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Development and testing of the Asthma Self-Management Questionnaire

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Abstract

Background—Assessing self-management knowledge can guide physicians in teaching patients necessary skills.

Objective—To develop and test the Asthma Self-Management Questionnaire (ASMQ).

Methods—The ASMQ was developed from patient interviews. Validity was evaluated by comparison with the established Knowledge, Attitude, and Self-Efficacy Asthma Questionnaire, and test-retest reliability was evaluated with repeated administration (mean, 5 days apart) in 25 patients (mean age, 41 years; 96% women). The ASMQ was further described in additional patients by comparison with cross-sectional self-management practices and longitudinal change in Asthma Quality of Life Questionnaire scores.

Results—The 16-item, multiple-choice ASMQ measures knowledge of preventive strategies, inhaler use, and medications and generates a score of 0 to 100, with higher scores indicating more correct responses. The ASMQ was correlated with the Knowledge, Attitude, and Self-Efficacy Questionnaire ($r = 0.58$) and had a Cronbach α of 0.71. The correlation between administrations was 0.78, and the intraclass correlation coefficient was 0.58. When given to another 231 patients (mean age, 41 years; 74% women), the mean (SD) ASMQ score was 60 (20). Patients with better ASMQ scores were more likely to own peak flow meters ($P = .04$) and to have received flu vaccines ($P = .03$). For 12 months, these patients received self-management information through workbooks and telephone reinforcement. Patients with higher ASMQ scores after 12 months were more likely to have clinically important improvements in quality of life compared with patients with lower ASMQ scores (65% vs 46%; $P = .01$).

Conclusions—The ASMQ is valid and reliable and is associated with clinical markers of effective self-management and better asthma outcomes.

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INTRODUCTION

Educating patients about asthma is an essential component of comprehensive care.¹ Ideally, this education should provide a foundation of knowledge and should focus on topics that are pertinent to each patient.² In addition to physicians, patients also derive knowledge from other sources, such as anecdotal experiences of others and the media. Given that accuracy of information from these sources may vary, physicians should evaluate patients' knowledge of asthma to address gaps in information, to reinforce correct practices, and to uncover misconceptions.

Several questionnaires have been developed to measure patients' general knowledge of asthma. For the most part, these questionnaires address a broad spectrum of topics, such as epidemiology, physiology, triggers, and treatments.^{3–6} These questionnaires are practical means to evaluate what patients understand about asthma, its complexity, and goals of therapy. They have been used with patients in ambulatory care and emergency department settings, as well as during asthma educational programs.^{4,5,7–12} General knowledge about asthma, however, is not the same as knowledge about self-management. Thus, a questionnaire specifically focusing on knowledge of self-management would be useful in assessing understanding of behaviors necessary to control asthma. The objectives of this study were to develop an asthma self-management questionnaire based on input from patients, to test its validity and reliability, and to demonstrate its performance in cross-sectional and longitudinal analyses with adult asthma patients followed up in a primary care practice.

METHODS

The development and testing of the Asthma Self-Management Questionnaire (ASMQ) were conducted in 3 phases. Patients for each phase were enrolled at the Cornell Internal Medicine Associates primary care practice in New York City. This study was approved by the Committee on Human Rights in Research at the Weill Cornell Medical College/New York Presbyterian Hospital. All patients provided written informed consent.

Phase 1: Assembly of Questions

Questions were assembled based on information from patients who were participating in a trial to improve asthma-related quality of life (Figure 1 and Figure 2). Patients were eligible for the trial if they had mild to moderate persistent asthma, were English speaking, and had no major comorbidity. As part of the trial, patients were asked open-ended questions about how asthma affected daily life and how they managed asthma. From their responses, challenges and misconceptions about self-management were gleaned, and 16 questions with multiple-choice response options were composed. Preferred (ie, correct) responses were formulated based on current expert opinion reported in the literature. Incorrect responses were formulated from misconceptions and inaccurate practices described by patients. The questions and responses then were presented to a convenience sample of 10 patients from the same trial who provided comments and suggested modifications.

