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Analysis of knowledge evaluation tools for pediatric patients participating in an asthma education program

Analyse des outils d'évaluation des connaissances pour les patients pédiatriques participant à un programme d'éducation sur l'asthme

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Abstract. Ensuring patients are informed and knowledgeable about their health and disease management has been identified as a key aspect of effective health care. Patient education has been incorporated in treatment guidelines for childhood asthma. The effectiveness of patient education should be evaluated. However, the best tool to evaluate educational interventions on children's knowledge and management of their asthma is unknown and guidelines do not recommend any standard knowledge evaluation tool. The objective was to identify and analyze the asthma knowledge evaluation tools available for children and their caregivers participating in asthma education programs. Methods: The study consisted of two parts: (i) observation of patient education sessions and review of international asthma guidelines to identify essential topics for education and (ii) a literature review to identify existing knowledge evaluation tools and assess how they addressed the essential topics. Results: Six essential topics (physiology of the respiratory system, physiopathology of asthma, trigger factors, asthma treatments, asthma exacerbation management and self-management education) and sixteen knowledge evaluation tools were identified. None of the tools evaluated all the essential topics. Understanding of the respiratory system was the topic most frequently lacking. Eight validated questionnaires were found. However, they did not address all the essential topics nor were designed for children under 9 years old. Conclusions: This study highlighted some gaps in the evaluation methods for asthma education and identified the essential elements of a pediatric asthma knowledge evaluation tool. New knowledge evaluation tools assessing the six essential topics identified and appropriate for children of various ages are needed.

Key words: patient education, asthma, pediatric, program evaluation, clinical pharmacy

Résumé. L'éducation thérapeutique (ETP) des patients asthmatiques a été identifiée comme un aspect clé du parcours de soin. Cependant le meilleur type d'éducation à fournir reste à déterminer et l'efficacité de chaque programme d'ETP nécessite d'être évaluée. L'objectif de cette étude était d'identifier et d'analyser les outils d'évaluation des connaissances dans l'asthme existants dans la littérature pour les enfants asthmatiques et leurs proches. *Méthode*: Cette étude comprenait 2 étapes: (i) observation de séances d'ETP pour enfants asthmatiques et revue des recommandations internationales afin d'identifier les thèmes essentiels à aborder en ETP; (ii) revue de la littérature pour identifier les outils d'évaluation des connaissances existant afin d'évaluer comment ils adressaient les thèmes précédemment définis. *Résultats*: Six thèmes essentiels topics (physiologie du système respiratoire, physiopathologie de l'asthme, facteurs déclenchants, traitements de l'asthme, gestion de la crise et l'auto gestion de l'asthme) et seize outils d'évaluation des connaissances ont été identifiés. Aucun des outils n'évaluait la totalité des thèmes. Huit des seize outils étaient des questionnaires validés, mais aucun n'était conçu pour des enfants de moins

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de 9 ans. *Conclusion*: Cette étude a démontré des lacunes dans les méthodes d'évaluation des connaissances en ETP et a permis d'identifier les éléments essentiels requis pour la création d'un outil standardisé d'évaluation des connaissances dans l'asthme en pédiatrie.

Mots clés : éducation thérapeutique, asthme, pédiatrie, pharmacie clinique

ver the past few years, the role of patients in the healthcare system has evolved and moved toward patient empowerment and inclusion of the patient as a member of the healthcare team and in shared decision making. An example of this new approach is the Montreal model, based on the partnership between patients and healthcare professionals to improve the quality of care [1]. In France, this new approach was made official in 2009, by the "Hôpital, Patient, Santé, Territoires" (HPST) law, which includes patient education as an essential part of patient care. In line with the philosophical shift in the healthcare system, the French national authority for health now incorporates patient education in their guidelines for the management of chronic diseases, and several patient education programs have been created. In the Paris region, 45 education programs for asthma were authorised by the health regional agency, as identified by the CART'EP project, a patient education program directory and information-sharing website of the programs created since 2010 [2].

