

**Review Article**

## A REVIEW OF HEALTH OUTCOME INSTRUMENTS FOR ASTHMATIC CHILDREN & THEIR CAREGIVERS

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### ABSTRACT

There are various developed general-as well as disease-or condition-specific health outcome instruments to assess an impact of asthma among asthmatic children but few of these instruments were developed in paired versions of child and caregiver. The objective of this review was to determine currently available unpaired and paired health outcome instruments for asthmatic children and their caregivers. Systemic search from Medline, Scopus and Science Direct was conducted to identify asthmatic children's and their caregivers' health outcomes tracking instruments that characterize basic properties of instruments such as instrument's developer and the published year, instrument's description, targeted age and time for completion, items and domains, administration way, scoring and scaling of instrument, type of study setting, tested sample size, availability of instrument in different languages, reliability and validity of the instrument. The results showed in total, 21 instruments were identified whereby 16 of them were administered by either asthmatic children or their caregivers, and remaining (n = 5) have paired version that was administered directly to both asthmatic children and their caregivers. Most of these instruments reported good validity and reliability (Cronbach's alpha between 0.60-0.95). There is a need to develop more paired disease-specific health outcome instruments targeted both asthmatic children and their caregivers to get full data of the impact and burden of asthma and its health intervention on the respective respondents.

**Keywords:** Asthmatic children, Caregivers, Health outcome instrument.

### INTRODUCTION

Childhood asthma is a serious health problem that results in impairment of physical and social life of the affected children and their immediate families [1, 2]. In other words; the quality of life of asthmatic children can be severely affected due to disease symptoms and dependence on medication. In Southeast Asian countries, 1 in 3 of asthmatic children having missed school in a year due to their asthma [3]. Furthermore, hospitalization rate is high in these countries; also the mortality and morbidity of asthma will increase if there is no control or no adherence to asthmatic treatments [4]. In a literature review study on the impact of mild asthma on the quality of life found that both severe and mild asthma caused negative effects on a patient's life [5].

Since the disease and its treatment do not only affect survival but the quality of life of a patient (physical, social and emotional well-being), the health outcomes from a patient's perspective tool was developed to examine the effect of the disease on a patient's life [6]. It consisted of generic and disease-specific health outcome measurements; generic measures which give comprehensive results which can be compared across respondents and across treatments, while disease-specific measures are more sensitive to the disease severity and more responsive to small changes in the quality of patient's life [7]. Over the past few years, efforts have been made to provide valid and reliable measurement instruments and have resulted in several validated measurements have been developed for different types of diseases and for different patient ages [8]. One of these types is asthmatic children's outcome measures, as importance to this area has increased to understand children's and caregivers' perceptions about the disease [9]. Both child and parent reports about the health status of the child are important, as in some cases parent's point of view is needed when the child is too young or very sick to respond [10]. Also another study has shown that caregivers can report accurately for some behaviour, such as symptoms and physical activities, but less accurate for emotional and psychological effects [11]. For childhood asthma, there are several psychometrically and well-established measures. Rutishauser *et al.* reviewed both generic and asthma specific instruments for children and adolescences, they found only four asthma specific instruments; Pediatric Asthma Quality of Life Questionnaire (PAQLQ), three forms of Childhood

Asthma Questionnaire (CAQ-A, CAQ-B, & CAQ-C), Life Activities Questionnaire for Childhood Asthma (LAQCA), and Questionnaire to measure perceived symptoms and disability in asthma (ASDQ) [12]. Davis *et al.* reviewed all the instruments that targeted children from 0 to 12 years, and they found only three questionnaires for asthmatic children PAQLQ, CAQs, and About My Asthma (AMA) [13]. Solans *et al.* reviewed generic and disease-specific health-related quality of life (HRQOL) instruments for children and adolescents up to 19 years old, they found 10 instruments for asthmatic children PAQLQ, AAQOL, AMA, ARQOL, ASDQ, CAQs, ITG-CASF, JSCA-QOL, LAQCA, & PAHOM [14]. Quittner, *et al.* reviewed the instrument that targeted children with respiratory disorders, and they found 12 instruments for asthmatic children, AMA, AAQOL, CAQs, CHSA, PAQLQ, PACQL, ARQOLS, TACQOL-Asthma, PedsQL, LAQCA, ITG-CASF, How Are You (HAY) [8]. There are various developed health outcome instruments to assess an impact of asthma among asthmatic children but few of these instruments were developed in paired versions of child and caregiver. The objective of this review was to determine currently available unpaired and paired health outcome instruments for asthmatic children and their caregivers.