Phase 2: Validity and Reliability Testing

An additional convenience sample of 25 patients from the same trial participated in phase 2. Validity was evaluated by comparing the ASMQ with the knowledge subscale of the Knowledge, Attitude, and Self-Efficacy Asthma Questionnaire (KASE-AQ).³ The KASE-AQ has been shown to be valid, reliable, and responsive. The knowledge subscale is composed of 20 multiple-choice questions that measure awareness of basic asthma physiology, use of medications, avoidance of triggers, and management of exacerbations. Raw scores can range from 0 to 20. For our study, the raw score was multiplied by 5 to range from 0 to 100, with

higher scores indicating more knowledge. To evaluate validity, the ASMQ and the knowledge subscale of the KASE-AQ were administered by trained interviewers during a single in-person interview at the time of a routine office visit. To evaluate reliability, the same patients completed the ASMQ a second time several days later during a telephone interview.

Phase 3: Demonstration

The properties of the ASMQ were demonstrated in another sample of patients enrolled in a 12-month trial to increase walking and exercise in asthma patients.^{13,14} Patients were eligible for this trial if they had mild to moderate persistent asthma, were English speaking, were willing to increase physical activity, and had no major medical or mobility-limiting comorbidity. Patients were enrolled during routine office visits and completed a series of clinical and psychosocial measurements, including the ASMQ. To minimize possible asthma exacerbations during the trial, patients were given an informational workbook about asthma.¹⁵ The workbook addressed asthma triggers and medications and suggested self-management techniques. Patients were reminded to review the workbook during bimonthly follow-ups. Of the 258 patients enrolled in the trial, 231 had time to complete the ASMQ at enrollment and again at 12 months. At both time points patients also completed the Asthma Quality of Life Questionnaire (AQLQ), a well-established 32-item questionnaire that assess symptoms, limitations, and emotional and environmental aspects of asthma.¹⁶ An overall AQLQ score can range from 1 to 7, and higher scores reflect better status. A change in score of 0.5 or more reflects a clinically important improvement.¹⁷ Information about self-management practices also were obtained at enrollment, specifically whether the patient owned and used a peak flow meter and whether the patient received a flu vaccine.

For phase 2, internal validity of the ASMQ was evaluated with the Cronbach α correlation. External validity between the ASMQ and the knowledge subscale of the KASE-AQ was evaluated with the Pearson correlation. Reliability between the first and second administration of the ASMQ was evaluated by measuring concordance with the intraclass correlation coefficient. The association between the first and second administration of the ASMQ also was measured with the Pearson correlation. For phase 3, the cross-sectional performance of the ASMQ was demonstrated by comparing ASMQ scores with self-management practices and asthma-related quality of life (AQLQ scores) using t tests. Within-patient changes in enrollment to 12-month ASMQ and AQLQ scores were compared with paired t tests. The longitudinal performance of the ASMQ was evaluated by comparing enrollment and 12-month ASMQ scores with the percentage of patients who did and did not have a clinically important improvement in AQLQ scores, defined as an increase of 0.5 or more, using χ^2 tests. Analyses were performed with SAS statistical software.¹⁸

RESULTS

Phase 1

On the basis of feedback from the convenience sample of 10 patients, modifications to the questionnaire were made, specifically restructuring terms for maintenance and rescue medications, reordering response options, and adding the response option of “I don’t know” to each of the 16 questions. The final questionnaire has a Flesch-Kincaid¹⁹ reading level of grade 6.8 and addresses knowledge of preventive strategies, proper use of inhalers, differences between maintenance and rescue medications, and use of peak flow meters. One point is assigned to each correct response, and the raw score equals the sum of all points. The final transformed score was determined by the equation $(\text{raw score}/16) \times 100$ and ranges from 0 to 100, with higher scores indicating more knowledge of self-management.

Phase 2

The 25 patients who participated in the validity and reliability testing had a mean age of 41 years and 96% were women (Table 1). The mean (SD) ASMQ score from the first administration was 65 (18) (range, 19–88), corresponding to 10 correct responses of a possible 16. The mean (SD) ASMQ score from the second administration, which occurred a mean of 5 (range, 2–9) days later, was 66 (15) (range, 38–88). The mean (SD) KASE-AQ knowledge score was 49 (15) (range, 25–80). The Pearson correlations between the KASE-AQ and the first and second administrations of the ASMQ were 0.58 and 0.64, respectively. The Pearson correlation between the first and second administration of the ASMQ was 0.78, and the intraclass correlation coefficient was 0.58.