For asthma, in 2015 the *Société de pneumologie de langue française* (SPLF), updated their guidelines and incorporated the importance of regular educational counseling for all patients with asthma, in order to achieve some degree of patient self-management [3]. These guidelines build on the 2002 *Agence nationale d'accréditation et d'évaluation en santé* (Anaes) guidelines for asthma patient education that established education tools, content of programs and items to assess in follow-up sessions [4, 5].

In parallel to these emerging recommendations, many studies of patient asthma education have shown a benefit in patient care and management of the disease. Educational interventions have been associated with a reduction in emergency department visits and hospitalizations [6]. Other studies have shown that patient education improved adherence to treatment and inhaler technique [7, 8]. The SPLF guidelines have described proper inhaler technique as essential to be able to achieve adequate disease control.

Although it has been established that the success of asthma care depends on patient knowledge of the disease, its management and proper inhaler device technique, as well as adherence to treatment, the best type of educational intervention for children remains unknown. Evaluating a program or choosing the best intervention requires having tools to evaluate knowledge and skill acquisition of the children and their caregivers. However,

existing treatment guidelines do not recommend an evaluation tool, making it challenging for clinicians to assess patient and caregiver education and their understanding of their disease.

The purpose of this study was to perform a review of the tools available to evaluate asthma knowledge among children with asthma and their caregivers, in order to identify the best tool to use in future studies to assess the quality of pediatric asthma education programs and tools.

Methods

This study was carried out in 2 phases:

- identification of the main topics to comprehensively assess the knowledge of pediatric asthma patients and their caregivers;
- a critical literature review to determine how existing tools address those main topics.

Phase 1: Topic identification

The aim of the first part of the study was to identify topics that were essential to address in an evaluation tool in order to comprehensively assess the knowledge of pediatric asthma patients and their caregivers.

A prospective observation of patient education group sessions was done. We observed four patient education group sessions, which were part of two educational programs at two different Children's Hospitals in Paris. The groups were selected because they represented the asthma pediatric population and the education programs were part of standard established asthma care in France. Each group session was dedicated to a different age-category: "Young "from 5 to 8 years old, "Middle "from 9 to 12 years old, "Teens "from 13 to 18 years old and Parents and caregivers "The sessions were led by trained asthma nurses or respiratory physicians. All the education programs and their content were approved by the French *Haute autorité de santé* (HAS).

We also analyzed the existing guidelines for patient education programs for pediatric asthma patients. The HAS report for asthma education for children and teenagers, written by the French Anaes respectively in June 2002 and June 2001, and the 2015 SPLF guidelines were the nationales guidelines analyzed [3-5]. The US Expert Panel Report 3 - Guidelines for the diagnosis and management of asthma (EPR-3), released by the National

heart lung and blood institute in 2007, the Canadian thoracic society guidelines of 2015 about the diagnosis and management of asthma in preschoolers and the 2018 Global Initiative for Asthma (GINA) guidelines were the international guidelines analyzed [9-11].

Topics were considered essential if they were included as a topic in all the patient asthma education sessions observed or if they were recommended in more than one asthma treatment guideline. A discussion between the investigator and the specialized asthma nurses delivering the educational programs also took place to confirm the inclusion of topics identified from observing the education sessions and described in the guidelines.

Phase 2: Critical literature review

The aim of the literature review was to identify the existing tools used to evaluate the knowledge of children with asthma and their caregivers. We searched the databases PubMed[®] [May 2008 - May 2018] and Embase[®] [May 2008 - May 2018] and used the MeSH (Medical sub headings) terms: "Patient Education" associated with "Asthma" and "Evaluation Studies" or "Program Evaluation". Another search using the same databases was also done, using the MeSH terms: "Patient Education" associated with "Asthma" and "Health Knowledge, Attitudes, Practice" or "Knowledge Management" or "Patient Medication Knowledge" or "Knowledge".

