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Abstract: Abstract

The Minneapolis and St. Paul Controlling Asthma in American Cities Project (CAACP) used a population-based symptom burden survey to inform community-based programming and provide an intermediate outcome measure of progress toward improving the community experience of asthma. The burden of asthma for children in grades K-8 was assessed every other school year from 2003-2007 using the Child Asthma Short Form (CASF), a validated health-related quality-of-life instrument. The survey was mailed to a randomly selected population in four languages (English, Spanish, Hmong, and Somali). The overall response rate was 47%, 41%, and 32% for Years 1, 3, and 5 respectively. Two out of three children for whom surveys were completed were children of minority populations; more than 50% were eligible for free or reduced-price meals. The changes in scores from the first round (2003-4) to the third round (2007-8) were statistically significant for daytime symptom burden ( $p < 0.05$ ) and functional limitations ( $p < 0.10$ ). Improvements were noted, but not statistically significant, for nighttime symptoms. Native American children and children eligible for free or reduced-price meals had the highest symptom burden. Findings were used to guide CAACP's program development and delivery to populations in greatest need. CAACP's experience in Minneapolis and St. Paul demonstrates that use of a symptom-burden survey is feasible (in terms of accessing a sample and obtaining resources) and useful for tracking trends and identifying high-risk populations.

## Population-Based Assessment of Asthma Symptom Burden in Children

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### Introduction

Asthma is one of the most common chronic medical problems of childhood. Symptom level is strongly associated with an increased risk for emergency department (ED) and hospital admissions.<sup>1</sup> Although asthma symptoms can significantly affect quality of daily life, the impact of asthma is generally measured in terms of disease prevalence, mortality rates, and health care utilization, primarily hospital and ED admissions.<sup>2</sup>

Quality-of-life and symptom-burden surveys are often used in specialized health care settings to study asthma, measuring the effect of treatment or interpreting the clinical relevance of changes in health-related quality of life.<sup>3</sup> Health-related quality-of-life surveys can also be used to detect asthma's impact on the general, or a particular, population. Examples include determining the prevalence of major co-morbidity in asthma and associations with quality of life and functional status in the general population,<sup>4</sup> asthma's contribution to the burden of ill health and impaired

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quality of life among individuals in a community,<sup>2</sup> the relative burden of asthma and allergic rhinitis among patients participating in the European Community Respiratory Health Survey<sup>5</sup> or as a function of gender and age in the general population,<sup>6</sup> and asthma symptom burden among children attending asthma summer camps in the US.<sup>7</sup>

Although the literature describes uses of population-based quality-of-life or symptom-burden surveys to describe the level of disease burden and prevalence in a community, it does not include the use of a population-based symptom-burden survey to inform community-based programming or measure intermediate outcomes toward improving the community experience of asthma. The Minneapolis/St. Paul Controlling Asthma in American Cities project (CAACP) used a symptom-burden survey for these purposes.

The mission of CAACP, a \$6 million demonstration project funded by the Centers for Disease Control and Prevention, was to improve health outcomes for children with asthma in Minneapolis and St. Paul. Administered by the American Lung Association in Minnesota (ALAMN), CAACP was a comprehensive, community approach to improving asthma using four broad strategies—school-based interventions, health systems/professional education interventions, community-based education and interventions, and policy initiatives. See Figure 1.

By implementing 14 interventions over a seven-year period, CAACP increased people's knowledge and systems' capacity to better manage pediatric asthma. Progress was measured by changes at the population level in

- Emergency department visits for children with asthma
- Hospitalizations of children with asthma
- School attendance of children with asthma
- Asthma-symptom burden as reported by parents

This article examines CAACP's use of a metropolitan-wide symptom-burden survey to 1) direct the project's community-based programming to those with greatest need and 2) assess the collective impact of CAACP interventions on symptom burden at the community level.