### Search strategy

A systemic review was conducted to recognize all available asthmatic children instruments, there are two ways were used; the first one is analyse previous reviews [8] & [14], and the other one is systemic search from Medline, Scopus and Science Direct. The search was conducted to identify asthmatic children's and their caregivers' health outcomes instruments, using several combinations of keywords: "asthmatic children", "asthmatic children and parents", "asthma in children", "parent with asthma child", "asthma questionnaires" and "asthma instrument". No restrictions on dates were utilized during online database searches, only studies that targeted asthmatic children were included, non-English articles, books, thesis, non-published material were excluded from this search. This review tracking instruments that characterize basic properties of instruments such as instrument's developer and the published year, instrument's description, targeted age and time for completion, items and domains, administration way, scoring and scaling of instrument, type of study setting, tested sample size, availability of instrument in different languages, reliability and validity of the instrument.

### Validity and reliability overview

In QoL studies, questionnaires are usually used to determine the health status of patients by measure of the mean of multi items instruments. In order of that, it is important to test the validity and reliability for a measure to reduce measurement errors [15]. The assessment of reliability examines the degree of consistency of a measure [16]. There are different methods for measuring reliability but all of them share the same definition. Internal consistency examines the degree of interrelation of items within a measurement instrument. In other words, it is the extent of the group of items to measure the same concept and can be statistically assessed by Cronbach's  $\alpha$  where internal consistency  $\geq 0.7$  is considered accepted for research purpose [17]. Test-retest reliability is another statistical measure which refers to the level of agreement between repeated administrations under the same condition over a short time interval. Some researchers suggested that low test-retest reliability does not indicate that the measure has poor reliability but may reflect some changes among some individuals [18]. Intra class correlation coefficient (ICC) one of tests that used to assess test-retest reliability. ICC is a statistical method that has been used to measure the correlation between pairs of observations that do not have obvious order, and it has also been used to measure the agreement between assessors, rather than between two methods [19]. The following guidelines in ICC were used for interpretation of the level of similarity or agreement: 0.81-1.00 is excellent agreement; 0.61-0.80 is good agreement; 0.41-0.60 is moderate agreement;  $\leq 0.40$  is poor to fair agreement [20].

Validity is "how well an instrument measures what it supposes to measure" [21]. There are different types of validity: content validity, criterion validity and construct validity. Content validity refers to whether a specific set of items for an instrument measures the content domain. Criterion related validity refers to comparing the measure with a criterion or a gold standard. Construct validity refers to whether the measurement instrument produces results that are agreed with expectations based on the hypothetical model or construct that support the instrument [15].

### Review of measures

The results showed in total, 21 instruments were identified whereby 16 of them were administered by either asthmatic children or their caregivers, and remaining (n = 5) have paired version that was administered directly to both asthmatic children and their caregivers. All the 22 instruments were developed to target age group between 4 to 17 years old, except Asthma Quiz for kids (1-17 years old), Pediatric Quality of Life Inventory (PedsQL) for asthma patients (2-18 years old), and Asthma Control and Communication Instrument asthma questionnaire (1-21 years old). Most of these instruments reported good reliability (Cronbach's alpha between 0.60-0.95), except Childhood Asthma Questionnaire (CAQ), PedsQL, and asthma knowledge test where their internal consistency is less than 0.06.

Most of the instruments were demonstrated good test-retest; the validity for these measures was determined by correlations between the new developed one and the well-established Paediatric Asthma Quality of Life Questionnaire (PAQLQ), or has been demonstrated by correlations with clinical parameter of asthma severity except Asthma Control Test (ACT) and asthma knowledge test where the validity have not reported and multi-attribute Paediatric Asthma Health Outcome Measure (PAHOM) where its reliability and validity has not reported. The items and domains differ from instrument to the other depending on the determination type if the instrument determine the quality of life or determine if the asthma is controlled or no. Only PedsQL and PAQLQ have availability in other languages and used in other studies. Also, the PAQLQ is the most widely used due to good reliability, validity, and responsiveness has been documented [8]. For the questionnaires that have both child-parent versions only CHSA and TACQOL have been used in different studies [22, 23] to examine the agreement between child's and parent's point of view.

Table 1 shows 16 questionnaires that administered by either asthmatic children or their caregivers, and table 2 shows five questionnaires that have child and parent versions.

**Table 1: Questionnaires that administered by either asthmatic children or their caregiver**

Instrument and instrument's developer and the published year	Instrument's description	Targeted age and time for completion	No. of items and domains	Administration, scoring and scaling of the questionnaire	Type of study setting and tested sample size	Psychometric properties (Reliability and validity)	Availability in other language	Applications of instrument in other studies
1. Questionnaire to measure perceived symptoms and disability in asthma (ASDQ) [24]	This questionnaire was developed to be completed by parents of asthmatic children to measure perceived symptoms and disability	5-14 years old Few minutes to complete (no specific duration)	17 items 3 domains: disability, nocturnal symptoms and daytime symptoms	Addressed for parent of asthmatic children 5-point likert scale. From 0 for "not at all" to 4 for "every day" or "every night" Disability, daytimes symptoms and nocturnal symptoms scores are 0-32 0-16 and 0-12, respectively	Clinical practice The sample size of survey A was 160 (asthmatic children were entered into a multicentre trial) Survey B was 55 (any asthmatic children)	Good content validity by comparing survey A with survey B Good internal reliability with $\alpha = 0.71-0.92$	Original English language Other languages not reported	[25] [14]

