

Congruence of Perception of Asthma Control Between parents, Children, and Clinicians

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Abstract

Childhood asthma is a serious public health issue due to high prevalence and costs. It is currently the most common chronic childhood illness, affecting approximately 7 million children ages 0-17 years. Under perception of asthma symptoms is a risk factor for ED visits and hospitalizations in children. It has been estimated that asthma costs the US healthcare system \$56 billion annually, inclusive of the direct cost of providing treatment (approx. \$1039/child/year) as well as lost productivity costs due to missed school and work and activity limitations. Poor perception of symptoms leads to poor medication adherence, which further exacerbates asthma symptoms. Evidence indicates that perception of pulmonary function and adherence to controller medications is worse in Puerto Rican and African-American children versus Caucasian children. Accurate perception of asthma symptoms and control and medication adherence is key to improving outcomes and reducing costs incurred. Purpose: This secondary analysis examines sociodemographic differences in parent and child perceptions of asthma control and compares these subjective perceptions with clinician ratings. Theory: The Common Sense Model of Illness Representation provides the theoretical framework for investigating outcomes through symptom perception, illness representations, and controller medication adherence. Subjects: Baseline data were collected from 514 Mexican and Puerto Rican caregivers and children ages 5-12 with asthma requiring daily controller medications. Families were recruited from 4 clinics in Phoenix, Arizona and Bronx, New York where there are higher populations of inner-city poor Mexican and Puerto Rican children with asthma. Method: This is a longitudinal study of parental illness representations, controller medication use, and asthma control among a sample of Latino families of children with asthma. Structured interviews with parents, short interviews with children, measures of children's lung function, and children's medical records reviews are conducted at enrollment, and 3, 6, 9, and 12 months post-enrollment. Chi-square, t-tests, and linear regression analyses were conducted. Results: There were statistically significant differences between parent's perception and clinician ratings of children's asthma control. Thirty-three percent of parents rated their children as well-controlled yet the clinician indicated poor control. This places the child at risk because medications may not be initiated or increased as required. Significantly more children viewed themselves as poorly controlled yet were rated well-controlled by the clinician (46%); they are over-perceiving symptoms which may lead to excess medication use. Predictors of well-controlled asthma were older child age, Mexican, and parent rating of good control. Conclusions: Significant discrepancies exist between parent's and children's subjective perception of control and clinician's objective assessment. Interventions are needed to improve symptom perception and medication adherence resulting in decreased ED visits, hospitalizations, and costs incurred.

Keywords: Illness Representation, Asthma Symptom Perception, Spirometry

1. State Of The Problem

1.1 Definition of Terms

Illness Representation – An individual’s ideas and beliefs about the nature of asthma, cause of the disease, ideas about medication use, treatment expectations, healthcare provider relationship, and emotional aspects of the child surrounding medication use. *Asthma Symptom Perception* – The perception of a bodily sensation including the physiological representation of location, intensity, or quality of a sensation. *Spirometry* – A pulmonary function test which measures the amount (volume) and/or speed (flow) of air inhaled and exhaled.

1.2 Introduction

Childhood asthma is a serious public health issue due to high prevalence and costs. It is currently the most common chronic childhood illness, affecting approximately 7 million children ages 0-17 years¹⁴. The prevalence in this age group is increasing at a rate of 1.4% per year, and rates are highest in the Northeast and Midwest²⁰. The costs associated with asthma are staggering. It has been estimated that asthma costs the U.S. healthcare system \$56 billion annually, inclusive of the direct cost of providing treatment (approximately \$1039/child/year) as well as lost productivity costs due to missed school and work and activity limitations¹.

African American and Puerto Rican children are disproportionately affected compared to White and Mexican children¹. Latino groups, in particular, seem to struggle the most with symptom perceptual accuracy⁸. Inaccurate perception of symptoms results in an increased likelihood of ED visits, hospitalizations, visits to school clinics, and utilization of primary care providers for asthma exacerbations⁸. Poor perception also leads to poor medication adherence, which further exacerbates asthma symptoms². Accurate perception of asthma symptoms, level of control and medication adherence are key to improving outcomes and reducing costs incurred.

1.3 Purpose of Study

This secondary analysis examines socio-demographic differences in parent and child perceptions of asthma control and compares these subjective perceptions with objective clinician ratings.

