Population-Based Assessment of Asthma Symptom Burden in Children

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ABSTRACT *The Minneapolis and St. Paul Controlling Asthma in American Cities Project (CAACP) used a school-based symptom survey to inform community-based programming and provide an intermediate outcome measure of progress toward reducing the burden of asthma. In collaboration with the two school districts, the project mailed the Child Asthma Short Form, a validated health-related quality of life instrument to parents of children in grades K–8 every other school year from 2003 to 2007. The survey was mailed to a randomly selected sample 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 (2003–2004) to the third round (2007–2008) were statistically significant for daytime symptom burden ($p < 0.05$). Improvements were noted, but not statistically significant, for nighttime symptoms and functional limitations. Children of some racial/ethnic minority groups 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 the feasibility of administering a symptom burden survey at low cost and in compliance with school system and institutional review board requirements to maintain confidentiality. The symptom-based survey may be a useful tool to track trends and changes in health disparities at a community and population level.*

KEYWORDS *Symptom burden, School-based survey, Asthma, Health disparities, Child asthma short form*

INTRODUCTION

Asthma is one of the most common chronic medical problems of childhood. Although asthma symptoms can affect quality of life,¹ asthma's impact is generally measured in terms of disease prevalence, mortality rates, and health care utilization, primarily hospital and ED admissions.²

Quality of life and symptom burden surveys are often used in specialized healthcare settings to measure the clinical effect of asthma treatment.³ Health-related quality of life surveys have also been used to determine the prevalence of asthma and its association with quality of life and functional status in the general population,⁴ to measure asthma's contribution to the burden of ill health and

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impaired quality of life among individuals in a community,² to quantify the relative burden of asthma and allergic rhinitis among patients participating in the European Community Respiratory Health Survey⁵ and as a function of gender and age in the general population,⁶ and to document the asthma symptom burden among children attending asthma summer camps in the United States.⁷

Although the literature reports uses population-based quality of life or symptom burden surveys to describe 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. The Minneapolis/St. Paul Controlling Asthma in American Cities Project (CAACP) used a symptom burden survey to identify populations of priority and to follow trends over three time points during the duration of this project.

The mission of CAACP, a 7-year 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).

CAACP implemented 14 interventions over a 7-year period to increase people’s knowledge and skills related to pediatric asthma and to improve the health care system’s and other institutional capacity to appropriately manage pediatric asthma. The CAACP measured progress at the population level by tracking:

- 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

FIGURE 1. CAACP’s approach to improving asthma uses four broad strategies: school-based interventions, health systems/professional education interventions, community-based education and interventions, and policy initiatives.

This article describes CAACP's administration of a symptom burden survey in the Minneapolis and St. Paul school districts. The purpose of the activity was to (1) assess the feasibility of conducting a survey through the school system, (2) direct the project's community-based programming to those with greatest need, and (3) assess the collective impact of CAACP interventions on symptom burden among school-aged children.

METHODS

CAACP used the Child Asthma Short Form (CASF)⁸ 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 8 questions that measure 3 aspects of symptom burden: daytime symptoms (2 items: experienced shortness of breath, exertion made 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). The recall period was that prescribed by the CASF: 4 weeks. The original CASF includes 2 optional questions that were not used for the CAACP survey.

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. The evaluators from the Minneapolis/St. Paul CAACP further classified the symptom burden scores for each scale into 3 levels—mild burden (≥ 75), moderate burden (26–74), and severe burden (≤ 25)—to correspond to the severity classifications in the 1997 National Heart, Lung, and Blood Institutes (NHLBI) guidelines.⁹

Alternate language versions of the CASF were needed to reach the diverse racial/ethnic groups in the Minneapolis and St. Paul area. A validated Spanish version was already available; the CAACP commissioned versions in 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). The schools distributed the survey in all 4 languages during intervention years 1 and 3, but discontinued use of the Hmong and Somali versions in year 5 because few surveys in those languages were returned during the first 2 cycles.

The sampling frame consisted of children with asthma in grades K–8 in Minneapolis and St. Paul Public Schools. The schools identified children with asthma in 3 ways: In addition to health records and licensed school nurse reports, both school systems routinely distributed a “breathing questionnaire” to all parents at the beginning of each school year. The questionnaire asked parents to report any issues/questions/symptoms related to the child's breathing. Positive responses prompted follow-up and the collection of additional information by the school nurse. In St. Paul Public Schools, a 50% random selection of all children identified with asthma was taken from the district's centralized registry. Minneapolis Public Schools did not have a centralized registry; rather, the student health records were maintained at the school health office level. Therefore, 8 Minneapolis Public Schools were randomly selected and all children known to have asthma in those schools were included. School district confidentiality rules did not permit linking the records of students participating in multiple years.