### DISCUSSION

Established and validated instruments are vital to determine health status and impact of asthma for this study targeted population in order to improve the quality of life for patients and caregivers, assess the standard of health care, assist the physicians and

pharmacists to identify the most appropriate drugs according to the patient's opinion thus improvement in asthma management [5]. In general, some child health outcome instruments have been developed depending on caregivers as a proxy respondent, while others depend on the children themselves. As accurate data are important for health services to improve quality of life for patient

and increase asthma control, some studies examined concordance between parent and child responses. Good agreement was found for observable behaviours such as physical activities and symptoms domains [83-85]. In other hand, poor agreement was found for non-observable behaviours such as social, emotional domains, and cognitive functioning [86]. Some studies examined how parents estimate their child's quality of life, Kieckhefer and co-researchers found that parent-child reports differed significantly in symptoms and sleep parameters. Parents most often reported fewer symptoms and awakenings and better quality of sleep than did their child [87]. Also in other study for a group of children with a chronic illness, parents reported significantly lower quality of life than their child [88]. In another study by Theunissen and co-researchers examined the effect of child's age in concordance between parent and child responses, they found the effects of age were moderated by the child's emotional state, children with negative emotions and older

age scored low agreement with their parents than younger children, and children with positive emotions agreed with their parent, in the same study the researchers examined the gender and how affecting agreement between child and parent responses, and they found that boys with low autonomy scores showed poorer concordance than girls with low autonomy. However, boys with high autonomy scores had higher concordance with their parents than girls with high autonomy scores [22].

Other study examined the health status of the child and how effects on the Concordance between parent and child responses, they found concordance between parent and child for somatic symptoms and disability to be much lower for psychiatric and well groups than for two groups with abdominal pain [89]. It can be concluded from the previous studies that both parent's and patient's point of view are important to give complete health outcome about the disease.

Instrument and instrument's developer and the published year	Instrument's description	Targeted age and time for completion	No. of items and domains	Administration, scoring and scaling of the questionnaire	Type of study setting and tested sample size	Psychometric properties (Reliability and validity)	Availability in other language	Applications of instrument in other studies
2. Life Activities Questionnaire for Childhood Asthma (LAQCA) [26]	This instrument divided to three parts for age of children 4-7, 8-11, and 12-16, determine QoL and distress caused by asthma during past week	5-17 years old Time not reported	71 items 7 domains: Physical, work, outdoor, emotions, home care, eating and drinking, and miscellaneous	Self-administered With the help of the parent for the young children 5-point likert as smiley faces responses Subscale and total scale score	Can be used in clinical setting, research, and policy making 40 children with asthma according to American Thoracic Society	By asking 92 children and their parent about the restrictions in their activities due to the asthma, the developers achieved the content validity The instrument is internally consistent by $\alpha = 0.97$ and test-retest = 0.76	Original: English (U. S.)	[12] [8] [14]

Instrument and instrument's developer and the published year	Instrument's description	Targeted age and time for completion	No. of items and domains	Administration, scoring and scaling of the questionnaire	Type of study setting and tested sample size	Psychometric properties (Reliability and validity)	Availability in other language	Applications of instrument in other studies
3. Childhood Asthma Questionnaire [27] CAQ-A CAQ-B CAQ-C	CAQ divided to three questionnaires depended on the age of child; all the three scales determine the QoL and the level of distress caused by asthma	CAQ-A: 4-7 years old Time: 10-15 min CAQ-B: 8-11 years old Time: 10-15 min CAQ-C: 12-16 years old Time: 10-15 min	CAQ-A: 14 items 2 domains: QoL and distress CAQ-B: 23 items 4 domains: Active QoL, passive QoL, distress and severity CAQ-C: 41 items	Self-administered With the help of the parent for the young children CAQ-A: 4-point scale of smiley faces CAQ-B & CAQ-C: 5-point scale of smiley faces	Use with in clinical trials to collect data and also to explore children's point of view Sample size was 242	CAQ-A was internally consistent by $\alpha = 0.60-0.63$ and test-retest = 0.59-0.63 CAQ-B was internally consistent by $\alpha = 0.57-0.84$ and test-retest is = 0.73-0.75 CAQ-C was internally consistent by $\alpha = 0.50-0.80$ and test-retest = 0.73-0.84 Validity was	Original: English Also Singapore language is available	[28] [29] [9] [30] [31] [12] [8] [14]