1.4 Significance of Study:

Given the minimal risks and large potential of knowledge to be gained, this study has a high benefit to risk ratio. Understanding parents’ and children’s perception of asthma control, parental illness representations of asthma, and how these two factors relate to clinician ratings of control is critical in identifying potential targets for intervention, which are aimed at improving children’s asthma health outcomes. Information from this study will serve to address gaps in our knowledge about Latino parents’ beliefs about their child’s asthma and its management, which may provide more explanation as to the large health disparities that exist within Latino children’s asthma health. The long-term goal is to inform future educational interventions aimed at improving symptom perception and medication adherence and reframing asthma illness representations to align with the professional model of asthma management resulting in decreased number of emergency room visits, hospitalizations, and missed school days.

1.5 Research Questions:

To examine socio-demographic differences in parent and child perceptions of asthma control. RQ #1: Does perceptual accuracy (child and caregiver) differ by age, sex, and ethnicity? Aim #2: Compare subjective parent and child perceptions of asthma control with objective clinician ratings. RQ #2: Are parent and child perceptions of control congruent with clinician ratings? Aim #3: Explore parents’ perception of asthma control, illness representations, and socio-demographic factors on clinician ratings of control. RQ#3: Does parent perception of asthma control predict clinician rated control? RQ#4: Is the relationship between parent perception of control and clinician rated control mediated by asthma illness representations?

2. Review Of The Literature

Asthma is the most common chronic childhood illness, currently affecting 9.5% of children in the United States². This results in a number of medical expenses, as well as costs incurred for missed school and workdays. Evidence shows that these costs are more strongly associated with children, minorities, and low-income populations. One in five children with asthma went to an emergency department for asthma-related care in 2009 with black and Hispanic children having more ED visits than white children¹. Accurate perception of asthma symptoms and medication adherence is key to improving outcomes and reducing costs incurred. Inaccurate perception of symptoms results in an increased likelihood to be hospitalized, have ED encounters, visit the school clinics, and utilize primary care providers for asthma exacerbations. In addition, poor perception leads to poor medication adherence, which further exacerbates asthma symptoms².

Pulmonary function perception is an important aspect in determining how accurate children are at perceiving their illness. A child's ability to accurately predict pulmonary function, results in decreased functional morbidity and fewer hospitalizations, ER episodes, and unscheduled doctor visits⁸. Levels of perceptual accuracy tend to increase as children get older with girls being overall less accurate than boys and also having greater magnification scores (over-estimation of symptom severity)⁸. Poverty is also associated with lower accuracy and higher magnification⁸. In contrast, higher occupational prestige correlated with increased accuracy and decreased symptom magnification⁹. One of the most significant discrepancies existed in children from ethnic minority groups. These children tend to have much lower accuracy and much higher symptom magnification than white children¹⁰. Latino groups in particular seem to struggle the most with accuracy and perception⁸.

Discrepancies also exist between parents' and children's individual reports as to how often asthma symptoms are occurring. In a questionnaire of 285 children ages ten to fifteen and their parents, the top three asthma triggers reported by both groups were weather, pollen, and exercise³. Despite this agreement regarding triggers, children consistently reported a higher prevalence of asthma symptoms compared with parent reports³. Exercise was only reported as a trigger by 35% of parents but by 58% of children³. When looking specifically at children's asthma symptoms within the last four weeks, 47% of parents stated that their child never had asthma symptoms triggered by physical activity, while 69% of children said that they did³.

Evidence shows that parent's knowledge regarding asthma pathophysiology, pharmacology, and triggers is actually quite accurate^{27,22}. Discrepancies exist, however, regarding symptom reporting and treatment for their children. The National Asthma Education and Prevention Program (NAEPP) guidelines stress the importance of treating even mild or moderate symptoms if they are persistent²⁵; however, 39% of parents say they would not report nighttime symptoms that occur more than twice a month, and 37% would not report the use of rescue medications more than twice a week²⁷. Experts for the National Asthma Control Initiative say both should be reported²⁷. Furthermore, the professional model states that asthma is a chronic illness, yet many parents describe asthma as episodic, acute, and uncontrollable and therefore only focus on treating acute exacerbations and severe symptoms. As a result, 27% of parents believe that medication should be a last resort in treating their child's asthma symptoms with the main concern being potential side effects associated with most anti-inflammatory medications²⁷. Parents and children who have accurate symptom perception and reporting are more likely to have asthma illness representations that are concordant with their health care provider and the professional model of asthma management^{27,23}. As a result, they are more likely to be on an appropriate medication regimen and have better controlled asthma^{27,23}. Children, however, are reporting a much lower rate of usage for maintenance medication and fast-acting reliever medication than parents. Forty-four percent of parents reported that their child had used their maintenance medication in the last four weeks, while only 35% of children said they had. Furthermore, 90% of parents said that a fast-acting medication had been used, but only 67% of kids said it had³.