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. Pre-survey alerts were not sent in year 3. A survey packet with a cover letter in 4 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 broadest 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. First-year costs (2003–2004) 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 (2005–2006) and \$3,640 (2007–2008).

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 2 weeks after the initial mailing. Second mailings to non-respondents were prepared and mailed following the same procedure.

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. This schedule was defined by the school districts. A passive consent process was proposed and accepted by the school districts—parents who returned the survey were presumed to give consent. To ensure compliance with Family Education Rights and Privacy Act (FERPA) standards, the research departments of both school districts granted permission to conduct the surveys. The Minnesota Institute of Public Health, Hennepin County Medical Center, and both school districts' research departments gave formal Institutional Review Board (IRB) approval.

Categorical descriptive variables were reported as proportions; continuous variables were reported as mean, standard deviation, and range. Student's *t* test of independent samples was used to test the significance of differences over time (two-tailed level of significance, $p < 0.05$). Analysis of variance was used to examine the relationship of demographic variables to symptom scores. Survey results were reported to the Minneapolis and St. Paul CAACP Leadership Team and workgroups at the completion of each survey year.

RESULTS

Response

Table 1 displays the self-reported demographic characteristics of respondents for the 3 survey years. Two out of 3 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.

TABLE 1 Characteristics of respondents to the CASF by year: Minneapolis and St. Paul Public Schools

	Survey year (no. of respondents)		
	2003–2004 (N=558)	2005–2006 (N=612)	2007–2008 (N=487)
Response rate (%)	47.5	41	32
Gender			
Female (%)	41	40	43
Race/ethnicity (% of respondents)			
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
Free/reduced-priced meals (% of total)	56	53	55

Response rates by year and school district fluctuated, but were highest the first year:

- 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)]

Strict adherence to procedures to ensure anonymity precluded an assessment of response bias. The number of surveys returned in languages other than English was small (<1%). Of those returned in languages other than English, almost all were in Spanish. The reason for the low number of non-English responses is not known.

Symptom Burden Scores

Table 2 shows the average scores from the combined school districts for daytime symptoms, nighttime symptoms, and functional limitations. For each scale, scores increased from 2003–2004 to 2007–2008, with higher scores associated with lower symptom burden. The change in daytime symptom scores from the first round (2003–2004) to the third round (2007–2008) is statistically significant ($p<0.05$). Nighttime symptom and functional limitation scores also improved, but the differences were not statistically significant. There was no association between

TABLE 2 Mean Child Asthma Short Form survey scores for all respondents by symptom/limitation and year: Minneapolis and St. Paul Public Schools

	2003–2004	2005–2006	2007–2008
Daytime symptoms	66.9	68.9	72.9 ^b
Nighttime symptoms	68.1	67.8	70.5
Functional limitations	78.4	79.9	81.5

^aHigher Child Asthma Short Form survey scores indicate lower symptom burden

^bStatistically significant from baseline (2003–2004), $p<0.05$ by Student's *t* test

pattern of improvement and demographic characteristics (data not shown). Average scores in the Native American children, while lowest in 2003–2004, were comparable to other ethnic groups in subsequent years.

The change in distribution of asthma severity classifications over time is presented in Figures 2 and 3. In 2003–2004, 11% of children reported daytime symptoms classified as severe; in 2007–2008, the percent of children in this classification declined to 5%. The percent of children reporting mild daytime symptom burden increased from 50% in 2003–2004 to 68% in 2007–2008.

In 2003–2004, 12% of children reported nighttime symptoms that were classified as severe; in 2007–2008, 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%.

In 2003–2004, 3.2% of children reported severe functional limitations; in 2007–2008, the percent of children reporting severe functional limitations declined to 2.5%. The percent of children reporting mild functional limitations increased from 68% in 2003–2004 to 74% in 2007–2008.

Table 3 presents symptom scores by 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, but the number of respondents in this category were small. Children who were eligible for free or reduced-price meals also has lower scores that those who did not qualify.

DISCUSSION

The CAACP experience in administering the CASF in two school districts demonstrated the feasibility of doing so at reasonable cost and in compliance with current FERPA and IRB standards. Previous collaboration between the CAACP project and the school districts in implementing school-based asthma interventions and the school districts’ interest in the results expedited the process. Unlike many school districts, Minneapolis and St. Paul Public Schools have active registration programs to identify students with chronic diseases, including asthma. This

FIGURE 2. Percent of responses to the CASF indicating mild symptom burden: Minneapolis and St. Paul public schools 2003–2004, 2005–2006, 2007–2008.

FIGURE 3. Percent of responses to the CASF indicating severe symptom burden: Minneapolis and St. Paul public schools 2003–2004, 2005–2006, 2007–2008.

registration process provided a credibly complete list of children with asthma as well as a sampling frame.