## Methods

CAACP used the Child Asthma Short Form (CASF)<sup>8</sup> to assess asthma burden every other year—project intervention years 1 (October 2003-June 2004), 3 (July 2005-June 2006), and 5 (July 2007-June 2008). The CASF, a validated health-related, quality-of-life instrument, consists of 10 questions that measure three aspects of symptom burden: daytime symptoms (2 items—being short of breath, exertion making symptoms worse), nighttime symptoms (2 items—coughed at night, awoke with wheezing/coughing), and functional limitations (4 items—stayed indoors, education suffered, asthma interfered with life, asthma limited activities). Originally developed as a tool to assist in the clinical management of pediatric asthma, CASF uses a standard scoring protocol with scores ranging from 0 to 100—the lower the score the higher the symptom burden.

CASF authors had validated English and Spanish versions. For this study, CAACP translated CASF into Hmong and Somali. These versions were reviewed for translation accuracy but not further validated. CAACP also added demographic questions (grade, gender, race/ethnicity, and eligibility for free or reduced-price school meals as a proxy for socioeconomic status). While the survey was distributed in all four languages during intervention years 1 and 3, use of the Hmong and Somali versions was discontinued in year 5 due to low response and the cost of including these additional surveys and cover letters in the mailing.

The sampling frame consisted of children in grades K–8 in Minneapolis and St. Paul Public Schools identified as having asthma through health records, annual breathing questionnaires, or licensed school nurse reports. In St. Paul Public Schools, 50% of all children identified with asthma were randomly selected. In Minneapolis Public Schools, all children known to have asthma in eight randomly selected schools were included.

For intervention years 1 and 5, parents received notification of the survey through school newsletters, flyers distributed at parent-teacher conferences, and/or notes from the school health office. No pre-survey alerts occurred in intervention year 3, due to lack of opportunity. A survey packet with a cover letter in four languages was mailed to each identified family. The cover letter contained logos of ALAMN and the respective school districts; the outer envelope displayed the

return address of the appropriate school district. The mailing packet also included a \$1 bill and a postage-paid, business-reply envelope addressed to ALAMN.

A mailed survey was preferred because it promised the widest possible participation given the anticipated socioeconomic status and language barriers of the families. The use of school lists increased the likelihood of the availability of the most current address for children with asthma. Moreover, a mailed survey was more cost-effective than a telephone survey. First-year costs (2003-4) of \$14,100 were the highest because of upfront costs associated with survey and cover letter translation and the purchase of business-reply envelopes for multiple years. Subsequent annual survey costs were \$3,639 (2005-6) and \$3,640 (2007-8).

ALAMN prepared and metered the survey packet. To ensure anonymity of student information, school health office personnel attached the recipient address labels, delivered the surveys to the post office, and retained a record of survey numbers linked to student names and addresses. Consecutive numbering of business-reply envelopes, outer envelopes, and labels facilitated sending a reminder survey to non-respondents two weeks after the initial mailing. Second mailings to non-respondents were prepared and mailed following the same procedure. Surveys received more than six weeks after the initial mailing were not included in the analysis.

Surveys were sent the second week of October for St. Paul Public Schools and the third week of January for Minneapolis Public Schools each intervention year. To ensure compliance with FERPA standards the research departments of both school districts granted permission to conduct the surveys. Formal IRB approval was also obtained from the Minnesota Department of Health and both school districts' research departments.

Analysis of variance (ANOVA) was used to examine differences in daytime symptom, nighttime symptom, and functional limitation scores. Control variables for the models included gender, grade (as a measure of age), eligibility for free or reduced-price meals (as a proxy for socioeconomic status), race/ethnicity, school district, and year of survey. All analyses were performed using SAS v9.1 (SAS Institute, Cary, NC). Categorical descriptive variables were

reported as proportions; continuous variables were reported as mean, standard deviation, and range.