			5 domains: Active QoL, teenage QoL, distress, severity and reactivity			determined by comparing between asthmatic and non-asthmatic		
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Instrument and instrument's developer and the published year	Instrument's description	Targeted age and time for completion	No. of items and domains	Administration, scoring and scaling of the questionnaire	Type of study setting and tested sample size	Psychometric properties (Reliability and validity)	Availability in other language	Applications of instrument in other studies
4. About My Asthma (AMA). [32]	It is an instrument to measure stress levels and QoL from asthmatic children's point of view	6-12 years old Time to complete: 15-20 min	55 items No domains total score only.	By interviewing with child 4-point scale The total score is the mean of the items score, with higher score indicating to more stress for asthmatic child Total score ranges from 1 to 55	Provide data for research use, and identify source of stress and perceptions of asthmatic children for clinical use Sample size was 35 children who attended an asthma day camp and these children required daily medication	Validity determined by increased levels of stress that assessed by AMA correlated with a decreased quality of life that measured by PAQLQ Reliability determined by internal consistency $\alpha = 0.93$ and test-retest = 0.57	Original: English (US) Also available in Spanish and Russian	[13] [8] [14]

Instrument and instrument's developer and the published year	Instrument's description	Targeted age and time for completion	No. of items and domains	Administration, scoring and scaling of the questionnaire	Type of study setting and tested sample size	Psychometric properties (Reliability and validity)	Availability in other language	Applications of instrument in other studies
5. Mini Paediatric Quality of Life Questionnaire (Mini PQLQ) [33]	A shortened version of PQLQ, it has 13 questions with the same domains; it measures the impairment in daily life of asthmatic children	7-17 Years old Mean time to complete: 7 min	13 items 3 domains: activity limitation, symptoms and emotional function	Self-Administered 7-point Likert scale The overall score is the mean of 23 items. The individual domain score is the mean of items of this domain	Used in clinical trials	Reliability was assessed by Cronbach's $\alpha = 0.85$ Intra class correlation coefficient (ICC) = 0.63 Pearson correlation between the questionnaire and FEV <sub>1</sub> was weak The effect size between both visits was 0.91	Original English Spanish Portuguese Dutch Arabic	[34]

In most recent review to recommend standardized measures of the impact of asthma on QOL for use in future asthma clinical research, they classified the outcome instruments into three categories: core,

supplemental, and emerging outcomes, they found that the currently available instruments are classified as either supplemental or emerging [90].

Instrument and instrument's developer and the published year	Instrument's description	Targeted age and time for completion	No. of items and domains	Administration, scoring and scaling of the questionnaire	Type of study setting and tested sample size	Psychometric properties (Reliability and validity)	Availability in other language	Applications of instrument in other studies
6. Integrated Therapeutics Group Child Asthma Short Form (ITG-CASF) [25]	It is a questionnaire measuring symptoms and disability in paediatric asthma patients administered by parents only	5-12 years old Time not reported	8 items 3 domains: daytime symptoms, night-time symptoms and functional limitations	Self-administered by parents 5-point Likert-type scale with higher scores indicating better functioning	Used in clinical practice data collected between 2002 and 2004 and parent-child pairs were n = 414	Internal consistency was $\alpha = 0.84-0.92$  Correlated with asthma ( $p < 0.01$ ) Correlated with the no. of days of school missed or limited activities for the child ( $r = 0.45$ ) and parent ( $r = 0.25$ )	Original language English Other translated version not reported	[8] [14]

Instrument and instrument's developer and the published year	Instrument's description	Targeted age and time for completion	No. of items and domains	Administration, scoring and scaling of the questionnaire	Type of study setting and tested sample size	Psychometric properties (Reliability and validity)	Availability in other language	Applications of instrument in other studies
7-How Are You (HAY) [35]	It is a tool covered generic domains and asthma domains	8-12 years old Time for completion: 20 min	32 items The domains divided to 4 generic domains: physical activities, cognitive activities, social activities, and physical complaints Asthma domains: asthma symptoms, emotions related to asthma, self-concept, and self-management	Self-reported by child	Used in clinical practice Children with asthma (whole questionnaire) and children without asthma (generic component only)	Reliability determined by internal consistency by Cronbach's $\alpha = 0.71-0.83$ and ICC = 0.11-0.83 Validity determined by comparing with healthy and asthmatic children	Only English version	[8]

Instrument and instrument's developer and the published year	Instrument's description.	Targeted age and time for completion	No. of items and domains	Administration, scoring and scaling of the questionnaire	Type of study setting and tested sample size	Psychometric properties Reliability and validity	Availability in other language	Applications of instrument in other studies
8. Adolescent Asthma	Asthma specific instrument to	12-17 years old Time to	32 items 6 domains: symptoms,	Self-administered by adolescent also	Clinical practice and to	Validity is determined by correlation	Original language is English	[37] [38] [8]

