Lay Experiences and Concerns with Asthma in an Urban Hispanic Community

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Background: National asthma guidelines are often not translated into practice. Barriers to translation impact both provider and patient adherence.

Purpose: This qualitative study describes how perceptions and experiences of patients with asthma or their caregivers affect disease management in a Puerto Rican community in Buffalo, NY.

Methods: Two community-based asthma workshops following a focus group format were conducted with 22 Puerto Rican adults with asthma or who cared for asthmatic children. A bilingual-bicultural community moderator used a semistructured interview guide to foster discussion on asthma definitions, triggers, management, coping and concerns. Four analysts interpreted data transcripts following the grounded theory approach, identifying salient thematic categories. Multiple analysts and a postsearch for conflicting evidence support analytical trustworthiness.

Results: Perceptions of illness revealed concerns about the deceiving character and burden of asthma. Recognition of indoor household triggers underscored concerns about the impact on quality of life, emergency department use, and the ineffectiveness or side effects of some prescribed therapies. Misconceptions about asthma and self-management strategies were identified.

Conclusions: Learning about lay perceptions and management approaches regarding asthma may afford healthcare professionals insight to better understand, educate and care for ethnic minority patients, and help to improve their asthma outcomes.

Key words: asthma ■ patient education ■ qualitative analysis ■ Latinos

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INTRODUCTION

Asthma is a chronic disease that can be managed with appropriate medication and education.[1] Some disparities in prevalence and related morbidity have been identified among minority populations, particularly children.[2,3] For example, Puerto Rican children have been documented to have higher prevalence rates of asthma compared to African Americans and non-Hispanic whites.[3,4] Specifically, data from the National Health Interview Survey found that 83% of Puerto Rican children who reported wheezing in the past year were diagnosed with asthma compared to 71% of African American and 57% of non-Hispanic white children.[3] While asthma prevalence among Hispanic adults in 2002 was lower than among non-Hispanic white adults (5% compared to 7.6%, respectively), prevalence in Puerto Rico was higher than in the 50 United States, and U.S. territories.[5] A study by Ledogar et al. also found that Puerto Ricans had higher rates of asthma than other Hispanic subgroups.[6] Similarly, Puerto Ricans had higher asthma mortality rates compared to African Americans and non-Hispanic whites (40.9 per million, 38.1 per million, and 14.7 per million, respectively.[4] Puerto Ricans also had higher asthma mortality rates than other Hispanic subgroups.[4] Hispanic adults with asthma were more likely than non-Hispanic white adults to present to the emergency room (26% and 14.5%, respectively), to have asthma-related urgent care visits (36.9% and 25.8%), to have sleep difficulty (64.7% and 47.4) and to have activity limitations (40.4 and 23.6).[5]

The National Heart, Lung and Blood Institute's asthma guidelines encourage patient education to improve management and thus improve outcomes.[1] The guidelines recommend a continuum of educational opportunities that are supported by all members of the healthcare team, with a focus on self-management. Education should be offered in a manner appropriate to the patient's culture, age and socioeconomic status. The preparation of a written asthma action plan is one educational component

that requires good provider–patient communication in order to devise a strategy for managing asthma that is medically appropriate as well as understandable, acceptable and practical to the patient.

The translation of patient education into a culturally appropriate model is challenging. It purports the amalgamation of two distinct idioms: the language of the biomedical professional developed in medical school, and the lay person's, which is molded by lived experience.[7] Zayas et al., for example, highlighted the need to bridge these two idioms, having demonstrated how members of a predominately Puerto Rican patient population with low levels of education characterize asthma according to the acute illness model in terms of symptoms and threats of illness rather than as a chronic biomedical disease.[8] Such disconnect can hamper the patient's assimilation of the practical knowledge transmitted during office-based asthma education and thus the implementation of the prescribed asthma management plan. By better connecting these two distinct world views, the clinician–patient relationship and patient self-management strategies may improve and, in turn, alleviate the burden of asthma and prove cost-effective.[9-11]

The purpose of this study is to describe patients' experiences and concerns with asthma that challenge disease management in an urban Puerto Rican community in Buffalo, NY, with a high burden of asthma. Specifically, the main study question was: "What are the common perceptions of and concerns with asthma that could affect proper self-management in this population?" Understanding these experiences may help care providers to better deliver asthma education that can be readily incorporated into the patients' everyday life.