## **Results**

### *Demographics*

Response rates were as follows:

- Year 1 – 47.5% (N=558/1,175)  
[Minneapolis 45% (N=265/589); St. Paul 50% (N=293/586)]
- Year 3 – 41% (N=612/1,491)  
[Minneapolis 44% (N=333/757); St. Paul 38% (N=279/734)]
- Year 5 – 32% (N=487/1,500)  
[Minneapolis 34% (N=271/800); St. Paul 31% (N=216/700)]

While the number of surveys returned was consistent over time, response rates fluctuated. Strict adherence to procedures to ensure anonymity of respondents precluded a mechanism to assess response bias. Although the survey packet for the first two years included cover letters and surveys in four languages (English, Spanish, Hmong, and Somali), the number of surveys returned in languages other than English was small (less than 1%). Of those returned in languages other than English, the overwhelming majority was in Spanish. The reason for the low non-English responses is not known.

Table 1 displays the response rates and demographic makeup of respondents for all three survey years. Two out of three children for whom surveys were completed were children of minority populations. More than 50% were eligible for free or reduced-price school meals, an indication of low economic status. These demographics are generally representative of the Minneapolis and St. Paul Public Schools populations.

### *Symptom Burden Scores*

Table 2 shows the results of daytime, nighttime, and functional limitations from students with asthma in Minneapolis and St. Paul Public Schools. For each scale, symptom-burden scores increased from 2003-4 to 2007-8 with higher scores associated with lower symptom burden. The

changes in scores from the first round (2003-4) to the third round (2007-8) are statistically significant for daytime symptom burden ( $p < 0.05$ ) and functional limitations ( $p < 0.10$ ). Nighttime symptom scores also improved, but the differences are not statistically significant.

There was no association between pattern of improvement and demographic characteristics. Average scores in the Native American children, while lowest in 2003-4, were comparable to other ethnic groups in subsequent years.

The symptom-burden scores for each scale were classified into three levels: mild burden ( $\geq 75$ ), moderate burden (26-74), and severe burden ( $\leq 25$ ). See Figures 2 and 3. For daytime symptom burden in 2003-4, 11% of children had severe burden scores; in 2007-8 the percent of children reporting severe burden declined 5%. For those same reporting years, the percent of children reporting mild daytime symptom burden increased from 50% in 2003-4 to 68% in 2007-8.

For nighttime symptom burden in 2003-4, 12% of children had severe burden scores; in 2007-8 the percent of children reporting severe nighttime burden declined to 8%. For those same reporting years, the percent of children reporting mild nighttime symptom burden remained about the same at 54%.

For functional limitations in 2003-4, 3.2% of children had severe burden scores; in 2007-8 the percent of children reporting severe functional limitations declined to 2.5%. The percent of children reporting mild functional limitations increased from 68% in 2003-4 to 74% in 2007-8.

(Insert Figure 2)

(Insert Figure 3)

Table 3 presents symptom burden by demographic groups (gender, race/ethnicity, and free or reduced-price school meal eligibility). At baseline, Native American children had lower (worse) scores than other racial/ethnic groups, as did children who were eligible for free or reduced-price meals.

## Discussion

The CAACP experience in Minneapolis and St. Paul, employing the CASF as a population-based, intermediate-outcome measure, demonstrates that a symptom-burden survey is both feasible (in terms of accessing a sample and obtaining resources) and useful for tracking trends and identifying high-risk populations. Symptom burden may be a more meaningful measure than other commonly reported population measures, such as asthma-related hospitalizations and ED visits, because influencing symptom burden is more immediate and has fewer social and policy influences, such as changes in eligibility and coverage for public health coverage programs.

The Evaluation Team regularly presented symptom-burden survey findings to the Minneapolis and St. Paul CAACP Leadership Team and workgroups for strategic planning purposes, such as focusing interventions on those with highest symptom burden. For example, survey findings led CAACP to tailor programming for Native American and African American childcare providers and deliver it in areas of the community with the highest concentrations of these populations.

Survey findings helped to focus CAACP efforts on the pediatric population with asthma living in the urban core, where the concentration of limited income children is high. The data also demonstrated the effectiveness of CAACP interventions. However, CAACP interventions were not the sole asthma improvement activities occurring in Minneapolis and St. Paul during this timeframe. Health plan disease management programs were operating and legislation reducing environmental tobacco smoke in public areas (i.e., restaurants) was enacted at the same time. Nonetheless, CAACP's work did positively affect the knowledge of people and the capacity of systems to better manage pediatric asthma.

