Original Article

Exploring Patient Engagement: A Qualitative Analysis of Low-Income Urban Participants in Asthma Research

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What is already known about this topic? It is well described that worse health outcomes are seen in low-income and minority patients. Common challenges to patient engagement include poor health literacy or limited education, or a limited sense of empowerment to participate.

What does this article add to our knowledge? This investigation demonstrates that patients who receive personal attention and a brief educational intervention feel empowered to be involved and more proactive in their health care, in both clinic and home settings.

How does this study impact current management guidelines? This study suggests a low-resource, feasible method to improve patient engagement with perceived education and personal attention.

BACKGROUND: Uncontrolled asthma is a common highly morbid condition with worse outcomes in low-income and minority patients in part due to barriers accessing and engaging with health care. We developed a patient advocate to educate about and assist with navigating access to care and provider-patient communication. Participants completed an End of Study Questionnaire (ESQ) that was analyzed to assess experience and engagement with the protocol.

OBJECTIVE: This study uses qualitative analysis to evaluate participant experience with the patient advocate and control group interventions.

METHODS: The ESQ aimed to prompt an open-ended discussion of study experience. Questions were developed from patient focus groups about the patient advocate intervention (PAI), and were revised based on early responses. The questionnaire was administered after 12 months of study participation: 6 months of control or PAI, followed by 6 months of follow-up. Answers were evaluated using qualitative coding and a grounded theory analytical approach.

RESULTS: A total of 102 low-income and minority adults with moderate or severe asthma who had completed the study protocol at the time of publication (approximately one-third of total participants) found PAI and control group activities acceptable. Four themes emerged from both groups: (1) appreciation of interpersonal and educational interaction, (2) perception of improved health care adherence, (3) preparedness for physician appointments, (4) improved patient-provider communication. Attention from study personnel and review of asthma-related information was unanimously well received and empowered patients' active health care participation.

CONCLUSIONS: Patient engagement and empowerment were elicited by perceived education and personal attention. This study suggests a low-resource, feasible method to improve patient engagement. © 2017 American Academy of Allergy, Asthma & Immunology (J Allergy Clin Immunol Pract 2017;■:■-■)

Key words: *Asthma; Patient advocate; Patient engagement; Access to health care; Health disparities; Adherence*

Asthma is a chronic, costly, and often debilitating medical condition that affects more than 25 million people in the United States[1] and results in significant health care utilization: over 10 million

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Abbreviations used
ESQ- End of Study Questionnaire
FEV1- Forced expiratory volume in 1 second
HAP2- Helping Asthma Patients 2 Study
PA- Patient advocate
PAI- Patient advocate intervention

outpatient appointments,[2] 1.5 million emergency department visits, and 400,000 hospitalizations,[3] costing over $30 billion[4] annually. It is well described that worse health outcomes are seen in low-income and minority patients. African American patients with asthma have double the risk of death related to this condition, and more than twice the number of hospitalizations and emergency department visits as compared with white patients. Similar disparities are seen in Puerto Rican patients.[1]

These trends are likely multifactorial, secondary to environmental factors, such as allergen and particulate matter exposures, as well as barriers to accessing and engaging with teams of health care providers.[5] Recent efforts have attempted to improve patient engagement, yet significant challenges exist. Patients may be impeded by poor health literacy or overall limited education, may not feel empowered to participate,[6] or may be uncomfortable fully discussing their concerns in a short clinical appointment. Provider factors may also impede effective communication, including professional pressures such as brief appointments and distracting alerts on electronic medical records, and personal characteristics such as lack of empathy.