The link between child perception and family response is important. Evidence suggests that when a child has a tendency to underestimate the severity of their symptoms, the family is more likely to have an inadequate asthma management plan and as a result, there is increased asthma morbidity¹³. A key aspect of this is the child's ability to accurately predict their peak expiratory flow readings. Modern electronic spirometers give children immediate feedback as to how accurate their estimations are compared to their actual flow score. Children with this immediate feedback have shown to be better perceivers and are more likely to adhere to their medication regimen^{16,6}.

In summary, kids and parents have differing perceptions of their asthma illness. Not only are parents less aware of their child's symptoms, but they are also not reporting symptoms that they should be due to misalignment of illness representations with the professional model. There is a hesitancy to use asthma medications, especially daily anti-inflammatories, because of their associated side effects. The lack of medication adherence causes increased asthma exacerbations, which leads to increased use of resources and increased costs. To improve these outcomes, it is

essential to understand parental illness representations of asthma, their beliefs regarding their child's asthma management plan, and why perception tends to be so inaccurate. This will allow the parent, child and healthcare provider to have a better understanding, and they will be able to work together to determine an appropriate plan to improve child and parent symptom perception.

3. Methodology

3.1 Research Design

This is a secondary analysis of a longitudinal study of parental illness representations and complementary and alternative medicines and controller medication use among a diverse sample of 300 Latino families (primarily Mexican and Puerto Rican) of children with asthma ages 5-12 years. Structured interviews with parents, short interviews with children, objective measures of children's lung function, and children's medical record reviews were conducted at enrollment, and 3, 6, 9, and 12 months post-enrollment. Chi-square, t-tests, and linear regression analyses were conducted.

3.2 Population and Sample Design

Baseline data were collected from 514 Mexican and Puerto Rican caregivers and children ages 5-12 years with asthma requiring daily controller medications. This age group was selected because children in this range have typically not assumed daily control for managing their own asthma. Families were recruited from clinics in Phoenix, Arizona and Bronx, New York where there are higher populations of inner-city poor Mexican and Puerto Rican children with asthma. Multiple sites were necessary to obtain a sufficient number of families to conduct the study.

3.3 Data Collection Procedures

To be eligible for the study, children met the following criteria: a) The child must be between the ages of 5 and 12, b) have a diagnosis of asthma as obtained from their medical record, c) identify as Latino as described by the child's primary care caregiver, d) have no other significant pulmonary complications or conditions, e) participating parent must have the majority responsibility for the child's day-to-day asthma management and care, f) no cognitive learning disability that would interfere with the parent or child's ability to participate in the interview process. Computerized data systems within each recruitment site were used to identify patients who fit the specified diagnosis, age, and ethnicity criteria. Eligible families were recruited through face-to-face invitations during clinic visits, by mailing recruitment letters from the health care provider to potential families, and by making phone calls inviting families to participate. The research nurse/assistant (RNA) at each practice site explained the study and reviewed eligibility criteria with each family before obtaining verbal assent to participate. An appointment was then made for the parent and child to complete the informed consent, child verbal assent, interviews, and spirometry tests. All materials were made available in both English and Spanish. Prior approval from the Institutional Review Boards of Arizona State University, Scottsdale Healthcare, Phoenix Children's Hospital, and Albert Einstein College of Medicine of Yeshiva University were obtained.