## References

1. Richardson LP, Lozano P, Russo J, McCauley E, Bush T, Katon W. Asthma symptom burden: relationship to asthma severity and anxiety and depression symptoms. *Pediatrics*. 2006;118(3):1042-1051.

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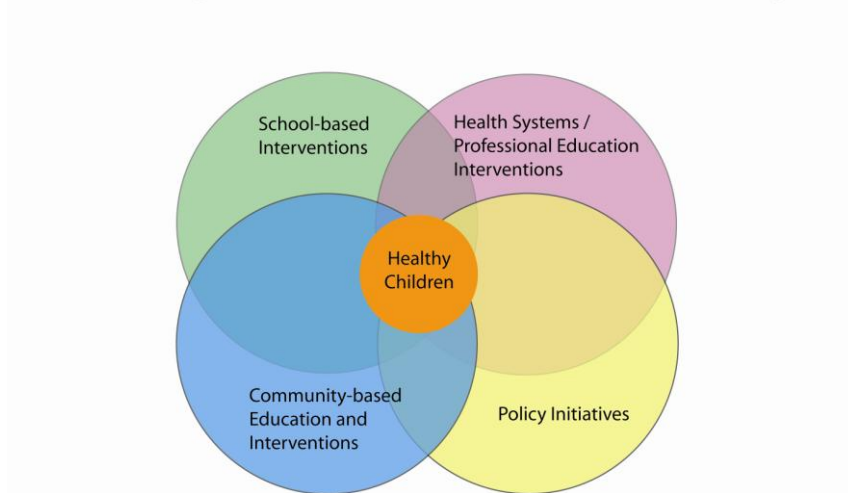
2. Ampon RD, Williamson, M, Correll PK, Marks, GB. Impact of asthma on self-reported health status and quality of life: a population-based study of Australians aged 18-64. *Thorax*. 2005;60(9):735-739.
3. Ehlers, PO, Nokela M, Stallberg B, Hjendahl P, Wikstrom Jonsson E. Brief questionnaires for patient-reported outcomes in asthma: validation and usefulness in a primary care setting. *Chest*. 2006;129(4):925-932.
4. Adams RJ, Wilson DH, Taylor AW, Daly A, Tursan d'Espaignet E, Dal Grande E, Ruffin RE. Coexistent chronic conditions and asthma quality of life: a population-based study. *Chest*. 2006;129(2):285-291.
5. Leynaert B, Neukirch C, Liard R, Bousquet J, Neukirch F. Quality of life in allergic rhinitis and asthma. A population-based study of young adults. *American Journal of Respiratory and Critical Care Medicine*. 2000;162(4 Pt 1):1391-1396.
6. Larsson U, Taft C, Karlsson J, Sullivan M. Gender and age differences in the relative burden of rhinitis and asthma on health-related quality of life—a Swedish population study. *Respiratory Medicine*. 2007;101(6):1291-1298.
7. Welch MJ, Carlson AM, Larson D, Fena P. Clinical profile, health-related quality of life, and asthma control in children attending US asthma camps. *Ann Allergy Asthma Immunol*. 2007;99:496-501.
8. Bukstein DA, McGrath MM, Buchner DA, Landgraf J, Goss TF. 2000. Evaluation of a short form for measuring health-related quality of life among pediatric asthma patients. *J of Allergy Clin Immunol*. 2000;105(2 Pt 1):245-251.