Quality of Life Questionnaire (AAQLQ) [36]	measure QoL for adolescent; focuses on patients' perception of their disease and evaluates the change over time	complete: 5-7 min	medication, physical activity, emotion, social interaction and positive effects	may be used as an interviewer-administered 7-point Likert scale Individual items are equally weighted. The domain scores from mean score of each item The total score can be calculating as domain score	assess the asthma impact on the adolescent life Sample size was 111 adolescent with persistent asthma	between AAQLQ and PAQLQ (p=0.81) and correlation with clinical parameter of asthma severity The reliability of the six domains was good by $\alpha = 0.70-0.90$ and for the total score was $\alpha = 0.93$ Test-retest for the domains was = 0.76-0.85 and for the total score was = 0.90.	There is no other language reported	[14]
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<b>Instrument and instrument's developer and the published year</b>	<b>Instrument's description</b>	<b>Targeted age and time for completion</b>	<b>No. of items and domains</b>	<b>Administration, scoring and scaling of the questionnaire</b>	<b>Type of study setting and tested sample size</b>	<b>Psychometric properties Reliability and validity</b>	<b>Availability in other language</b>	<b>Applications of instrument in other studies</b>
9. Japanese School-aged Children with Asthma (JSCA-QOL) [39]	A tool for measuring the QoL of Japanese school-aged children with asthma	10-18 years old Time for completion: 10 min	First version was 40 items but was decreased in version 3 to 25 items in 5 domains: asthma attack triggers, change in daily life, family support, satisfaction with daily life, and restriction in participating in daily activities	Self-reported by children Each item was evaluated on a 5-point scale. For example 5 for "none" and 1 for "more than a lot"	Can be used in clinical practice 142 children aged from 10 to 18 years old with asthma	The internal consistency reliability coefficient (Cronbach's $\alpha$ ) of the JSCA-QOL v.3 was (0.07-0.86) Test-retest reliability (Spearman's rho) = 0.6, p<0.01 It is valid because there were significant correlations among the domains	In Japanese only	[40] [41] [14]

<b>Instrument and instrument's developer and the published year</b>	<b>Instrument's description.</b>	<b>Targeted age and time for completion</b>	<b>No. of items and domains</b>	<b>Administration , scoring and scaling of the questionnaire</b>	<b>Type of study setting and tested sample size</b>	<b>Psychometric properties Reliability and validity</b>	<b>Availability in other language</b>	<b>Applications of instrument in other studies</b>
10. Asthma Control Test (ACT) [42]	A patient-based tool for identifying patients with poorly controlled asthma. ACT is developed to assess the patient's level of	6-13 years old Time not reported	35 items 5 domains: restriction of social life, physical disturbances, limitation in physical activity, daily inconvenience in managing the	Administered by child Four-point Likert-type scale was designed for levels of agreement with items; the higher the score, the better the respondent's ARQOL	To assess disease-specific QOL in practice and in clinical research studies for asthmatic children 474	Reliability was determined by internal consistency $\alpha = 0.81-0.96$ Validity not reported	Other language not reported	[43]

asthma control and should discriminate between groups of patients according to level of asthma control	disease, and emotional distress	children with asthma: 251 children with asthma were recruited from three medical centers and 223 from six elementary schools in Taiwan
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<b>Instrument and instrument's developer and the published year</b>	<b>Instrument's description</b>	<b>Targeted age and time for completion</b>	<b>No. of items and domains</b>	<b>Administration, scoring and scaling of the questionnaire</b>	<b>Type of study setting and tested sample size</b>	<b>Psychometric properties (Reliability and validity)</b>	<b>Availability in other language</b>	<b>Applications of instrument in other studies</b>
11. The Asthma Quiz for Kidz [44]	The asthma quiz is a discriminative, reliable and responsive measure of asthma control. It provides complementary information but does not replace lung function tests	1-17 years old Time not reported	6 items Four of the 6 questions namely, day and night symptoms, beta2-agonists and normal physical activity pertains to the previous 7 days; the remaining two questions namely, school absenteeism and unscheduled medical visits, pertain to the preceding 30 days	Item number 1-6 completed by parents Item number 6-9 completed with the assistance of their parents Item number 9-17: self-administered Scored as 1 for "yes" and 0 for "no" A score of 2 or more is indicative of poor asthma control	Used in clinical, education, and research setting Sample size not reported	Reported as valid and reliable without published analysis	Validated translations: Canadian French Canadian English Non validated translation: Portuguese	[45]

