

Validation of Parental Reports of Asthma Trajectory, Burden, and Risk by Using the Pediatric Asthma Control and Communication Instrument

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What is already known about this topic? National asthma guidelines recommend that clinicians routinely assess multiple dimensions of asthma morbidity. Patient-reported outcomes are emerging as an important clinical measure. Most asthma questionnaires measure only asthma control.

What does this article add to our knowledge? The Pediatric Asthma Control and Communication Instrument domains of Direction, Bother, and Risk are valid and discriminating measures of parent-reported asthma morbidity. A brief questionnaire can be used by clinicians to simultaneously measure multiple dimensions of asthma morbidity.

How does this study impact current management guidelines? The Pediatric Asthma Control and Communication Instrument offers clinicians a new means to meet guideline recommendations to assess multiple dimensions of asthma health.

BACKGROUND: Despite a growing interest, few pediatric asthma questionnaires assess multiple dimensions of asthma morbidity, as recommended by national asthma guidelines, or use patient-reported outcomes.

OBJECTIVE: To evaluate a questionnaire that measures multiple dimensions of parent-reported asthma morbidity (Direction, Bother, and Risk).

METHODS: We administered the Pediatric Asthma Control and Communication Instrument (PACCI) and assessed asthma

control (PACCI Control), quality of life, and lung function among children who presented for routine asthma care. The PACCI was evaluated for discriminative validity.

RESULTS: A total of 317 children participated (mean age, 8.2 years; 58% boys; 44% African American). As parent-reported PACCI Direction changed from “better” to “worse,” we observed poorer asthma control ($P < .001$), mean Pediatric Asthma Caregiver Quality of Life Questionnaire (PACQLQ) scores ($P < .001$), and FEV₁% ($P = .025$). Linear regression showed that, for each change in PACCI Direction, the mean PACQLQ score decreased by -0.6 (95% CI, -0.8 to -0.4). As parent-reported PACCI Bother changed from “not bothered” to “very bothered,” we observed poorer asthma control ($P < .001$) and lower mean PACQLQ scores ($P < .001$). Linear regression showed that, for each change in PACCI Bother category, the mean PACQLQ score decreased by -1.1 (95% CI, -1.3 to -0.9). Any reported PACCI Risk event (emergency department visit, hospitalization, or use of an oral corticosteroid) was associated with poorer asthma control ($P < .05$) and PACQLQ scores ($P < .01$).

CONCLUSIONS: PACCI Direction, Bother, and Risk are valid measures of parent-reported outcomes and show good discriminative validity. The PACCI is a simple clinical tool to assess multiple dimensions of parent-reported asthma morbidity, in addition to risk and control. © 2014 American Academy of Allergy, Asthma & Immunology (J Allergy Clin Immunol Pract 2014;2:186-92)

Key words: Risk; Children; Burden; Trajectory; Survey; Validation; PACCI; Patient-reported outcomes

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Abbreviations used

ANOVA- Analysis of variance

FEV₁- Forced expiratory volume in the first second

FEV₁%- FEV₁ percent predicted

NIH- National Institutes of Health

PACCI- Pediatric Asthma Control and Communication Instrument

PACQLQ- Pediatric Asthma Caregiver Quality of Life Questionnaire

Asthma guidelines published by the National Institutes of Health (NIH) suggest that health care providers assess multiple dimensions of patient asthma morbidity, including the signs and symptoms of asthma, quality of life and/or functional status, history of exacerbations, pharmacotherapy (adherence, adverse effects), lung function, and patient-provider communication.¹ The guidelines encourage clinicians to use patient self-assessment questionnaires as a means of obtaining information on these dimensions of asthma control from the perspective of the patient and/or the patient's family. However, most currently available self-assessment questionnaires evaluate just one or two of these dimensions of morbidity,²⁻⁵ always impairment, and rarely risk. Furthermore, these questionnaires do not capture the patient or parent perspectives regarding quality of life or changes (improvements or worsening) in disease morbidity.⁶

We have shown that clinicians do use multiple dimensions of asthma health to assess and treat asthma,⁷⁻⁹ including disease trajectory (eg, direction of asthma getting worse or better), burden (bother), and risk for poor outcomes. Analysis of those findings, along with asthma guidelines and other published work, suggests that the treatment decisions made by health care providers involve a multiplicity of clinical assessments and cognitive tasks.¹⁰ Therefore, if clinicians are truly to provide care consistent with national asthma guidelines, then there may be a benefit to development and validation of tools that facilitate the work of clinicians to successfully carry out as many of these clinical assessments and tasks as possible.

