared to identify concordant and discordant perspectives of SBA.

3. Results

3.1. Participant demographics

Caregiver and children's sociodemographic characteristics are displayed in Table 3 (n = 26). All participants were African American, and cared for children with mild to moderate asthma. 42% were fully employed, and 54% had an annual household income of less than \$20,000. Sociodemographic characteristics of providers (n = 14) are displayed in

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