Phase 3

The 231 patients who participated in the demonstration phase had a mean age of 41 years, and 74% were women (Table 1). The mean (SD) enrollment ASMQ score was 60 (20) (range, 0–100; median, 62.5). No differences were found in score based on age ($P = .60$) or sex ($P = .81$). Only 1 patient (0.4%) had a score of 0 (floor score), and 3 patients (1.3%) had a score of 100 (ceiling score). With respect to self-management practices, only 34% owned a peak flow meter and 29% received a flu vaccine for the most recent winter season. The mean (SD) quality-of-life (AQLQ) score was 5.0 (1.3) (range, 1.6–7.0). The ASMQ scores were higher for patients who owned a peak flow meter, received a flu vaccine, and had better quality-of-life scores (Table 2).

The mean (SD) ASMQ score at 12 months was 68 (18) (range, 13–100; median, 68.8) (Table 2). The mean (SD) within-patient change between enrollment and 12-month ASMQ scores was 8 (15) ($P < .001$). The mean (SD) 12-month AQLQ score was 5.9 (1.0) (range, 2.5–7.0), the mean (SD) within-patient AQLQ change after 12 months was 0.9 (1.1) ($P < .001$), and 59% had an increase in score of 0.5 or more, corresponding to a clinically important improvement. Patients with higher ASMQ scores after 12 months were more likely to have a clinically important improvement in AQLQ scores compared with patients with lower ASMQ scores (65% vs 46%; $P = .01$).

DISCUSSION

The 16-item ASMQ is valid and reliable and corresponds to change in clinical asthma status over time. The questionnaire addresses knowledge of preventive strategies, proper use of inhalers, differences between rescue and maintenance medications, and use of peak flow meters. A major strength of the questionnaire is that it was not developed a priori by physicians but instead was derived during an iterative process based on feedback from patients. As such, the questions address real day-to-day situations and decisions faced by patients, and the incorrect response options reflect misconceptions that patients have about managing asthma. Thus, the final patient-derived questionnaire captures self-management issues from the patient's point of view.

An important goal in developing the questionnaire was to balance ease of administration with comprehensiveness. To increase comprehensiveness, we used a multiple-choice response format, which permitted us to expand the breadth of the material covered per question. This is beneficial because reasons why certain responses are incorrect can be discussed when the questionnaire is reviewed with patients. In addition, offering the response option of "I don't know" decreases the chances of guessing the correct answers and also communicates to patients that not knowing correct answers is anticipated and acceptable. When presenting the questionnaire to patients, we encouraged them to choose this option, where applicable, to identify what topics we needed to focus on during subsequent discussions.

To maximize ease of administration, we composed short phrases for questions and responses. The questionnaire has a Flesch-Kincaid reading level of grade 6.8 and requires approximately 5 minutes to complete when self-administered. When administered during an interview, approximately 8 to 10 minutes should be allocated to repeat questions and responses if necessary. We found the questionnaire to be well received by patients when administered both ways. In addition, we found that questions about rescue and maintenance medications were better understood if names of familiar medications were given as examples. Therefore, we recommend the patient's medications be cited in these questions, or representative examples of medications be cited if the questionnaire is given to a group of patients, such as in a research trial.

Although recruited from the same practice, patients in the testing and demonstration samples differed somewhat clinically. These differences were due to variations in eligibility criteria for the parent trials from which these patients were drawn. For example, patients in the demonstration sample were enrolled in a trial to increase walking and exercise and thus tended to have milder symptoms, to not require maintenance medications, and to have better asthma-related quality-of-life scores. Including patients with different disease severity in the various phases, however, permitted us to evaluate the ASMQ in patients with a range of clinical conditions.

We tested our questionnaire against the 20-item knowledge subscale of the KASE-AQ, a reliable general questionnaire that measures various aspects of asthma knowledge.³ The KASE-AQ was developed to account for patient-centered factors that may contribute to difficulties in managing asthma. The factors measured by the KASE-AQ were found to be associated with certain outcomes, such as medication compliance and the use of emergency asthma care.¹² Other scales, such as the 31-item Asthma General Knowledge Questionnaire for Adults, were developed to evaluate effectiveness of asthma educational programs and showed improvement in areas specifically addressed by the programs.^{4,5} The National Heart, Lung, and Blood Institute assembled a survey of 9 questions entitled "Check Your Asthma IQ," which offers a simple way to increase patients' awareness of issues related to asthma.²⁰ This brief quiz showed poor understanding of asthma among patients who presented to the emergency department for exacerbations.^{8,11} Also, several general knowledge questionnaires have been developed specifically for pediatric asthma patients and their caregivers.^{6,21}

With the exception of the KASE-AQ, which has multiple-choice responses, most of these other questionnaires have true or false responses with a third option to cover uncertainty.^{5,6,20} Although simpler to complete, these questionnaires are less likely to depict the process patients use in making treatment decisions. At the other end of the spectrum, several studies evaluated self-management knowledge by presenting patients with narratives of asthma exacerbations and asking them open-ended questions about what actions they would take at various stages.^{22,23} Points were assigned for actions that were appropriate at each stage. Although this technique approximates clinical reality, it is time consuming and difficult to administer to large groups of patients.