The filters used to target the most relevant articles were "children: birth-18 years", published "less than 10 years ago", and "French or English language". Reference lists of articles retrieved were searched by hand by one author for relevant papers.

The selection of studies for inclusion was conducted in 3 steps. First, the articles were screened, selected based on their titles. Then, the articles were further screened based on the abstract and finally, the selection was based on the complete reading of the remaining articles.

The exclusion criteria were:

- studies with no full text available;
- studies that had only clinical outcomes (e.g. Number of exacerbations, number of ER visits) and no mention of asthma knowledge outcomes;
- studies that did not describe the evaluation tool used (e. g. Items assessed by the tool).

The inclusion criteria were:

- studies that had asthma knowledge as a primary or secondary outcome;
- studies about the validation of an asthma knowledge questionnaire:
- studies that described the evaluation tool used, whether it was validated or not.

Finally, a cross analysis of the items identified as essential and the knowledge evaluation tools identified in the literature was done. We used a dichotomous approach

(items present or absent) to analyse if the evaluation tools were assessing the items in their questionnaires.

Results

Phase 1: Topics identification

Six items were identified as essential to patient knowledge evaluation and patient education programs. The six items were: (1) Physiology of the respiratory system, (2) Pathophysiology of asthma, (3) Environment and trigger factors, (4) Asthma treatments, (5) Asthma exacerbation management and (6) Self-management education. The items (2) to (6) were described in the international and French guidelines for asthma management and patient education. Following our observations of child education group sessions, we identified that in addition to items (2) to (6), item (1) was essential for young children in order to help them understand their disease. The descriptions of the six items are in *table 1*.

Phase 2: Critical literature review

One hundred and twenty-four articles matching the research criteria (MeSH terms and filters) were retrieved. The screening of those articles led to the identification of sixteen evaluation tools of asthma knowledge [12-26] (figure 1).

Evaluation tool description

Nine of the sixteen (56%) evaluation tools were intended for children only, four (25%) were intended for the parents or caregivers of the children, and three (19%) were intended for both children and parents. Three of the sixteen (19%) evaluation tools were administered by study personnel and thirteen (81%) were self-report questionnaires. The minimum age of the patients participating in any of the knowledge evaluation studies was 8 years old, and no evaluation tools designed for children under 8 years old were found.

Eight of the sixteen (50%) questionnaires were validated with statistical testing (Cronbach alpha or KR-20) to assess the reliability of the questionnaires. The remaining eight questionnaires, newly created or adapted from previously validated questionnaires, were not validated.

Cross analysis between the 6 items identified and the knowledge evaluation tools

We used a dichotomous approach to analyse if the knowledge evaluation tools were assessing the 6 essential topics. The description and comparison of the different knowledge evaluation tools can be found in *table 2*.

Table 1. Description table of the 6 items identified as essentials to a patient's knowledge evaluation.

Items	Description	Sources
Physiology of the respiratory system	 Identify where the respiratory organs are Explain how the lungs work (air flow path) Describe what is exhalation/inhalation 	Children education group sessions
Pathophysiology of asthma	Define asthmaExplain the pathophysiology of asthmaInterpret the peak expiratory flow value	Children education group sessions International and National guidelines [3-5, 9-11]
Environment and trigger factors	List possible triggers from the environment Identify asthma-triggering situations in order to take preventive action	Children education group sessions International and National guidelines [3-5, 9-11]
Asthma treatments	 Explain the action and purpose of drugs Demonstrate how to use asthma medications Differentiate between the action of long-term therapy and quick-relief therapy for an acute attack 	Children education group sessions International and National guidelines [3-5, 9-11]
Asthma exacerbations' management	 Recognize warning signs of exacerbation of asthma Recall personal asthma action plan Define the different states of asthma attacks 	Children education group sessions International and National guidelines [3-5, 9-11]
Self-management education	 Adjust treatment in relation to the risks identified in the personal and social environment, and during a change of environment Correctly use a written asthma action plan Recognize when to seek medical care Do physical exercise in relation to exercise tolerance 	Children education group sessions International and National guidelines [3-5, 9-11]