**Figure**

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Figure 1:

## Controlling Asthma in American Cities Project



**Table 1**

**Demographics and Response Rate of Symptom Burden Survey  
Minneapolis and St. Paul Public Schools**

	<b>2003-4 N=558</b>	<b>2005-6 N=612</b>	<b>2007-8 N=487</b>
<b>Response rates</b>	47.5%	41%	32%
<b>Gender</b>			
Male	59%	60%	57%
Female	41%	40%	43%
<b>Race/ethnicity</b>			
African American	33%	33%	29%
Caucasian	33%	30%	33%
Multiracial	19%	16%	18%
Hispanic	7%	9%	11%
Asian	6%	6%	5%
Native American	1%	2%	2%
Unreported	1%	4%	2%
<b>Free/reduced-priced meals (proxy for socioeconomic status)</b>	56%	53%	55%

Table 2: **Daytime, Nighttime, Functional Limitations from a Pediatric Asthma Symptom Burden Survey Minneapolis and St. Paul Public Schools 2003-2007**

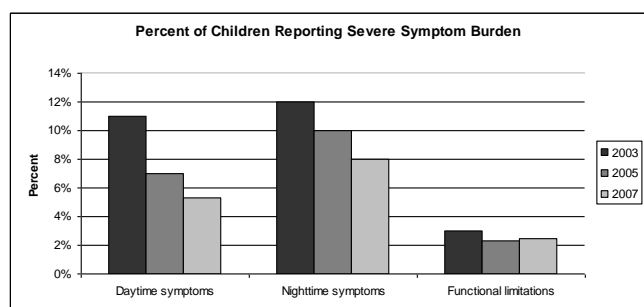
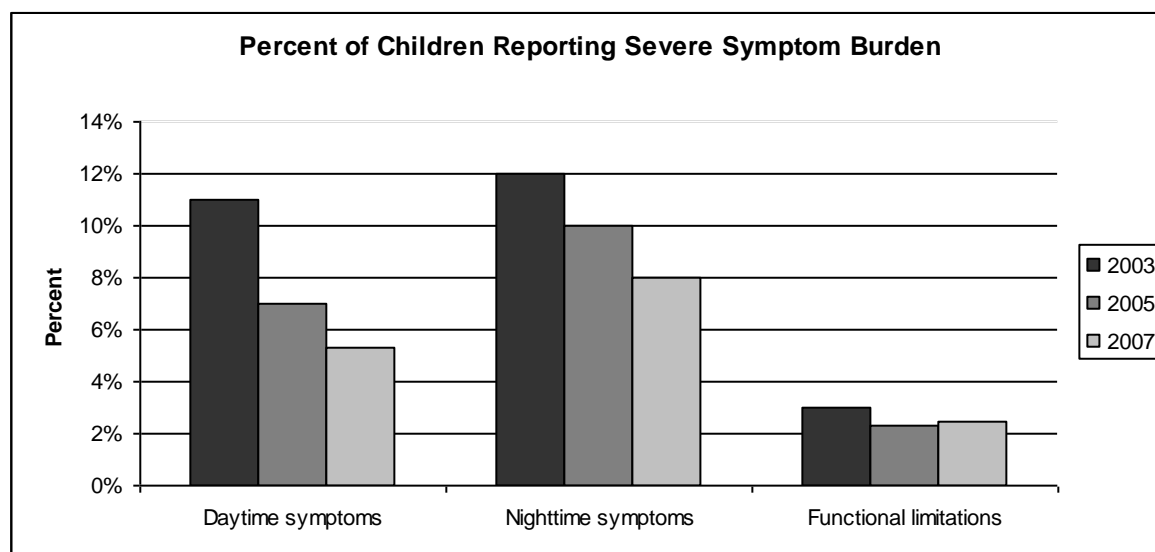
	<b>2003-4</b>	<b>2005-6</b>	<b>2007-8</b>
<b>Daytime symptoms</b>	66.9	68.9	72.9*
<b>Nighttime symptoms</b>	68.1	67.8	70.5
<b>Functional limitations</b>	78.4	79.9	81.5**

\*statistically significant from baseline  $p < 0.05$   
\*\*statistically significant from baseline  $p < 0.10$