BACKGROUND

The Lower West Side of Buffalo, consisting of six geographically contiguous census tracts, is home to 24,951 residents. According to the 2000 U.S. Census, 35% of the population is Hispanic, 86% of whom are of Puerto Rican origin. The neighborhood is young, with 27% <18 years old and only 11% age ≥65 years. Thirty-seven percent of the population fall below poverty level and 22% receive public assistance.[12]

A community health needs assessment, conducted in 1994, revealed that 14% of Hispanics age ≥12 years or older had asthma, compared to 10% of African Americans and 6% of Non-Hispanic whites.[13] Twenty-one percent of Hispanic children (<12 years old) were reported to have asthma compared to 14% of African Americans and 11% of non-Hispanic whites.[13] One-third of people with asthma reported their health status as sick or poor, and 14% reported not having a primary care physician.[13] Another study conducted in the same area found that 41% of households had at least one person living there with an asthma diagnosis.[14]

Table 1. Six key questions leading the focus group discussions

Question	Description
1.	What do you think asthma is?
2.	What do you think gives people asthma?
3.	What things worry you about your asthma?
4.	Does your asthma limit your activities? How so?
5.	How do you treat your asthma?
6.	How do you deal with your asthma?

METHODS

Two asthma workshops were held that were targeted to the Puerto Rican population in the community. They were held in different locations to accommodate convenience of participants. The workshops were recommended in an earlier participatory research study that explored actual and potential asthma education interventions in ethnic minority communities of western New York State.[15] Questions for the asthma workshops were derived in part from the focus group moderators guide used in the previous study. The workshops allowed participants to learn from each other by sharing their experiences. Twenty-two adults (≥18 years of age) who had asthma or were household caretakers of children with asthma participated; one workshop included nine participants, the other 13 participants. Self-reported asthma diagnosis was confirmed by the patient's medication prescription. The participants were invited through flyers and word of mouth in community centers. Interested parties voluntarily contacted the project director in order to participate. The University at Buffalo's institutional review board approved this project.

The workshops followed a focus group discussion format. A bilingual Puerto Rican moderator from the community facilitated the workshop. The moderator was trained in facilitation techniques by a qualitative research expert, specifically in clarifying expectations, managing the agenda, equally engaging all participants, probing without leading, prompting stories with content and context, and group management issues. A semistructured interview guide consisting of six questions about asthma perceptions, known triggers, management, healthcare utilization, and other experiences and concerns was prepared for discussion (Table 1). Group discussion was predominately in Spanish and lasted approximately 45 minutes. Group discussion was

audiorecorded, transcribed and translated into English for analysis by bilingual research staff.

An analytical team of four researchers trained in qualitative analysis manually reviewed the data transcripts. Three bilingual analysts consulted the Spanish transcriptions, while one English-speaking-only researcher worked exclusively with the English translation. The analysis followed a theory-emergent grounded theory approach.[16,17] This analytical approach involves a systematic iterative process in which the researcher "constantly and recursively compares research interpretations ... against the data."[17] First, the analysts read both texts independently to identify meaningful, context-dependent units or segments of information (words or phrases) in each transcript that pertained to the workshop questions. Then, they met to discuss their preliminary findings before collectively classifying them into thematic categories related to the general areas of inquiry through consensus. Two of the analysts searched for conflicting evidence in the transcripts to enhance the trustworthiness of the findings.[18] Conflicting opinions were resolved through the debate of supporting evidence for interpretation until consensus was reached.

