The Pediatric Asthma Control and Communication Instrument asthma questionnaire: For use in diverse children of all ages

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Background: National Institutes of Health asthma guidelines recommend questionnaires to assess asthma control, but these questionnaires are not useable across the entire pediatric age spectrum and have not been validated among significant numbers of minority or Spanish-speaking children.
Objective: We sought to evaluate a questionnaire designed to assess asthma control across a broad age range of minority and Spanish-speaking children cared for in an outpatient setting.
Methods: Between July 1, 2007, and September 30, 2010, we collected information using the Pediatric Asthma Control and Communication Instrument (PACCI), the Asthma Control Test (ACT; or the childhood ACT for children 4-11 years old), the Pediatric Asthma Caregiver Quality of Life Questionnaire, and lung function and clinicians' ratings of asthma status among a population of children presenting for routine asthma specialist care. The PACCI measure of asthma control was validated by evaluating accuracy, internal reliability, and concurrent, discriminative, and known-groups validity.
Results: We collected information on 265 English- and 52 Spanish-speaking children (mean age, 8.2 years; 58% male; 44% African American). Across all age groups and in both languages, PACCI control showed good internal reliability and strong concurrent, discriminative, and known-groups validity with ACT and Pediatric Asthma Caregiver Quality of Life Questionnaire scores and clinicians' ratings of asthma control. The accuracy of the PACCI in classifying children with uncontrolled asthma was good (area under the curve, 0.83; 95% CI, 0.79-0.88).
Conclusions: The PACCI accurately measures asthma control in English- and Spanish-speaking children. The PACCI should be useful to clinicians to assess and classify asthma according to National Institutes of Health asthma guidelines. (J Allergy Clin Immunol 2013;132:55-62.)

Key words: *Impairment, control, children, assessment, accuracy, survey, validation, Pediatric Asthma Control and Communication Instrument, Spanish*

Underestimation of asthma control by parents, clinicians, or both can lead to inappropriate treatment and poorer outcomes.[1-8] The use of a validated asthma questionnaire might help to overcome this issue by standardizing and improving the accuracy of asthma evaluations by clinicians and parents.[9] Furthermore, use of validated asthma questionnaires has been encouraged in the most recent asthma guidelines from the National Institutes of Health (NIH).[10]

However, few published asthma questionnaires are available for use in children of all ages.[11,12] In addition, the publicly available questionnaires are limited by 1 or more of the following because they do not: (1) assess NIH guideline indicators of both impairment and risk; (2) measure disease activity across the full pediatric age spectrum; (3) have extensive validation data among racial/ethnic minority populations, those from low socioeconomic backgrounds, or both; (4) have evidence of validity in Spanish; or (5) incorporate the multidimensional measures of asthma morbidity outlined in the NIH asthma guidelines (eg, history of asthma exacerbations, pharmacotherapy, and patient-provider communication).[11-20]

We developed the Pediatric Asthma Control and Communication Instrument (PACCI) to facilitate the outpatient evaluation of childhood asthma, including control, risk, adherence, patient-provider communication, and a treatment algorithm to assist clinicians in asthma management. The purpose of this study was to evaluate the construct validity and reliability of the Control domain of the PACCI among a diverse pediatric population, including African American and Latino children, across the age spectrum.

METHODS

Questionnaire development and content

The PACCI was developed in conjunction with the adult Asthma Control Communication Instrument (ACCI).[21] Both asthma assessment tools are written at a fifth-grade reading level, were designed for use across diverse patient populations, and are intended to help clinicians better use patient/parent-reported information to guide asthma treatment.

The conceptual domains incorporated into the PACCI were derived from a variety of patient and physician focus groups,[21,22] including inner-city, African American, Latino, and Spanish-speaking patients, as well as pediatricians,

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Abbreviations used
ACCI: Asthma Control Communication Instrument
ACT: Asthma Control Test
AUC: Area under the curve
C-ACT: Childhood Asthma Control Test
FVC: Forced vital capacity
JHCC: Johns Hopkins Children's Center
NIH: National Institutes of Health
PACCI: Pediatric Asthma Control and Communication Instrument
PACQLQ: Pediatric Asthma Caregiver Quality of Life Questionnaire
ROC: Receiver operating characteristic
SFGH: San Francisco General Hospital

family practitioners, and pediatric asthma specialists. The PACCI was further evaluated through cognitive testing[22] and vignette-based surveys of pediatricians.[23,24] It is a 12-item parent-completed questionnaire (see Fig E1 in this article's Online Repository at www.jacionline.org) that assesses 5 conceptual domains of asthma status:

1. *Direction*—perceived changes in asthma status;
2. *Bother*—perceived disease burden;
3. *Risk*—reports of emergency department visits, hospitalizations, and oral steroid use;
4. *Adherence* to daily controller medications; and
5. *Control*—frequency of daytime symptoms, short-acting β_2-agonist use, asthma attacks, activity limitation, and nocturnal symptoms (ie, guideline-based measures of impairment).[10]