<b>Instrument and instrument's developer and the published year</b>	<b>Instrument's description</b>	<b>Targeted age and time for completion</b>	<b>No. of items and domains</b>	<b>Administration, scoring and scaling of the questionnaire</b>	<b>Type of study setting and tested sample size</b>	<b>Psychometric properties (Reliability and validity)</b>	<b>Availability in other language</b>	<b>Applications of instrument in other studies</b>
12. Asthma therapy assessment questionnaire (ATAQ) [46]	It is a questionnaire to assist clinicians and health plans to identify children at risk for adverse	5-17 years old Time not reported	20-item asthma control, patient-provider communication, attitudes and behaviours (such as	Parent-completed questionnaire Score ranging from 0 to 7; with a higher score indicating more controlled problems	Used in clinical setting Sample size was 434 children that were treated for asthma and enrolled in	Cronbach's alpha was 0.83 for the asthma symptom scale, 0.93 for asthma problems, 0.87 for family impact, and 0.96 for	Original English Other language not reported	No study reported

outcomes of asthma	dissatisfaction with treatment), and self-efficacy or belief in their child's ability to take medications to control asthma)	three managed care organizations	satisfaction Intercorrelations between the ATAQ measures were generally less than moderate (0.01–0.39)
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<b>Instrument and instrument's developer and the published year</b>	<b>Instrument's description</b>	<b>Targeted age and time for completion</b>	<b>No. of items and domains</b>	<b>Administration, scoring and scaling of the questionnaire</b>	<b>Type of study setting and tested sample size</b>	<b>Psychometric properties (Reliability and validity)</b>	<b>Availability in other language</b>	<b>Applications of instrument in other studies</b>
13-Multi-attribute Paediatric Asthma Health Outcome Measure (PAHOM) [47]	It is a tool for monitoring the QoL of asthmatic children, for providing information about QoL to caregivers and decision-makers, and for helping them in choosing the good plan for asthma management	7-12 years old Time for completion not reported	7 items three domains: Symptom, emotion, activity	Self-reported by children The scoring way by assigning the preference weights of (s1, e1, a1), (s2, e1, a1), and (s3, e1, a2) to mild, moderate, and severe asthma symptom states, respectively	Can be used in clinical practice 72 asthmatic children	Not reported	Only in English	[14]

<b>Instrument and instrument's developer and the published year</b>	<b>Instrument's description</b>	<b>Targeted age and time for completion</b>	<b>No. of items and domains</b>	<b>Administration, scoring and scaling of the questionnaire</b>	<b>Type of study setting and tested sample size</b>	<b>Psychometric properties (Reliability and validity)</b>	<b>Availability in other language</b>	<b>Applications of instrument in other studies</b>
14. Asthma-Related Quality of Life Scale (ARQOLS) [48]	It is a questionnaire to examine asthma-related QoL among asthmatic children	6–13 years old Time for completion not reported	35 items 5 domains: restriction of social life, physical disturbances, limitation in physical activity, daily inconvenience in managing the disease, and emotional distress	Administered by child Four-point Likert-type scale was designed for levels of agreement with items; the higher the score, the better the respondent's ARQOL	To assess disease-specific QoL in practice and in clinical research studies for asthmatic children 474 children with asthma: 251 children with asthma were recruited from three medical centers and 223 from six elementary schools in Taiwan	Reliability was determined by internal consistency $\alpha = 0.81-0.96$ Validity not reported	Other language not reported	[8] [14]



Instrument and instrument's developer and the published year	Instrument's description	Targeted age and time for completion	No. of items and domains	Administration, scoring and scaling of the questionnaire	Type of study setting and tested sample size	Psychometric properties (Reliability and validity)	Availability in other language	Applications of instrument in other studies
15. Asthma knowledge test [49]	Asthma knowledge test was designed especially for 8 to 10 years old Children The test also had a spread of scores that reflect both high and low asthma knowledge, and is sensitive enough to detect differences across a range of study populations within the age group	8-10 years old Time to completion: 10-15 min	24 items: 23 true/false questions and one open ended question about asthma symptoms	Self-administered by asthmatic children Can be administered as a group exercise or individually True/false items were scored by 1 for a correct response and 0 for incorrect response. The final item, a score of 1 was given for each symptom that was correct Correct answers were summed, with a minimum–maximum score range of 0–26	Used in clinical setting Sample size was 151	It has low internal consistency reliability determined by KR-20 coefficient = 0.27 Validity not reported	Original language English Other language not reported	Other studies not reported

Instrument and instrument's developer & the published year	Instrument's description	Targeted age and time for completion	No. of items and domains	Administration, scoring and scaling of the questionnaire	Type of study setting and tested sample size	Psychometric properties (Reliability and validity)	Availability in other language	Applications of instrument in other studies
16. Asthma Control and Communication Instrument asthma questionnaire (PACCI) [50]	It measures asthma control in English-and Spanish-speaking children; can be self-administered or by parent report Also it measures multiple dimensions of parent-reported asthma morbidity (Direction, Bother, and Risk)	1-21 years old Time not reported	It is a 12-item computed in 5 domains: 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; 5. Control—frequency of daytime symptoms, short-acting b2-agonist use, asthma attacks, activity limitation, and nocturnal symptoms	Parent-completed questionnaire The PACCI control domain can be scored in 3 ways: 1. The sum score 2. The problem index dichotomously scores 3. Categories uses a classification scheme based on NIH asthma guideline	The PACCI should be useful to clinicians to assess and classify asthma according to NIH guideline The questionnaire was completed by 265 English-and 52 Spanish-speaking children (mean age, 8.2 years; 58% male; 44% African American)	PACCI control showed good internal reliability and strong concurrent, discriminative, and known-groups Validity with ACT and PACQLQ scores and clinicians' ratings of asthma control	Original language Spanish Translated version English	[51] [52]