The Pediatric Asthma Control and Communication Instrument (PACCI) is a parent-completed assessment questionnaire that assesses 5 dimensions of asthma health. The PACCI has previously been validated as a measure of asthma control,¹¹ as has the adult version, the Asthma Control and Communication Instrument.¹² The purpose of this study was to evaluate the validity of 3 other PACCI domains unique from control: disease trajectory (Direction [eg, asthma getting worse or better], burden [Bother], and Risk domains [systemic use of corticosteroids, emergency department (ED) visits, hospitalizations]) in a diverse pediatric sample, including black, Latino, and Spanish-speaking children, across the age spectrum (0-21 years).

METHODS

Questionnaire development and content

The development of the PACCI has been previously described.¹¹ It is written at a fifth-grade reading level, has been validated to measure asthma control among diverse, English- and Spanish-speaking patient populations, and is intended to help clinicians better use patient-parent reported information to guide asthma treatment. The PACCI is a 12-item parent-completed questionnaire (see [Figures E1 and E2](#) in this article's Online Repository at www.jaci-inpractice.org) that assesses 5 conceptual

domains of asthma morbidity (direction, bother, risk, adherence, and control). The assessments are based on parental report of the child's asthma since the last visit with the physician (or over the past 2 months if the child has not previously seen the physician). The current analysis focuses on 3 of the 5 domains:

1. Direction: the trajectory of how the child's asthma has changed (better, the same, or worse).
2. Bother: how much the parent is bothered by the child's asthma (not bothered, somewhat bothered, very bothered) as an indication of how burdensome asthma has been on the child's parents.
3. Risk: the occurrence of ED visits, hospitalizations, and/or oral corticosteroid use for asthma.

Procedures

This was a cross-sectional study that took place between July 2007 and September 2010. This study was approved by the Johns Hopkins University and University of California, San Francisco, institutional review boards. Before seeing a clinician, the parents completed the following: the PACCI; established questionnaires that measure asthma morbidity (described below); and a demographic questionnaire. Spirometry was obtained only at the Johns Hopkins Children's Center, at the discretion of the treating clinician.

Sample

A convenience sample of subjects was recruited among patients who presented for outpatient asthma care at Johns Hopkins Children's Center or the University of California, San Francisco, in established asthma specialty care clinics with practices modeled after NIH guidelines. The patients were seen by pediatric pulmonologists, general pediatricians, and nurse practitioners. Subjects were eligible if they (1) had self-reported physician-diagnosed asthma, (2) were accompanied by a caregiver who could give consent, and (3) spoke English or Spanish. Caregivers provided informed consent, and children older than 8 years of age provided assent in their preferred languages.

Established asthma morbidity measures

Asthma control was measured by using the PACCI Control domain, which has been validated previously.¹¹ For this analysis, control was scored in 2 ways:

1. Sum score is a summation of the score assigned to each response option (0-5 for questions 7, 8, 10, 11; 0-4 for question 9), which range from 0 (best asthma control) to 19 (worst asthma control).
2. Problem index dichotomously scores each of the 5 Control items (questions 7-11) as 0 ("green" responses) or 1 (all other responses), which are then summed and which range from 0 (no control problems) to 5 (5 control problems).

The Pediatric Asthma Caregiver Quality of Life Questionnaire (PACQLQ)¹³ consists of 13 questions that assess the impact of asthma on activity limitation (4 questions) and emotional function (9 questions) during the previous week. Each question is scored on a 7-point scale. The final PACQLQ score is a mean of the 13 scores, with higher scores indicating better quality of life. The PACQLQ has been shown to be a valid measure of asthma-specific quality of life for children with stable and unstable asthma, and with different levels of asthma severity.¹⁴⁻¹⁶ The emotional function domain of the PACQLQ is designed to

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