RESULTS

Study findings reflect the participants' lay conceptualizations, principal misgivings, coping strategies and basic misconceptions about asthma. These are presented here as themes: 1) deceiving nature of asthma; 2) household environment triggers; 3) lifestyle restrictions; 4) emergency department use; 5) medication use and side effects, and 6) coping strategies (Table 2). These themes are to be viewed as interrelated. A thematic narrative of the findings follows below.

Narrative of Findings

1. Deceiving nature of asthma. Participants clearly held a deceiving and deeply worrisome perception about asthma. For example, a mother of two teenage girls with asthma described how one of them "... gave me most problems since she was born ... her asthma is very deceiving ... she could be fine and all of the sudden get asthma ..." In this same case, the mother describes her daughter's asthma as ephemeral: "... she doesn't get it like others do ... her asthma is temporary, she doesn't get it after coughing or with a fever, no, it hits her suddenly." Asthma was perceived by some as "deadly:" "...you get worried because it's deadly ... you're watching someone having an attack and rushing them to the ER ... seeing people all over the person you love ..." Others personified asthma as a "traitor" or "demon." As one respondent described, "... I call it my enemy ... the demon that comes after [me] ... When I'm in the middle of something good, this little devil comes out of nowhere and attacks me ... I can't stand it."

2. Household environment triggers. Above all, participants were specific about a variety of indoor household allergens compared with outdoor ones, particularly as residents spend more time inside their homes during the cold winter season. Allergens that participants were more aware of and concerned about included: heaters, pets, dust, house cleaning products and tobacco smoke. For example, one respondent noted that her "... mother's heater is constantly 100° and she used to dress up with lots of clothes ... she needs some fresh air...three times in two months she would go to the hospital with asthma." Another one stated: "... when I get around bleach ... it's over with. It just hurts ... strong cleaners ... I can't get near ..." Others cited: "the rugs in the house accumulate the dust and that affects you." Also, "... whenever I get a chest cold or am around cigarette smoke ..." in the house were mentioned as common triggers.

3. Lifestyle restrictions and adaptations. Quality of life was central to all the workshop participants. Loss of sleep for both children and parents appeared to have significant impact on their quality of life. As one parent put it, "... at night ... you can never get enough sleep because you worry that something is going to happen [to the child] if you're not there." Another one complained, "[the child] will sleep at night, but I have to be up every four hours making sure he's breathing alright ... I'm the one who's up all night." Participants were also very concerned about the interference of asthma on their children's school attendance and school performance. One mentioned that "... my little boy gets sick all the time ... sometimes misses two or three days in a row, and I have to send him sick to school to avoid problems ... about absences ... though I've informed the school about my son's [asthma]." Parents were concerned that school staff would not recognize when their child required medical attention.

Several participants described the limiting effect of their asthma on singing, exercise and outings. Most were particularly concerned with the unknown threats and uncertainties of asthma that could further limit their way of life.

4. Emergency department use. Participants recounted several instances when they had to run to the emergency department or be hospitalized because of their asthma. For example, they were concerned about the perceived inevitability of emergency department visits, particularly when medications prove ineffective. According to one parent "... sometimes the asthma machine at home and other medicines didn't help her [daughter] ... we had to take her to the hospital ..." Another one reported,

"... we ended up going to the ER three times ... sometimes it gets out of control...the pump doesn't work when you're having a severe asthma attack and you need steroids." Lack of health insurance was also a concern for others who felt compelled to defer medical treatment. When probed for why most end up in the emergency department, one respondent also noted: "... for insurance reasons, you don't have any medication at home."

5. Medication use and side effects. The topic of asthma treatments also raised some important issues besides their perceived role in hospital visits. Participants were concerned about the side effects of some medications, including vomiting, coated throat and hyperactivity, among others. Some participants were frustrated and confused by similarities between asthma symptoms and those of other illnesses. Some used cough syrup to treat a cold before learning that they should "not give her [child] cough or cold suppressant or anything like that, just to let the cold come out on its own ..." Furthermore, some participants believed that the "machine" (nebulizer) is for cleaning and decongesting the lungs. Some reiterated that occasionally asthma medications were not efficacious, sometimes resulting in an emergency department visit.