The RNA conducted a structured interview with the parent that included the Asthma Illness Representation Scale AIRS©, Parent/Health Care Provider Relationship Scale^{19,22}, Parent-Childhood Asthma Symptom Checklist, Asthma Trigger Inventory¹⁷ and Stephenson Multigroup Acculturation Scale²⁴, as well as information regarding demographics, the child's asthma control, controller medications, and any alternative therapies that are currently being used. Interviewers conducted the interview in either English or Spanish based on parent preference, and each took approximately 60 to 90 minutes. Interviews were completed at enrollment and 3, 6, 9, and 12 months post-enrollment.

Child interviews and spirometry maneuvers were done independently of the parent interviews. Spirometry was done per the guidelines set forth by the American Thoracic Society, and the child should have continued to use his/her prescribed medications prior to any tests. The interview with the child included the Asthma Control Test^{15,12} to assess the child's reports of symptoms during asthma exacerbations. Interviews were conducted in Spanish or English per child's preference and took approximately 20 to 30 minutes. The spirometry assessment took place after the interview. These sessions took place at enrollment and 3, 6, 9, and 12 months post-enrollment.

4. Research Results

4.1 Response Rate of Sample/Population:

Table 1. Enrollment Table

Site	Total Enrolled	Number of Withdrawals	Adjusted Total of Enrolled (A-B=C)	Number of Withdrawals that completed 3+ interviews	Number of “past due” families that have completed at least 3 interviews
Phoenix Children’s Hospital	105	7	98 (148, PCH+SHC)	0	1
Scottsdale Healthcare Organization	53	3	50	1	2
Jacobi Medical Center	114	38	76	8	9
Total	272	48	224	9	12

Site	3-Month	6-Month	9-Month	12-Month (Completed)
PCH	92	86	87	81
SHC	43	37	44	45
Jacobi	57	49	48	49
Total	192	172	179	175

Table 1 presents the enrollment data and follow-up assessments completed as of 3/31/14. The overall attrition rate to date is 17.6%. This is lower than the 20% estimated for the power calculations. The higher than anticipated attrition rate in New York occurred due to Hurricane Sandy. A number of families were displaced from their homes when the hurricane hit and ended up moving out of the area.

4.3 Summary Of Findings

Table 2. Parent Perception of Control By Sex

		Parent Perception of Control		
		Not Well-Controlled	Well-controlled	Total
Caregiver’s Sex	Male	3	10	13
	Row Percent	23.1%	76.9%	100%
	Column Percent	5.3%	4.8%	4.9%
	Female	54	200	254
Row Percent	21.3%	78.7%	100%	
Column Percent	94.7%	95.2%	95.1%	
Total	57	210	267	
Row Percent	21.3%	78.7%	100%	
Column Percent	100%	100%		

$\chi^2 = 0.02, p = 0.88$

The chi-square test for Parent Perception of Control by Sex shows no statistically significant differences (Table 2). Although the majority of the participating parents were females, the percentage of parents reporting well-controlled and not well-controlled for both sexes was approximately the same.

Table 3. Parent Perception of Control by Education Level

		Parent Perception of Control		
		Not Well-Controlled	Well-controlled	Total
Parent Education Level	No High School Degree Row Percent Column Percent	25 18.8% 43.9%	108 81.2% 51.7%	133 100% 50%
	High School Degree Row Percent Column Percent	32 24.1% 56.1%	101 75.9% 48.3%	133 100% 50%
	Total Row Percent Column Percent	57 21.4% 100%	209 78.6% 100%	266

$\chi^2 = 1.09, p = 0.3$

There were no statistically significant differences for Parent Perception of Control by Education Level (Table 3). The number of parents with a high school degree versus without a high school degree is exactly equal. Eighty-one percent (108/133) of the parents without a high school degree rated their child's asthma as well-controlled compared to 76% (101/133) of the high school graduates.

Table 4. Child's Perception of Control by Ethnicity

		Child's Perception of Control		
		Not Well-Controlled	Well-controlled	Total
Child's Ethnicity	Mexican Row Percent Column Percent	166 88.8% 69.5%	21 11.2% 77.8%	187 100% 70.3%
	Puerto Rican Row Percent Column Percent	73 92.4% 30.5%	6 7.6% 22.2%	79 100% 29.7%
	Total Row Percent Column Percent	239 89.8% 100%	27 10.2% 100%	266

$\chi^2 = 0.8, p = 0.37$

The chi-square test for Child's Perception of Control by Ethnicity shows no statistically significant differences (Table 4). The overwhelming majority of the children in both ethnic groups reported that they are not well-controlled.