The majority of studies investigating approaches to improving asthma outcomes in this population have proposed either educational interventions targeting patients, or systems-level interventions targeting providers.[2] We adapted the patient navigator initially proposed by Freeman et al[7,8] and developed a patient advocate program that introduces a new clinical role fulfilled by a young college graduate, namely the patient advocate (PA), with the goal of helping patients to successfully navigate access to care and facilitate provider-patient communication. Initial results demonstrated acceptability, feasibility, and positive patient response to the patient advocate pilot,[9] which prompted continuation of this project with more participants and longer follow-up. As part of this ongoing effort, an End of Study Questionnaire (ESQ) was developed to further investigate participants' experiences with the study. This investigation aimed to evaluate patients' experiences with both the control and intervention arms of this study, with particular focus on sense of patient empowerment and engagement as well as acceptability of this protocol and thus sustainability of intervention.

METHODS

Study design

The ESQ was incorporated into the ongoing Helping Asthma Patients 2 (HAP2) study. This study is a randomized, controlled clinical trial that investigates the effects of a patient advocate intervention (PAI) on asthma outcomes in low-income or minority patients with moderate-to-severe asthma. A total of 312 patients were recruited from 8 clinics serving low-income inner city neighborhoods, and were randomized 1:1, stratified by practice, to either receive the PA intervention or control for 6 months, followed by 6 months of observation.

Research coordinators: patient advocates and data collectors

A research coordinator acted as either a PA or a data collector for any individual patient. Research coordinators were college graduates interested in health care careers. They were trained in asthma education, patient interaction, research principles, protocol integrity, cultural competence, and spirometry, but no other medical tasks. Participants randomized to control received routine medical care from their providers and had contact with a data collector during the intervention period; participants randomized to PAI had contact with both a data collector and their assigned PA. Each participant randomized to PAI was assigned a PA who followed him or her longitudinally. Primarily Spanish-speaking participants had PA's who could communicate effectively in that language. The PA responsibilities included assisting with appointment reminders, clinic visit preparation and agenda, and administrative tasks to navigate health care. They attended appointments with the participant and took notes, and ensured that the participant could "teach back" important information from the visit. Data collection visits occurred every 3 months with all participants in both groups; these included asking questions about knowledge of inhaled corticosteroids, inhaler technique, and basic asthma facts. Incorrect answers on the Inhaled Corticosteroid Knowledge Questionnaire (Table E1, available in this article's Online Repository at www.jaci-inpractice.org) and the Inhaler Techniques Questionnaire (Table E2, available in this article's Online Repository at www.jaci-inpractice.org) were reviewed and corrected for patients in both control and PAI groups.

End of Study Questionnaire

The ESQ (Table I) was administered at the final data collection visit, designed to occur 12 months after initial recruitment and randomization. The ESQ comprises 9 items and aimed to prompt participants to discuss their experience with HAP2 in an open-ended manner. Questions were developed initially from patient responses to questions about PAs in focus groups from which the PA role was developed.[10] Later the questions were revised based on participant responses, with additional questions added regarding visit preparation, changes in communication from the doctor to the patient, and changes in communication from the patient to family and friends.[9,11] Thirty-three participants received the first version of the ESQ, and 69 participants received the updated version; thus only the latter group of participants answered the 3 questions referenced above. Participants were asked to rate their perceptions of various aspects of the study and to qualitatively describe their reasoning.

Participants

Participants in both arms of the HAP2 study were the respondents to this questionnaire. Inclusion criteria included age 18 years or older with the physician's diagnosis of asthma and prescription of either inhaled corticosteroid and long-acting bronchodilator combination therapy (n = 92), medium dose inhaled corticosteroid (n = 6), or otherwise met National Heart, Lung, and Blood Institute Guideline criteria for moderate or severe persistent asthma including reduced forced expiratory volume in 1 second (FEV1) (n = 4). All participants had spirometry showing evidence of reversible airflow obstruction with (a) FEV1 < 80% predicted at the time of screening or within 3 years earlier, and (b) improvement with bronchodilator: either (i) an increase of at least 15% and 200 mL in FEV1 with asthma treatment over the previous 3 years, or (ii) an increase in FEV1 or forced vital capacity > 12% and improvement in FEV1 by at least 200 mL within 30 minutes after 4