6. Coping strategies. Participants shared some of the strategies they used to cope with limitations caused by their asthma. Participants felt that they could at least try to control household triggers, as many were frustrated by their perceived lack of control, for example, over others who smoke outside the home. Restrictions on lifestyle patterns were a major concern and often resulted in straying from management strategies. Some creatively adjusted their lifestyle to engage in new activities related to what they love to do. For example, one participant discussed her child's limited physical activity due to asthma but found that swimming helped and, thus, kept her child engaged in such activity instead of in running. Some respondents avoided taking prescribed medications because of the side effects and instead "waited out" an asthma episode or performed deep-breathing exercises. Participants also shared sleeping patterns that made it easier for them to breathe. As one respondent stated, "when I sleep on my back, I feel like my lungs are deflated ... If I sleep on my side ... my arm is pressing down and I cannot breathe, so I always have to sleep with three pillows ..."

DISCUSSION

Patient experiences identified in these group discussions highlighted areas for improvement in the delivery of asthma education and medical care that are community-oriented and enmeshed with day-to-day living. The discussions revealed a need for patient education that integrates perceptions of illness, concerns about potential medication side effects, the impact of lifestyle adjustments on quality of life, and recognition of and response to asthma symptoms. Workshop participants expressed a desire to learn more about managing their [or their child(ren)'s] asthma. They demonstrated knowledge regarding asthma triggers and the medications needed to control symptoms but were challenged to modify their way of life to avoid triggers or maintain a medication regimen. They creatively crafted ways to manage their asthma that did not entirely compromise their quality of life. Some of their coping strategies also countered the biomedical management model for asthma.

Recent exploratory qualitative studies have also identified similar patients' needs for asthma educa-

Table 2. Summary of findings

Themes

1. Deceiving Nature of Asthma
   - Traitor
   - Demon
   - Temporary
   - Deceiving
   - Unpredictable
   - Deadly
2. Household Environment Triggers
   - Heaters
   - Dust
   - House cleaning products
   - Pets
   - Tobacco smoke
3. Lifestyle Restrictions/Adaptations
   - Sleep deprivation
   - Missed school days
   - Limitations in physical activities
4. Emergency Department Use
   - Ineffective medications
   - Long-term hospitalizations
   - Lack of health insurance
5. Medication Use and Side Effects
   - Side effects of medications
   - Cold medicine for coughing
   - Machine use to decongest lungs
6. Coping Strategies
   - New activities
   - Avoid taking medicine
   - Alternatives to medicine
   - Sleep upright
   - Control indoor triggers if possible

tion.[15,19] These educational needs included but were not limited to: medication side effects, triggers of asthma attacks, lifestyle concerns and control of symptoms.[19] In addition, Davis et al. also found that confusion with infection was the most common diagnostic problem identified in managing asthma among providers and patients who participated in a focus group to identify educational needs of providers.[20] Others also noted the importance of addressing patients' worries and perceived threats of asthma, which are part of their lay definition of asthma, in their education and counseling.[8,21]

This study highlights a disconnect between the lay and biomedical approaches to asthma, identifying a need for better communication between patient and physician in a disenfranchised minority community. This disconnect is similarly recognized by providers who identified a need for bilingual education for families and healthcare provider training to deliver socioculturally appropriate care to Latinos living in the inner city as essential to improving quality of asthma care.[22] Similarly, "an educational dialog founded on open communication between clinician and patient" that elicits patient perceptions, worries, social support and cultural frameworks is recognized as necessary for successful partnerships in asthma care.[23] The National Asthma Education and Prevention Program has emphasized the need for clinicians to establish "partnerships" with their patients to facilitate better asthma outcomes that would require bridging the experiential and professional discourses.[1]