Table 5. Child's Perception of Control by Age

	Not Well-Controlled (N = 239)	Well-Controlled (N = 27)	p-Value	t-Value	DF
Average Age of Child (Standard Deviation)	9.2 (2.04)	12.5 (0.42)	p < .05	-21.17	194.6

Table 6. Parent's Perception of Control by Age

	Not Well-Controlled (N = 57)	Well-Controlled (N = 210)	p-Value	t-Value	DF
Average Age of Parent (Standard Deviation)	36.8 (7.4)	36.2 (8.0)	0.63	0.49	94.89

The t-tests for child and parent perception of control by age (Tables 5 and 6) shows statistically significant differences for the children but not for parents. Older children reported their asthma as well-controlled significantly more than younger children. The mean age of parents reporting well-controlled or not well-controlled is about the same.

Table 7. Child's Perception of Control Versus Clinician Control Rating

		Child's Perception of Control		
		Not Well-Controlled	Well-controlled	Total
Clinician Control Rating	Not Well-Controlled	108	13	121
	Row Percent	89.3%	10.7%	100%
	Column Percent	48.9%	50%	49%
	Well-Controlled	113	13	126
Row Percent	89.7%	10.3%	100%	
Column Percent	51.1%	50%	51%	
Total	221	26	247	
Row Percent	89.5%	10.5%		
Column Percent	100%	100%		

$$\chi^2 = 0.012, p = 0.91$$

The chi-square test for Child's Perception of Control versus Clinician Control Rating (Table 7) revealed no statistically significant differences. Forty-nine percent of the time the child and clinician agreed about the child's level of control. Children tended to over-estimate their lack of control. Forty-six (113/247) percent viewed themselves as not well-controlled when the clinician rated their asthma as well-controlled. Only 5% (13/247) of the children reported their asthma as well-controlled when the clinician rated them as not well-controlled.

Table 8. Parent’s Perception of Control Versus Clinician Control Rating

		Parent’s Perception of Control		
		Not Well-Controlled	Well-controlled	Total
Clinician Control Rating	Not Well-Controlled	41	80	121
	Row Percent	33.9%	66.1%	100%
	Column Percent	77.4%	41%	48.8%
	Well-Controlled	12	115	127
Row Percent	9.5%	90.6%	100%	
Column Percent	22.6%	59%	51.2%	
Total	53	195	248	
Row Percent	21.4%	78.6%		
Column Percent	100%	100%		

$\chi^2 = 22.02, p < .05$

Table 9. Parent’s Perception Of Control Versus Child’s Perception Of Control

		Parent Perception of Control		
		Not Well-Controlled	Well-controlled	Total
Child’s Perception of Control	Not Well-controlled	54	185	239
	Row Percent	22.6%	77.4%	100%
	Column Percent	94.7%	88.5%	89.8%
	Well-controlled	3	24	27
Row Percent	11.1%	88.9%	100%	
Column Percent	5.3%	11.5%	10.2%	
Total	57	209	266	
Row Percent	21.4%	78.6%		
Column Percent	100%	100%		

$\chi^2 = 1.9, p = 0.17$

Table 9 illustrates that although not statistically significant, parents and children only agreed 29% (78/266) of the time about the child’s level of control. The large majority of children are reporting that they are not well-controlled while parents are reporting well-controlled asthma (70%, 185/266).

Table 10. regression model

Predictors	R-Square	β	F Value	p value
Model Fit	0.14		4.41	<.0001
Ethnic Group		1.21	5.43	0.02
AIRS: Total Score		0.38	1.70	0.19
Parent Perception of Control		4.28	19.18	<.0001
High School Graduate		0.027	0.12	0.73
Parent-Provider Relationship		0.00036	0.00	0.97
Child's Age		1.07	4.81	0.03
# Family Members with Asthma		0.045	0.20	0.65
Asthma Duration (Months)		0.075	0.34	0.56
Poor		0.18	0.82	0.37

The regression model accounted for 14.3% of the variance in asthma control (Table 10). Ethnic group ($p < .05$, $F = 5.43$), parent perception of control ($p < .05$, $F = 19.18$), and age of the child ($p < .05$, $F = 4.81$) showed the most statistically significant data. Older children were more likely to report being well-controlled. By clinician rating, 56.5% of Mexicans are under good control, and 38.3% of Puerto Ricans are under good control. In this analysis, asthma illness representations did not mediate the relationship between parental perception of control and clinician-rated control.