Table 2: Questionnaires with child and parent versions

Instrument and instrument's developer and the published year	Instrument's description	Targeted age and time for completion	No. of items and domains	Administration, scoring and scaling of the questionnaire	Type of study setting and tested sample size	Psychometric properties (Reliability and validity)	Availability in other language	Applications of instrument in other studies
1. Children's Health Survey for Asthma (CHSA) Parent version: [53] Child version: [10]	This instrument was developed to determine how asthma affects the everyday life of the asthmatic children and their caregivers. It is a condition-specific and self-report measure. There are two versions one for the parents and the other for the child.	Parent version: the age of children between 5-12 years old Time for completion not reported. Child version: from 7 to 16 years old Time to complete: 7-13 min	Parent version: 48 items 5 domains: physical health, activity (child), activity (family), emotional health (child), emotional health (family) Child version: 25 items 3 domains: Physical health, child activities and emotional health	Self-administered by parent For child version: administered by children 5-point likert scale Computed scores transformed to a 0-100 scale	Used in clinical trials Sample size was 52 children with a wide range of asthma severity	Parent version: Validity was assessed by symptoms severity and treatment use Reliability by $\alpha = 0.81-0.92$ And test-retest = 0.62-0.86 Child version: Validity was determined by comparing and correlated with parent report about their children health status Reliability was $\alpha = 0.61-0.93$ Test-retest = 0.57-0.96	Original language English Spanish version is available	[54] [55] [56] [57] [58] [59] [8]
2. Paediatric Asthma Quality of life Questionnaire (PAQLQ) [60]	It is an instrument to identify troubles that face asthmatic children in their daily life (physical, emotional and social)	7-17 years old Time to complete: 10 min	23 items 3 domains: Activity limitation, symptoms and emotional function	Self-administered or interviewer administered 7-point Likert scale The overall score is the mean of 23 items The individual domain score is the mean of items of this domain	Used in clinical trials Sample size was 52 children with a wide range of asthma severity	Validity determined by comparing between disease severity Reliability determined by ICC=0.84-0.95	Original language English Spanish Dutch French Portuguese Mandarin Malay Filipino Arabic	[61] [62] [63] [64] [65] [66] [67] [8] [14] [68]
Paediatric Asthma	It is an instrument to	7-17 years old	13 items 2	Self-administered by	This instrument	Validity determined by	Original	[70] [63]

Caregiver's Quality of life Questionnaire (PACQLQ) [69]	measure the problems that face the parents or caregivers of asthmatic children	time to complete not reported	domains: Activity limitation and emotional function	parent 7-point Likert scale The overall score is the mean of 13 items The individual domain score is the mean of items of this domain	is used in paediatric asthma clinical trials and research Sample size was 529 families	comparing between disease severity Reliability determined by ICC = 0.84-0.95	language English Spanish French Portuguese Dutch Arabic	[71] [67] [8]
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Instrument and instrument's developer and the published year	Instrument's description	Targeted age and time for completion	No. of items and domains	Administration, scoring and scaling of the questionnaire	Type of study setting and tested sample size	Psychometric properties (Reliability and validity)	Availability in other language	Applications of instrument in other studies
3. PedsQL-Asthma Module [72]	It is an instrument designed to measure health related QoL for asthmatic children. There are two: one for the child and other for the parent	2-18 years old Time to complete : less than 4 minutes	28 items 4 domains: asthma symptoms (11 items), treatment problem (11 items), worry (3 items) and communication (3 items)	2-4 years old: by parents. 5-18 years old: both child and parent 5-point Likert scale For the young children 5-7years old: 3-point Likert scale Transform from 0-4 to 0-100 as follows 0=100 1=75 2=50 3=25 4=0	Can be used in the clinical practicing for discrimination within asthma severity groups 298 asthmatic children	Validity was determined by: comparing between healthy children and asthmatic children, and correlated with PAQLQ Reliability: internal consistency (child): $\alpha = 0.58-0.85$ ; for parent $\alpha = 0.82-0.91$ ; child parent agreement was = 0.29-0.87	English USA English UK Spanish Russian Turkish Italian Mandarin Icelandic Hindi Punjabi Portuguese Sinhala	[73] [74] [75] [76] [77] [8] [78] [79]