This study has several limitations. First, it was developed in an urban primary care practice and may not reflect self-management issues of patients in other settings. Second, there is no standard method to measure test-retest reliability for an informational questionnaire because the learning effect from the first administration may affect responses to the second administration. Therefore, we reported both the Pearson and intraclass correlation coefficients. Third, to establish validity it would have been ideal to compare the ASMQ with observed or documented self-management behaviors. In addition, the utility of the ASMQ in clinical practice would be confirmed by measuring changes in behavior resulting from completing the questionnaire and discussing it with physicians. Fourth, we did not formally test responsiveness

during a longer period or time in the demonstration sample because we did not administer the self-management intervention according to a set protocol. However, all patients in the demonstration sample received information about self-management through a workbook and periodic reinforcements by telephone. Therefore, our finding that asthma quality-of-life and ASMQ scores changed in parallel provides preliminary evidence that the ASMQ corresponds to clinical status over time.

The ASMQ is a valid and reliable questionnaire that is associated with effective self-management behaviors and outcomes. It addresses multiple aspects of self-management and can be used in clinical and research settings.

Acknowledgments

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ASTHMA SELF-MANAGEMENT QUESTIONNAIRE

Please circle the letter that corresponds to your answer for each question.

1. A main method to prevent asthma flare-ups is to...

- a. take medicines before meals
- b. take steroids in pill form
- c. get a flu vaccine
- d. go to the emergency room at the first sign of symptoms
- e. I don't know

4. Maintenance medicines...

- a. help prevent future symptoms
- b. don't need to be taken every day
- c. make you breathe better right after you take them
- d. can only be taken in pill form
- e. I don't know

2. Taking the prescribed two puffs of your inhaler two times a day...

- a. is the same as taking one puff four times a day
- b. is the same as taking four puffs once a day
- c. can be arranged in any way as long as you take a total of four puffs a day
- d. is not the same as any other regimen
- e. I don't know

5. The correct way to use a peak flow meter is to...

- a. take a deep breath and then blow into the mouthpiece slowly
- b. start exhaling and then put the mouthpiece in your mouth
- c. put the mouthpiece in your mouth and then inhale and exhale
- d. take a deep breath then blow into the mouthpiece as fast as you can
- e. I don't know

3. If you are not having asthma symptoms...

- a. your lungs are not sensitive to irritants
- b. it is OK to skip some doses of medicine
- c. you should still avoid triggers
- d. you are probably cured of asthma
- e. I don't know

6. Rescue medicines...

- a. should not be taken more than three or four times a day
- b. help prevent future flare-ups
- c. have no side effects
- d. do not cause you to become tolerant to medicine
- e. I don't know

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Please circle the letter that corresponds to your answer for each question.

7. When using your inhaler, you should...

- a. take shallow breaths
- b. inhale quickly
- c. inhale slowly
- d. press your inhaler several times while you are inhaling
- e. I don't know

10. Taking more rescue medicines than prescribed...

- a. is really not harmful
- b. is a good way to manage symptoms caused by exercise
- c. may mean you can take less maintenance medicine
- d. may mean you need more maintenance medicine
- e. I don't know

8. After you have used your inhaler, you should...

- a. hold your breath for several seconds
- b. take the second puff as soon as possible after the first puff
- c. keep taking puffs until you feel better
- d. wash the inhaler in a tub of water
- e. I don't know

11. The benefit of using a peak flow meter every day is...

- a. you can detect small changes in lung function even before symptoms start
- b. it can tell you when you can decrease your medicines
- c. you can see how well you can inhale
- d. you can have a way to compare yourself to other people with asthma
- e. I don't know

9. If you are having symptoms and don't know why, the first thing you should do is...

- a. take some doses of steroid medicine
- b. call your doctor
- c. count how fast you are breathing
- d. change your immediate environment
- e. I don't know

12. For people with asthma, exercise...

- a. is something that should not be done regularly
- b. can help improve breathing capacity
- c. is only good if done for at least 30 minutes at a time
- d. can trigger symptoms because the lungs are not taking in enough oxygen
- e. I don't know

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Please circle the letter that corresponds to your answer for each question.