Educational interventions that combine the biomedical and lay models of care have shown effectiveness. For example, an intervention that included a peer leader in combination with a nurse and physician education improved asthma care.[24] Another intervention that involved a home treatment plan with provider follow-up was also found to be cost effective in improving outcomes, such as decreases in clinic visits and use of oral anti-inflammatory drugs.[25]

Although the experiences noted in this Puerto Rican sample are not unique, the findings support the overall need for education in a personal and sociocultural context. These community workshops were limited in size and scope and may not be generalizable to other similar communities. No data was collected to provide demographic characteristics of the workshop participants. In addition, the workshops were conducted in February and March in Buffalo. The seasonal nature of asthma may have biased some of the responses. However, the information gathered here raises important questions about the delivery of patient education and can be used as a baseline to gather more in-depth information on how interventions may be structured to better improve office-based asthma education and patient management of asthma.

In order to bridge the gap between the lay and biomedical management models for asthma, healthcare providers should be trained to understand the patients' perception of disease, with an emphasis on the cultural background and socioeconomic situation of the patient. Providers must ask about patient's perceived indoor asthma triggers and reinforce effective and creative strategies that the family is already using to reduce these exposures. Having knowledge of community programs could help offset the cost and encourage implementation of other remediations. There is a need for better follow-up with primary care providers after an emergency department visit for an asthma episode to assess the context that resulted in the visit. Patients need to have continued education on medication administration with discussion on strategies to lessen side effects or determine if other medications are necessary. Asthma-related limitations vary among individuals. Alternative treatments to improve quality of life should be addressed in response to an individual's limitations, with an emphasis on practicality. Providers should encourage positive approaches already being practiced, elicit and dispel misperceptions, and identify other alternative practices that improve quality of life that complement the biomedical management model.

Considering the competing demands of primary care providers, creative ways to incorporate in-depth education are needed in the office setting.[26] For example, a staff member may become a certified asthma educator to assist the provider in undertaking personalized asthma education. The National Cooperative Inner-City Asthma Study found that a Masters-in-social-work-trained asthma counselor was effective in conducting a personalized asthma educational intervention among low-income children.[27,28] This model can be incorporated into the primary care setting. Interventions within the primary care setting that improve patient–physician communication and processes for extending educational efforts to other office staff can be tested within primary care settings serving minority patients. Through improved patient–physician communication and the extension of educational efforts within the primary care setting, a more comprehensive medical management model may evolve.

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REFERENCES

1. NAEPP. *National Asthma Education and Prevention Program (NAEPP), Expert Panel Report 2: Guidelines for the Diagnosis and the Management of Asthma.* Bethesda, MD: National Heart, Lung, and Blood Institute; 1997.

2. Findley S, Lawler K, Bindra M, et al. Elevated asthma and indoor environmental exposures among Puerto Rican children of East Harlem. *J Asthma.* 2003;40(5):557-569.

3. Akinbami LJ, Rhodes JC, Lara M. Racial and ethnic differences in asthma diagnosis among children who wheeze. *Pediatrics.* 2005;115(5):1254-1260.

4. Homa DM, Mannino DM, Lara M. Asthma mortality in U.S. Hispanics of Mexican, Puerto Rican, and Cuban heritage, 1990-1995. *Am J Respir Criti Care Med.* 2000;161(2 Pt 1):504-509.

5. CDC. *Asthma Prevalence and Control Characteristics by Race/Ethnicity —United States, 2002* February 27, 2004;53(07).

6. Ledogar RJ, Penchaszadeh A, Garden CC, et al. Asthma and Latino cultures: different prevalence reported among groups sharing the same environment. *Am J Public Health.* 2000;90(6):929-935.

7. Crismore A. *Problems for the Average Adult in Understanding Medical Language* 1982. Position Paper. http://SearchERIC.org/ericda/ED226336.htm.

8. Zayas LE, Jaen CR, Kane M. Exploring lay definitions of asthma and interpersonal barriers to care in a predominantly Puerto Rican, inner-city community. *J Asthma.* Sep 1999;36(6):527-537.