**Figure**

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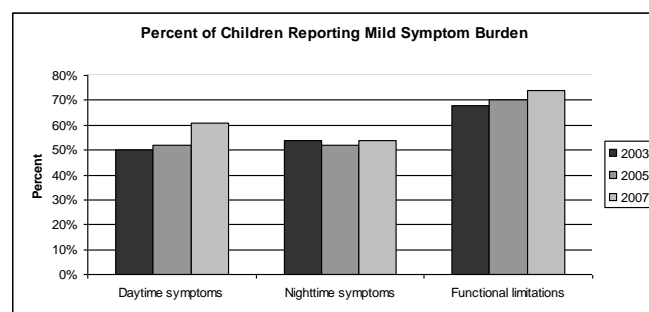
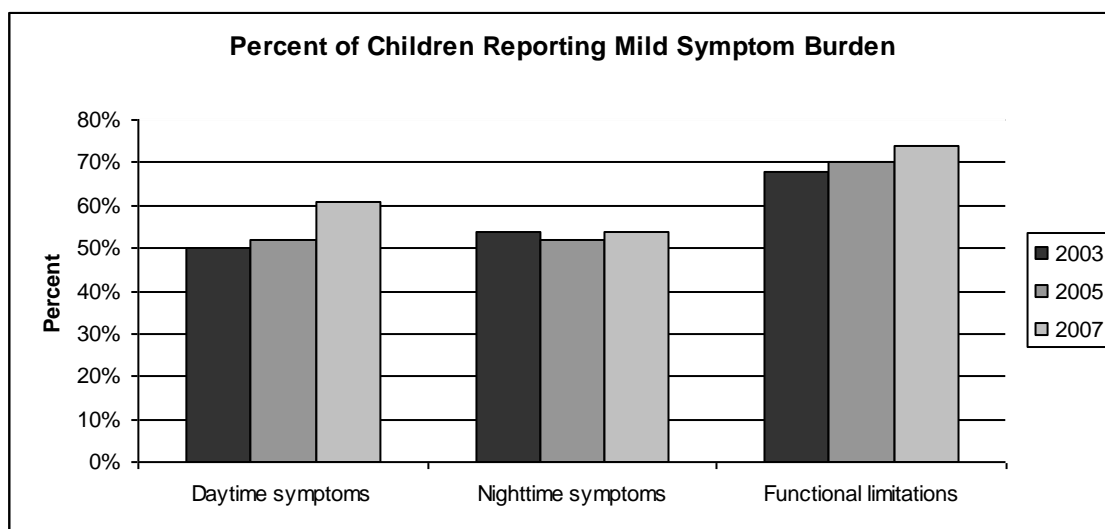
Figure 2: Change in Severe Symptom Burden Scores



**Figure**

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Figure 3: Change in Mild Symptom Burden Scores



**Table 3:**  
 Change in Symptom Burden Scores by Demographics for Each Survey Year

	Daytime Symptoms			Nighttime Symptoms			Functional Limitations		
	2003-4	2005-6	2007-8	2003-4	2005-6	2007-8	2003-4	2005-6	2007-8
<b>Gender</b>									
<b>Male</b>	68.6	69.9	74.5	69.5	67.9	72.7	79.1	80.8	83.4
<b>Female</b>	63.3	68.2	70.4	66.3	68.2	67.7	76.8	79.7	78.9
<b>Race/Ethnicity</b>									
<b>AfricanAmerican</b>	59.4	59.9	65.7	60.5	59.5	63.4	72.3	73.4	74.7
<b>Caucasian</b>	74.4	79.8	79.1	78.1	76.5	76.5	86.2	89.9	88.2
<b>Multiracial</b>	62.8	73.0	70.9	65.8	72.6	68.1	75.1	83.7	80.1
<b>Hispanic</b>	68.8	62.3	75.5	62.8	58.7	74.5	79.9	70.9	82.4
<b>Asian</b>	75.8	65.5	67.3	76.1	70.6	66.1	79.4	81.3	74.7
<b>Native American</b>	39.3	64.8	72.2	32.1	63.6	65.3	50.0	72.7	76.4
<b>Free/Reduced-price meals</b>									
<b>Qualified</b>	59.3	61.1	66.2	60.5	60.5	64.3	71.9	73.9	74.9
<b>Not qualified</b>	76.4	78.0	81.0	77.8	75.9	78.3	87.1	87.3	90.1