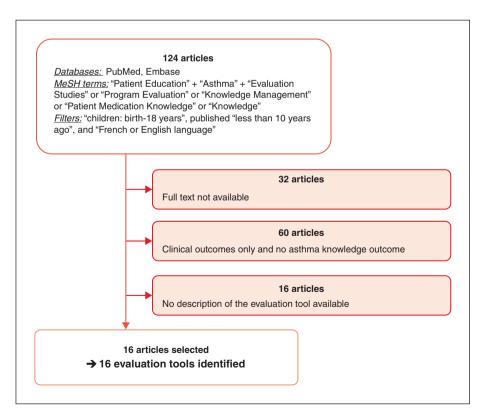


Figure 1. Articles review selection.

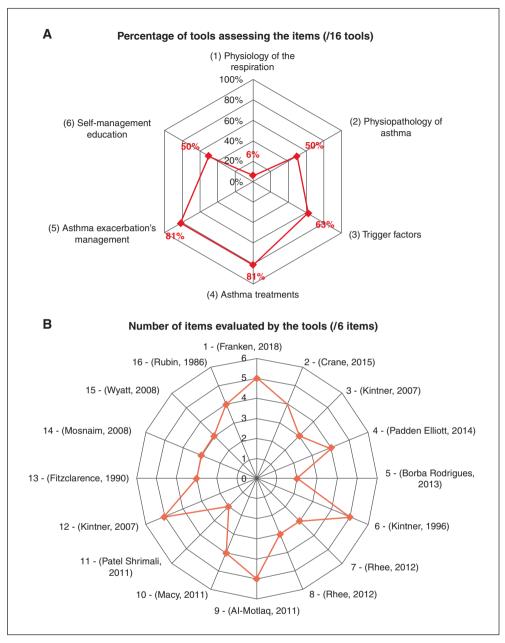


Figure 2. Cross analyses between the six items identified and the sixteen knowledge evaluation.

The most evaluated items were: (4) Asthma treatments and (5) Asthma exacerbations management, both evaluated in thirteen (81%) of the sixteen tools and (3) Environment and trigger factors, evaluated in ten (63%) of the tools. The item least assessed was: (1) Physiology of the respiratory system, which was evaluated in 1 (6%) of the tools (figure 2A).

Eight of the sixteen (50%) tools evaluated at least 4 of the 6 essential topics. None of the tools evaluated all six topics (*figure 2B*).

Discussion

Despite national and international consensus about the requirement to complete an educational program to improve patient care, no standard tool is available to evaluate patient knowledge about asthma and its management, in order to estimate the benefit of the educational intervention to pediatric patients. This study showed that the evaluation of the educational interventions is not harmonized and none of the tools identified

Table 2. Comparative table of the knowledge evaluation tools and the items evaluated.