The Evaluation Team regularly presented symptom burden survey findings to the leadership team and workgroups of the Minneapolis and St. Paul CAACP Coalition for strategic planning purposes, such as focusing interventions on populations with the highest symptom burden. Survey findings about race and ethnicity 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 also 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 Minneapolis and St. Paul CAACP coalition followed the results of the CASF as a population-based, intermediate measure of the effectiveness of its interventions. While evaluations of specific interventions confirmed that individual children benefitted from CAACP-sponsored programs, they could not address population impact. The trend toward improved scores on the CASF, although small, provided a piece of evidence that the CAACP interventions were reaching a large enough number of children to achieve outcomes measurable at the population level. It is of concern, however, that the trends did not indicate a relatively greater increase in scores (decrease in symptoms) among the groups targeted by CAACP interventions—racial/ethnic minorities and children receiving reduced-price or free meals. It is not known whether this failure to reduce disparities is due to the ineffectiveness of the interventions in reaching disparate populations, reporting bias, other socioeconomic barriers, or a combination of factors.

The interpretation of the CASF survey results is subject to several limitations. First, it is difficult to attribute causality to the observed improvement in symptom scores. Although multiple CAACP interventions were operating at the same time within the communities to address asthma in multiple venues including schools, childcare centers, emergency departments, pharmacies, and clinics, other asthma-related activities occurred in Minneapolis and St. Paul during this time frame.

TABLE 3 Mean Child Asthma Short Form survey scores by demographic characteristics and survey year: Minneapolis and St. Paul Public Schools

	Daytime symptoms			Nighttime symptoms			Functional limitations		
	2003–2004	2005–2006	2007–2008	2003–2004	2005–2006	2007–2008	2003–2004	2005–2006	2007–2008
Gender									
Male	68.6	69.9	74.5	69.5	67.9	72.7	79.1	80.8	83.4
Female	63.3	68.2	70.4	66.3	68.2	67.7	76.8	79.7	78.9
Race/ethnicity									
African American	59.4	59.9	65.7	60.5	59.5	63.4	72.3	73.4	74.7
Caucasian	74.4	79.8	79.1	78.1	76.5	76.5	86.2	89.9	88.2
Multiracial	62.8	73.0	70.9	65.8	72.6	68.1	75.1	83.7	80.1
Hispanic	68.8	62.3	75.5	62.8	58.7	74.5	79.9	70.9	82.4
Asian	75.8	65.5	67.3	76.1	70.6	66.1	79.4	81.3	74.7
Native American	39.3	64.8	72.2	32.1	63.6	65.3	50.0	72.7	76.4
Free/reduced lunch									
Qualified	59.3	61.1	66.2	60.5	60.5	64.3	71.9	73.9	74.9
Not qualified	76.4	78.0	81.0	77.8	75.9	78.3	87.1	87.3	90.1

^aHigher Child Asthma Short Form survey scores indicate lower symptom burden

Health plans offered asthma disease management programs and legislation reduced environmental tobacco smoke in public areas (i.e., restaurants) during this time.

As with any survey, it is difficult to obtain an adequate response rate and to determine whether the response is biased. While parents were notified about the survey in multiple ways, the response rate in the first year was 47.5% and declined to 32% in the third survey. Parents of children with a higher understanding and concern about their child's asthma may have been more likely to complete and return the survey. Furthermore, the effect of language and culture on response rates is unknown. Although the impression of the school district staff was that the racial/ethnic distribution of responses was representative of the population in the school systems, data were not available to confirm this. While few surveys were returned in languages other than English, parents who self-identified as Hmong, Somali, or Hispanic did complete and return the English version. Furthermore, some respondents may have been included in more than one survey year. School district policies prevented CAACP from obtaining identifiers of any kind. This study was not intended to be a longitudinal study, rather to identify trends over time and populations of priority for a given year.

While surveys were sent to Minneapolis and St. Paul public school parents 4 months apart, they were sent within the same allergy season. In Minnesota, the spike in fall asthma hospitalizations is over by October, when there are typically hard frosts and seasonal allergens are at very low levels.¹⁰ Regardless, once the schedule was established, the timing of the survey in each district was followed for all 3 years.

CAACP's experience indicates the feasibility of administering an asthma symptom burden survey in a school-based population and the usefulness of survey results in directing the project's community-based programming to those with the greatest need. This tool for measuring intermediate, population-based outcomes can provide information on race/ethnicity and socioeconomic status that is not typically available for other population-based indicators such as emergency department visits and hospitalizations. If it can be confirmed that race/ethnicity and SES do not substantially influence response rates, then this tool may offer a way of tracking a project's impact on health disparities.

Although the CASF survey results alone cannot attribute causality to the project, they contribute credible evidence to support its effectiveness. They must be considered in the context of other evaluation findings and other indicators of the project's impact on the target population.

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