9. Bodenheimer T, Lorig K, Holman H, et al. Patient self-management of chronic disease in primary care. [see comment]. *JAMA.* 2002;288(19):2469-2475.

10. Schermer TR, Thoonen BP, van den Boom G, et al. Randomized controlled economic evaluation of asthma self-management in primary health care. *Am J Respir Criti Care Med.* 2002;166(8):1062-1072.

11. Tschopp JM, Frey JG, Pernet R, et al. Bronchial asthma and self-management education: implementation of guidelines by an interdisciplinary programme in health network. *Swiss Med Wkly.* 2002;132(7-8):92-97.

12. U.S. Census Bureau. U.S. Census 2000. http://factfinder.census.gov/servlet/BasicFactsServlet. Accessed 09/03.

13. Center for Urban Research in Primary Care. *The Lower West Side Health Needs Survey Report, 1994, Buffalo, New York.* Buffalo, NY: State University of New York at Buffalo, Center for Urban Research in Primary Care; 1994.

14. Lwebuga-Mukasa JS, Wojcik R, Dunn-Georgiou E, et al. Home environmental factors associated with asthma prevalence in two Buffalo inner-city neighborhoods. *J Health Care Poor Underserved.* 2002;13(2):214-228.

15. Zayas LE, McLean DM. Asthma patient education opportunities in predominantly minority urban communities. *Health Educ Res.* 2005; in press.

16. Glaser BG. *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory.* Vol x. Mill Valley, CA: Sociology Press; 1974.

17. Miller WL, Crabtree BF. Clinical Research: a multi-method typology and qualitative roadmap. In: Crabtree BF, Miller WL, eds. *Doing Qualitative Research.* 2nd ed. Thousand Oaks, CA: Sage Publications; 1999:3-30.

18. Kuzel AJ, Like RC. Standards of Trustworthiness for Qualitative Studies in Primary Care. In: P.G. Norton ea, ed. *Primary Care Research: Traditional and Innovative Approaches.* Newbury Park, CA: Sage Publications; 1991:138-158.

19. Caress AL, Luker K, Woodcock A, et al. An exploratory study of priority information needs in adult asthma patients. *Patient Educ Couns.* 2002;47(4):319-327.

20. Davis P, Man P, Cave A, et al. Use of focus groups to assess the educational needs of the primary care physician for the management of asthma. *Med Educ.* 2000;34(12):987-993.

21. Nocon A, Booth T. The social impact of asthma. *Fam Pract.* 1991;8(1):37-41.

22. Lara M, Allen F, Lange L. Physician perceptions of barriers to care for inner-city Latino children with asthma. *J Health Care Poor Underserved.* 1999;10(1):27-44.

23. Stoloff S. Janson S. Current asthma management: the performance gap and economic consequences. *Am J Manag Care.* 2000;6(17 Suppl):S918-S925; discussion S918-S925.

24. Lozano P, Finkelstein JA, Carey VJ, et al. A multisite randomized trial of the effects of physician education and organizational change in chronic-asthma care: health outcomes of the Pediatric Asthma Care Patient Outcomes Research Team II Study. *Arch Pediatr Adolesc Med.* 2004;158(9):875-883.

25. Dinelli DL, Higgins JC. Case management of asthma for family practice patients: a pilot study. *Mil Med.* 2002;167(3):231-234.

26. Jaen CR, Stange KC, Tumiel LM, et al. Missed opportunities for prevention: smoking cessation counseling and the competing demands of practice. *J Fam Pract.* 1997;45(4):348-354.

27. Sullivan SD, Weiss KB, Lynn H, et al. The cost-effectiveness of an inner-city asthma intervention for children. [see comment]. *J Allergy Clin Immunol.* 2002;110(4):576-581.

28. Mitchell H, Senturia Y, Gergen P, et al. Design and Methods of the National Cooperative Inner-City Asthma Study. *Pediatr Pulmonol.* 1997;24:237-252. ■