5. Conclusions And Recommendations

5.1 Conclusions:

Significant discrepancies exist between parent and children's subjective perception of control and clinician's objective assessment. Evidence demonstrates that children, particularly younger children, are poor perceivers of asthma symptoms who frequently over-estimate the severity of their symptoms and under-estimate their level of control when compared with the healthcare provider's objective assessment. Although not the majority, a large proportion of parents have also shown to be poor perceivers of their child's asthma symptoms; however, they are more likely to under-estimate the severity of their child's asthma symptoms and over-estimate their level of control compared to the healthcare provider's objective assessment. There is a clear disconnect between the child's perception of his or her own symptoms and the parent's perception of his or her child's symptoms. The overwhelming majority of parents and children are incongruent in their perception of asthma symptoms with most children over-perceiving their symptoms and most parents under-perceiving their child's symptoms. The sex, education level, and age of the parents had no effect on their perceptual accuracy. Age and ethnicity of the child, however, played significant roles in their perceptual accuracy with older children being more accurate perceivers and Mexican children being more well-controlled by clinician rating.

5.2 Limitations:

Because this study was a secondary analysis, it was limited to data that had already been previously collected. Additional variables that may have impacted this study but were not measured are objective data for medication adherence collected at baseline, measure of self-efficacy, and measure of barriers to asthma management. Measurement of these variables may have provided more insight as to why there are such discrepancies in perception of symptoms between parents, children, and clinicians, and also why certain socio-demographic qualities make a person more likely to be well-controlled. In addition, measurement of socioeconomic status was based on the parent's subjective rating of living well off, living very comfortable, living reasonably comfortably, just getting along, nearly poor, or poor. To have a more accurate measure of this variable, response options could have listed ranges of annual income and asked the parents to choose which range they fit into.

5.3 Implications Of Study:

Evidence has demonstrated that significant discrepancies exist between parent and children's subjective perception of control and clinician's objective assessment. As a result, it is imperative that healthcare providers, parents, and children develop a more unified understanding of asthma illness beliefs and treatment regimens. Healthcare providers, regardless of their practice setting, can best treat children with asthma if they understand what beliefs parents hold about their child's asthma and the factors that influence this. If parents' beliefs are discordant with the healthcare providers' beliefs and are not addressed when devising the management plan, there is increased risk for non-adherence. If parents feel that they are part of the decision-making process regarding treatment of their children's asthma, they may be more likely to adhere to the prescribed medication regimen thereby reducing exacerbations of asthma symptoms, ED visits, hospitalizations, and fatal asthma attacks. Healthcare providers have an opportunity to intervene at the individual level to effect changes aimed at improving adherence to the prescribed treatment regimen through improved communication, education (both parents and themselves), and partnership with the families.

5.4 Recommendations:

Interventions that heighten parents' and children's awareness of asthma symptoms and address cultural beliefs and practices and potential barriers are likely to increase adherence with asthma self-management plans. In addition, interventions that enhance parent-child-provider communication and care coordination will lead to improved self-management. It is important that healthcare providers not only provide information about asthma and self-management strategies but also engage parents and children in discussions about asthma illness beliefs, ethno-cultural practices, and social, cultural, environmental or healthcare system barriers that prevent the child from achieving optimal management. Beliefs, practices, and barriers are frequently overlooked during the asthma visit but are critical factors in children's medication adherence^{18,20,21,28}. Interventions which elicit this information can serve to enlighten the healthcare provider about these factors, lead to a respectful, sensitive discussion and thus, a shared plan for optimal outcomes. When parents and children feel that they are a part of the decision-making process they may be more likely to adhere to the management plan^{4,5,7,11,26}. This may lead to short screening questionnaires being used in health care provider offices to give them better insight into their patients. As a result, educational tools and interventions can be tailored to meet the specific needs of the child and the family. Younger children may enjoy the use of a game, while older children may appreciate the use of modern technology in their education. To adequately affect sustained behavior change, however, asthma self-management education must be integrated into and coordinated across all points of care (clinic, hospital, school, pharmacy and home).

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