Tool name	Target population	Administra- tion format	Timing	Validation	Number of items	(1) Physiology of the respiration	(2) Patho- physiology of asthma	(3) Trigger factors	(4) Asthma treat- ments	(5) Asthma exacerba- tion	(6) Self- manage- ment education
Adaptated Rodriguez-Martinez questionnaire (Franken, 2018) [12]	Parents	Self-report questionnaire	Unknown	YES Cronbach 0.73	21	×	>	>	>	>	>
Open Airways pre and post program questionnaire (Crane, 2015) [14]	Children (8 to 12 year old)	Self-report questionnaire	First day and at the end of the program	NO NO	==	×	×	>	>	>	>
Asthma Health Behaviors Survey (Kintner, 2007) [13]	Parents	Self-report questionnaire	Pre-intervention, 1, 12 and 24 months post intervention	YES Cronbach 0.73	34	×	×	>	>	>	>
Simplified version of Fitzdarence and Henry's Asthma Knowledge Questionnaire (Padden Elliott, 2014) [15]	Parents and children (5-17 year old)	Administered by study personnel	Beginning and end of each camps	ON	14	×	>	>	>	>	×
Questionnaire for inhalation technique (Borba Rodrigues, 2013) [16]	Children (> 14 year old)	Evaluated by study personnel	Pre and 3 month post education program	NO	~	×	×	×	>	×	>
Knowledge of Asthma Survey (Kintner, 1996) [18]	Parents and children (9-12 year old)	Self-report questionnaire	Pre-intervention, and 1, 12 months post intervention	YES Cronbach 0.70	18	>	>	>	>	>	×
Modified existing children's asthma knowledge questionnaire (Rhee, 2012) [17]	Children (16-20 year old)	Self-report questionnaire	Baseline, 3, 6 and 9 months post camp	YES Cronbach 0.62	30	×	>	>	×	>	×
Child Asthma Self-Efficacy questionnaire (Rhee, 2012) [17]	Children (16-20 year old)	Self-report questionnaire	Baseline, 3, 6 and 9 months post camp	YES Cronbach 0.83	14	×	×	×	>	>	>
Asthma knowledge test (Al-Motlaq, 2011) [21]	Children (8 to 10 year old)	Self-report questionnaire	During class activity at school	YES KR-20 0.27	24	×	>	>	>	>	>
Modified National Asthma Education and Prevention Program asthma knowledge questionnaire (Macy, 2011) [20]	Parents	Orally adminis- tered survey	Baseline and 6-week telephone follow-up	ON	14	×	>	>	>	>	×
11-question survey (Patel Shrimali, 2011) [19]	Children (11-12 year old)	Self-report questionnaire	Pre intervention and again 3 months after the final class	NO	11	×	×	×	>	×	>
Reasoning about Asthma Scenarios (Kintner, 2007) [23]	Children (9-12 year old)	Self-report questionnaire	Pre-intervention, 1, 12, 24 months post-intervention	YES Cronbach 0.80	18	×	>	>	>	>	>

Table 2

Tool name	Target population	Administra- Timing tion format	Timing	Validation	Number of items	Number (1) Physio- (2) Patho- (3) Trig of items logy of the physiology factors respiration of asthma	(2) Pathophysiology of asthma	(3) Trigger factors	Validation Number (1) Physio- (2) Patho- (3) Trigger (4) Asthma (5) Asthma of items logy of the physiology factors treat- exacerba- manage respiration of asthma ments tion education education.	(5) Asthma exacerba- tion	(6) Self- manage- ment education
Newcastle Asthma Knowledge Questionnaire (Fitzclarence, 1990) [22]	Parents	Self-report questionnaire	Upon arrival to the YES hospital, and before Cronbach 0.72 the appointment	YES Cronbach 0.72	31	×	>	>	>	>	×
Modified ZAP Caregiver Asthma Knowledge (Mosnaim, 2008) [25]	Children Self-report (10 -18 year old) questionnaire	Self-report questionnaire	Pre-intervention, 6 weeks, 12 weeks post intervention	NO	39	×	>	>	×	>	×
The Asthma Information Quiz (Wyatt, 2008) [24]	Children Self-report (8 to 11 year old) questionnaire	Self-report questionnaire	Baseline and 1 week NO and 2 week after intervention	NO	23	×	×	>	>	>	×
Asthma Behavioral Assessment Questionnaire (Rubin, 1986) [26]	Parents and children (8-12 year old)	Self-report questionnaire	At follow-up	NO	17	×	×	>	>	>	>

: item present, X: item absent.

evaluated an exhaustive list of essential topics representing all the required patient knowledge and skills.

To our knowledge, this is the first study reviewing evaluation tools for pediatric patient asthma education programs. The study highlights a lack of a standardized and validated method to evaluate asthma patient and caregiver educational interventions.