Instrument and instrument's developer and the published year	Instrument's description	Targeted age and time for completion	No. of items and domains	Administration, scoring and scaling of the questionnaire	Type of study setting and tested sample size	Psychometric properties (Reliability and validity)	Availability in other language	Applications of instrument in other studies
4. Asthma Knowledge Questionnaire for Use With Parents or Guardians of Children With Asthma [80]	It is a self-administered instrument completed by parents and/or guardian of asthmatic children	Mean age of asthmatic children was 4.5 years old Time to complete: from 4-7 min	17 items 3 domains: myths and beliefs about asthma, asthma knowledge, and other aspects such as physical activity and smoking	Self-administered by parents or guardian of asthmatic children A Likert-type scale of 5 points Item scores ranging from 17 to 85, with higher scores indicating greater knowledge of asthma	Used in clinical setting 120 asthmatic children and their parents	Reliability by Cronbach's $\alpha$ was 0.73 for the questionnaire as a whole Validity was determined by correlation coefficients = 0.92	Original language Spanish No other language reported	Not reported

<b>Instrument and instrument's developer and the published year</b>	<b>Instrument's description.</b>	<b>Targeted age and time for completion</b>	<b>No. of items and domains</b>	<b>Administration, scoring and scaling of the questionnaire</b>	<b>Type of study setting and tested sample size</b>	<b>Psychometric properties Reliability and validity</b>	<b>Availability in other language</b>	<b>Applications of instrument in other studies</b>
Questionnaire to Measure Asthmatic Patients' Knowledge of Their Disease [81]	It is a self-administered instrument in Spanish to measure the Knowledge asthmatic patients have of their disease. This questionnaire included concepts about asthma and its management in a simple and practical way	4-78 years old Time to complete: not reported	20 questions classified as: 1 on the causes of asthma; 1 on the triggers of crises; 1 on pathophysiology; 2 on treatment goals; 1 on activities that asthmatic patients can carry out; 7 on everything to do with medication; 3 on techniques for inhaler medication; and 4 on self-management	Self-administered and the children who cannot read or write parents can help them Multiple-choice type questions were designed with 3 possible responses, including the option "I don't know"	Used in clinical setting The questionnaire was completed by 120 parents, 66 of them were having a high level of asthma knowledge and 54 of whom had a low level of knowledge	Before intervention: direct consistency was between 0.81 and 1 in 76% of the cases. $\kappa$ statistic= 0.41 and 1 in 96% of the cases After intervention: Direct consistency was between 0.81 and 1 in 92% of the cases $\kappa$ statistic= 0.81 and 1 in 88% of the cases	Original language Spanish Other languages not reported	Not reported
5. TACQOL Asthma [82]	It is asthma specific instrument for appraisal of asthma status of the patients and can be used alone or with the generic TACQOL	8-16 years old Time to complete: not reported	68 items 5 domains: (spontaneous asthma symptoms), situations (that provoke symptoms), treatment (visits to doctors), medication (use of), and emotions (negative emotions)	Administered by child and parent as proxy to help child to understand the questions One single score is attributed to each pair of items. Low scores reflect a low level of HRQoL and high scores reflect a high level of HRQoL	It is useful in clinical practice and investigation 100 asthmatic patients who attended the educational program with a diagnosis of persistent asthma	Reliability was determined by internal consistency $\alpha = 0.60-0.85$ for child, $\alpha = 0.64-0.82$ for parents, parent child agreement = 0.64-0.76 Validity was determined by comparing with disease severity except in compliant domain also correlated with PAQLQ	Not reported	[8]

Most the previous studies they agreed that PAQLQ, CHSA, and PedsQL-Asthma module are the most reliable, valid, and responsive instruments [8, 12, 13, 14,]. However, no particular quality of life instrument is recommended as a standard. Selecting from the currently available instruments will depend on the domains of interest and the characteristics most relevant to a particular clinical

research project. So it is important to identify exactly what an instrument measures and what domains generate the scores derived from the questionnaire. Research is strongly recommended to develop instruments that provide a separate measure of the patient's perception of the impact of asthma on quality of life and that tap all the key dimensions of quality of life. Instruments that

focus on the patient's perspective on asthma's impact on his or her quality of life could add unique value to the outcome measures.

For instruments that targeted both child and his or her caregivers are still not enough, and there is a need to develop more outcomes for both asthmatic children and their caregivers, Quittner, *et al.* Indicated that although significant progress has been made, more research is needed on the convergence between parent and child health outcomes instruments [8].

## CONCLUSION

Most of the instruments that developed for asthmatic children and their caregivers in paired version available in one or two language, except PAQLQ and PACQLQ where available in different languages, so there is a need to develop more paired disease-specific health outcome instruments targeted both asthmatic children and their caregivers or translate the developed ones to other languages to use them in research to get full data of the impact and burden of asthma and its health intervention on respective respondents to improve asthma management.

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## CONFLICTS OF INTERESTS

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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