<p>13. Asthma can be cured by...</p> <ul style="list-style-type: none">a. taking daily medicineb. avoiding triggers, such as dust and cigarette smokec. using a peak flow meterd. there is no known cure for asthmae. I don't know	<p>15. If you are prescribed a seven-day course of steroid pills...</p> <ul style="list-style-type: none">a. you don't have to avoid triggers while you are taking the pillsb. your symptoms can't get worse while you are taking the pillsc. you don't need to use your peak flow meter while you are taking the pillsd. you should finish the prescription even if you feel better after several dosese. I don't know
<p>14. Asthma flare-ups...</p> <ul style="list-style-type: none">a. usually occur suddenly without warningb. can occur when several minor triggers come togetherc. cannot be triggered by strong emotionsd. always cause wheezinge. I don't know	<p>16. Which of the following can help control asthma?</p> <ul style="list-style-type: none">a. reducing stress levelsb. drinking plenty of water to stay hydratedc. avoiding foods with sulfites, such as dried fruits and wined. all of the abovee. I don't know

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Figure 1.
Asthma Self-Management Questionnaire. Reproduced with permission from Hospital for Special Surgery; © copyright 2008 Hospital for Special Surgery. All Rights reserved.

ASTHMA SELF-MANAGEMENT QUESTIONNAIRE	
Scoring	
Question number	Preferred response
1	c
2	d
3	c
4	a
5	d
6	a
7	c
8	a
9	d
10	d
11	a
12	b
13	d
14	b
15	d
16	d

1. Assign one point for each preferred response.
2. Sum all points to generate the raw score. The raw score ranges from 0 to 16.
3. Transform the raw score to range from 0 to 100.
Transformed score = (raw score / 16) x 100.
4. Report the transformed score.
Higher scores indicate more knowledge of asthma self-management.

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Figure 2.

Asthma Self-Management Questionnaire scoring. Reproduced with permission from Hospital for Special Surgery; © copyright 2008 Hospital for Special Surgery. All Rights reserved.

Table 1Patient and Asthma Characteristics at Enrollment for Testing and Demonstration Samples^a

Characteristics	Testing sample (n = 25)	Demonstration sample (n = 231)
Age, mean (SD), y	41 (13)	41 (11)
Women	24 (96)	170 (74)
Race		
White	13 (52)	131 (57)
African American	10 (40)	44 (19)
Other	2 (8)	56 (24)
Latino	10 (40)	70 (30)
College graduate	9 (36)	148 (64)
Asthma duration, mean (SD), y	25 (11)	22 (14)
FEV ₁ , ^b mean (SD), %	86 (20)	91 (18)
Medications ^c		
None	0 (0)	14 (6)
β-Agonists only	3 (12)	96 (42)
Maintenance medications	22 (88)	121 (52)
Owns a peak flow meter	16 (64)	78 (34)
Received flu vaccine	Not recorded	66 (29)
Ever hospitalized for asthma	13 (52)	73 (32)
Ever treated in the emergency department for asthma	23 (92)	139 (60)
AQLQ score, mean (SD)	3.9 (1.4)	5.0 (1.3)
ASMQ score, mean (SD)	65 (18)	60 (20)

Abbreviations: AQLQ, Asthma Quality of Life Questionnaire; ASMQ, Asthma Self-Management Questionnaire; FEV₁, forced expiratory volume in 1 second.

^aData are presented as number (percentage) of patients unless otherwise indicated.

^bFEV₁ was measured at enrollment with a portable spirometer.

^cMedications reported to be currently taking.

Table 2

ASMQ Scores Compared With Self-management Practices and Quality-of-Life Scores for the 231 Patients in the Demonstration Sample

	Cross-sectional sample at enrollment	
	ASMQ score, mean (SD)	<i>P</i> value
Owens peak flow meter	64 (19)	.04
Does not own peak flow meter	58 (21)	
Received flu vaccine	65 (21)	.04
Did not receive flu vaccine	59 (21)	
AQLQ score better than group mean	64 (20)	.003
AQLQ score worse than group mean	56 (20)	

Abbreviations: ASMQ, Asthma Self-Management Questionnaire; AQLQ, Asthma Quality of Life Questionnaire.