The lack of evaluation tools assessing all six essential items can be explained by the lack of inclusion of evaluation of "Physiology of the respiratory system". While some clinicians may argue that patient understanding of the function and purpose of the respiratory system is less important than the other topics, this may be because older children and adults will have covered the purpose and function of the respiratory system in their school curricula and therefore have acquired this knowledge from other resources. This may explain why it has not been specifically described in any of the asthma guidelines. For vounger children, the function of the respiratory system may not have yet been covered in their school curriculum. This concern and our observations of the child asthma education sessions, where a complete session was dedicated to the "Physiology of the respiratory system", led us to integrate this topic as one of the essential items to assess in a knowledge questionnaire. It can be inferred that to understand and control asthma a patient and their caregivers need to understand how the respiratory system works, including being able to identify where the respiratory organs are, how they work, and be able to explain the airflow path and define inhalation and exhalation. All the tools analyzed in this study were designed for children over 8 years old. This may explain why the first item was so poorly addressed by the tools.

Another weakness identified was the lack of age-based evaluation tools. The questionnaires were only designed for either children with asthma or the parents/caregivers of children with asthma. But none of the evaluation tools differentiated between young children and teenagers, whom are known to have different baseline knowledge regarding human anatomy, as well as different learning abilities and comprehension. The notion of different cognitive stages in childhood was first described in 1952, by the French psychologist Jean Piaget who published a theory that the cognitive development of children occurs in four distinct stages: sensorimotor stage (birth through about 2 years), preoperational stage (age 2 to 7 years), concrete operational stage (age 7 to 11 years), and formal operational stage (age 11 years and older) [27]. Piaget's theory is still relevant and should be considered when creating educational interventions or evaluation questionnaires for children [28].

Our study found sixteen evaluation tools assessing pediatric asthma knowledge including tools assessing knowledge mobilization to make decisions as part of the children self-management of their disease (eg. The questionnaire "Reasoning about asthma scenarios" by Kintner et al., 2007 [23]). The question that arises from the analysis of the evaluation tools is: "Should a knowledge questionnaire evaluate patient theoretical knowledge of asthma only or should it also include an assessment of their application of this knowledge in managing their asthma?" Although many guidelines recommend having educational interventions for patients with asthma and several studies demonstrated benefit in asthma management, the relationship between knowledge and asthma management is not always straight forward. There are only a few studies that have tried to determine whether the changes in patient knowledge lead to changes in disease management behaviours. One study investigated the relationship between asthma management and knowledge about asthma [29]. The study reported that children's knowledge about asthma can influence asthma management but only under conditions of at least a moderate level of knowledge. Therefore, evaluating the topic of patient self-management education (application of knowledge, e.g. "What would you do in this situation?") is complementary to evaluating patient theoretical knowledge (e.g. "What are asthma symptoms?"), if we want to obtain an accurate assessment of the impact of educational intervention on patient knowledge and their application of this knowledge.

These observations and analyses of the existing tools can be used to identify the essential criteria that an asthma knowledge evaluation tool must include, in order to create a more exhaustive, adequate and standard knowledge evaluation tool. We suggest that an adequate knowledge evaluation tool should:

- evaluate all 6 topics previously identified as essential to comprehensive asthma knowledge for childrenand their parents/caregivers;
- be customized for different children age groups (as described in the different cognitive stages in childhood [27]):
- Ages 1 to 6 (deferred to the parents/caregivers)
- Ages 7 to 11 years old
- Ages 12 to 18 years old
- Parents/caregivers (adults)
- evaluate theoretical knowledge, as well as self-management thatis a reflection of patient knowledge;
- be validated using a statistical method to assess the reliability of the tool (e.g. Cronbach alpha, intraclass correlation, Pearson correlation...).

Conclusion

This study highlighted several gaps in the management of patient education in asthma; the lack of inclusion of basic respiratory system information for young children, the lack of guidelines specifying evaluation methods, as well as the lack of standardized knowledge evaluation tools for children with asthma. This study also identified essential requirements that a knowledge evaluation tool for pediatric asthma must contain. The literature review and the field observation of collective education sessions will be used to create new questionnaires, tailored to age groups, to evaluate the patient knowledge as well as their management of asthma to assess the effectiveness of educational interventions.

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