The time frame of recall for the Control domain items is 1 week, except for nocturnal awakening, which is 2 weeks. The 12th item is an open-ended question designed to enhance patient-centered communication with the clinician. As described previously for the adult ACCI,[21] the PACCI Control domain can be scored in 3 ways:

1. The *sum score*[25] is a summation of the score assigned to each response option (0-4 for questions 7, 8, 10, and 11 and 0-3 for question 9), ranging from 0 (best asthma control) to 19 (worst asthma control).
2. The *problem index*[26] dichotomously scores each of the 5 Control domain items as 0 (controlled) or 1 (not controlled), which are then summed, ranging from 0 (no control problems) to 5 (5 control problems).
3. *Categories* uses a classification scheme based on NIH asthma guideline assessments by categorizing patients into 4 severity/control categories (intermittent/controlled, mild persistent/partly controlled, moderate persistent/uncontrolled, and severe persistent/poorly controlled). In this study because we do not have data on patient medication use, the focus will be on assessment of the control categories only. The category chosen is based on responses to questions 7 to 11 of the PACCI. An instruction is provided for the clinician, stating "Assign patient's current level of asthma control by looking at the box checked farthest to the right on questions 7-11 and match the box color to the level of asthma control in this section." For simplicity, 2 control categories can be used instead ("controlled" and "not controlled").[10] "Intermittent" symptoms are considered "controlled," whereas "persistent" symptoms are considered "not controlled."

Spanish PACCI

The Spanish-language PACCI is shown in Fig E2 in this article's Online Repository at www.jacionline.org. The English-language PACCI was translated by a native Spanish-speaking clinician coinvestigator (JAL). This Spanish version was then back-translated by a clinician coinvestigator (DAT, a native English speaker fluent in Spanish) and another clinician coinvestigator (CMP, a native Spanish speaker fluent in English). Differences in the Spanish and English versions were reconciled among the translators.

Procedures

This was a cross-sectional study that took place between July 2007 and September 2010. The study was approved by the Johns Hopkins University and University of California, San Francisco, Institutional Review Boards. Before seeing a clinician, parents completed the PACCI, established questionnaires measuring asthma morbidity (described below), and a demographic questionnaire. The University of California, San Francisco, site (San Francisco General Hospital [SFGH]) saw both English- and Spanish-speaking patients, and therefore either version of the PACCI was used based on the patient's language preference. All Spanish-speaking participants were recruited at SFGH. Clinicians at SFGH spoke Spanish with varying degrees of fluency. Interpreter services were available if needed. Spirometry was obtained at the discretion of the treating clinician.

Sample

A convenience sample of participants and their caregivers was recruited among patients presenting for outpatient asthma care at Johns Hopkins Children's Center (JHCC) or SFGH. Participants were eligible if they (1) had self-reported doctor-diagnosed asthma, (2) were accompanied by a caregiver who could provide consent, (3) spoke English or Spanish, and (4) were 21 years of age or younger. In their preferred language caregivers provided informed consent, whereas children older than 8 years of age provided assent.

Established asthma morbidity measures

The Asthma Control Test (ACT; for patients ≥12 years of age)[25] or the Childhood Asthma Control Test (C-ACT; for patients 4-11 years of age)[20] are 5- and 7-item questionnaires, respectively, that assess asthma control (eg, symptom frequency) over the prior month.[20,25] The scores for the ACT items are summed to yield a total score ranging from 5 (poor control of asthma) to 25 (complete control of asthma [or 0-27 for the C-ACT]). A score of greater than 19 indicates well-controlled asthma. For Spanish-speaking participants, the Spanish version of the ACT/C-ACT was completed.

The Pediatric Asthma Caregiver Quality of Life Questionnaire (PACQLQ)[27] consists of 13 questions that assess the effect of asthma on activity limitation and emotional function 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. No validated Spanish-language PACQLQ was available.

Spirometry was obtained at the discretion of the clinician for the 118 children who were able to perform it.

Clinician's assessment

Patients were evaluated by pediatric clinicians (pulmonologists, pediatricians, and nurse practitioners) in established asthma specialty care clinics with practices modeled after NIH guidelines.[10] On the basis of history, medications, and physical examination and spirometric results (FEV_1 and FEV_1/forced vital capacity [FVC] ratio), clinicians were asked to classify the patient's asthma disease status in one of 2 ways: (1) controlled or not controlled or (2) intermittent or persistent (mild, moderate, or severe). The clinician provided an assessment of asthma control based exclusively on the information obtained during the encounter while blind to the parent-completed measures.

Analysis

Means and proportions were used to describe the characteristics of the study population. Floor and ceiling effects of the PACCI sum score and problem index scores were evaluated to determine whether respondent scores were clustered at the low or high ends of these scales; such clustering would suggest that the PACCI is not useful in discriminating different levels of asthma control. We used Cronbach α values to evaluate the internal reliability of the PACCI Control domain. To evaluate concurrent construct validity, we evaluated the correlations between the PACCI Control domain (sum score and problem index) with (1) the ACT/C-ACT, (2) the PACQLQ