Clinical profile, health-related quality of life, and asthma control in children attending US asthma camps

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Background: Approximately 120 asthma camps presently serve nearly 10,000 children nationwide. A clinical profile of the children who attend asthma camps has not been published.

Objectives: To create a standardized universal health history camp application that includes an assessment of health-related quality of life using the Child Asthma Short Form; to test a newly validated tool, the Childhood Asthma Control Test (C-ACT), to assess asthma control in children; to provide a clinical snapshot of the overall status of children with asthma in the United States; and to determine the benefit of children's asthma camps.

Methods: Participating camps distributed the universal health history and the Child Asthma Short Form as part of their application. The C-ACT was distributed separately.

Results: A total of 1,783 campers from 24 camps in 17 states provided the requested information. Camp attendees generally had moderately severe asthma, as indicated by a mean ± SD parent-reported severity rating of 4.86 ± 2.10 on a 10-point scale. Average daytime and nighttime symptom scores and functional limitation scores indicated children moderately burdened by their asthma symptoms. Using the C-ACT, 37% of children were found to have inadequately controlled asthma. Children who had attended asthma camp the previous year reported better use of asthma management tools, were more likely to be using controller therapy, and had more responsibility for taking their medication ($P < .05$).

Conclusion: The burden of asthma experienced by children attending asthma camps is substantial, suggesting that there is an opportunity to improve the lives of children attending asthma camps.

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INTRODUCTION

Approximately 120 asthma camps presently serve nearly 10,000 children nationwide according to surveys conducted annually by the Consortium on Children's Asthma Camps (CCAC) (http://www.asthmacamps.org). The camps strive to provide positive outdoor experiences in a traditional residential camp setting for children with asthma.[1–6] In addition to typical camp activities, asthma education with an emphasis on management skills is provided to the children, and health professionals are available 24 hours a day.

Although several single-camp descriptions exist,[3,4,7] a nationwide, clinical profile of the children who attend asthma camps has not been published, to our knowledge. Each camp generally obtains clinical information about their campers using an individual application process. Collecting national information about the functional status, medication use, quality of life, and overall asthma control of children attending asthma camps would provide a snapshot of childhood asthma and asthma management in the United States.

A recent telephone survey of 801 parents of children with asthma, *Children and Asthma in America*, revealed that a disappointingly high percentage of children with asthma in this country have poorly controlled asthma.[8] However, the survey used a random, impersonal telephone screen; interviewers relied only on the parent to identify that their child had asthma; and no accepted scientific survey tools to evaluate health-related quality of life (HRQL) and overall asthma control were used.

The CCAC, a coalition of nonprofit organizations with an interest in asthma camps, attempted to generate a larger and more expanded survey of children who have asthma by profiling children attending asthma camps. A standardized universal health history (UHH) application was created to be used by a variety of asthma camp programs from various regions of the United States. By having a common application process that included an evaluation of HRQL, detailed information could be collected and analyzed from a large sample of children with asthma. This CCAC project provided an additional opportunity to test a newly validated tool made available to evaluate asthma control in children, the Childhood Asthma Control Test (C-ACT). The C-ACT is an instrument that measures control of asthma in children aged 4

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to 11 years using parent and child input.[9] Inclusion of the C-ACT in the UHH project allowed for its further evaluation in many children with asthma in the age range for which this tool is intended. Finally, this project attempted to determine the value and benefit of children's asthma camps, previously based on anecdotal evidence.[10] This was accomplished by comparing the profile of children who have gone to an asthma camp previously (returnees) with the profile of children attending camp for the first time.

METHODS

Twenty-four asthma camps in 17 states were invited by the CCAC to participate in the project after a selection process open to all member camps (Table 1). Each participating camp used its own established application process to enroll children but agreed to include the UHH in their camp application materials. The UHH is a standardized asthma health history containing information that would assist volunteer health care providers in managing a child's asthma while attending summer camp. The UHH was developed for a small pilot study[11] of the clinical profile of children attending camps conducted in 2003.

In addition to the medical history and general information about a child's asthma, the UHH included the Child Asthma Short Form (CASF). The CASF is a 10-question, validated instrument available in English and Spanish that measures HRQL in pediatric asthmatic patients.[12] It consists of 3 symptom scales (daytime symptoms, nighttime symptoms, and functional limitations) and 2 single-question items (life interference with inhaler use and family adjustments). The instrument is scored using a scoring protocol, with scores ranging from 0 to 100; lower scores are associated with poorer HRQL.

Table 1. Participating Camps and Their Sponsors

Camp	Sponsor
ALA Asthma Camp	ALA of Arkansas
Asthma Camp	ALA of South Dakota
Asthma Camp Experience	ALA of Pennsylvania
Camp Action	ALA of Metro Chicago
Camp Asthmania	AnMed Health
Camp Breathe Easy–CA	ALA of East Bay
Camp Breathe Easy–GA	ALA of Georgia
Camp Breathe Ezzzze	North Mississippi Medical Center
Camp Coast	ALA of North Carolina
Camp Sierra	ALA of Central California
Camp Super Breathers	ALA of Idaho
Camp Superkids–IA	ALA of Illinois/Iowa
Camp Superkids–IL	ALA of Illinois/Iowa
Camp Superkids–MN	ALA of Minnesota
Camp Superkids–NW OH	ALA of Ohio–Northwest Region
Camp Superkids–OH	ALA of Ohio
Camp Wheez	ALA of Santa Barbara and Ventura County
Camp Wyatt	ALA of Utah
Champ Camp	ALA of Colorado
Dakota Superkids Asthma Camp	ALA of North Dakota
Med Camp Asthma Camp	ALA of Arkansas
SCAMP Camp	ALA of Orange County
SCAMP Camp	ALA of San Diego and Imperial Counties
Young Teen Asthma Camp	Camp Winnataska, Pell City, Alabama

Abbreviation: ALA, American Lung Association.

A second instrument, the C-ACT, was distributed separately to campers. Most, but not all, of the camps participating in the project provided the C-ACT tool to their campers. The C-ACT is a 7-item questionnaire for measuring the relative degree of asthma control in pediatric asthmatic patients aged 4 to 11 years.[9] Responses to the 7 questions are summed into a composite score with a range from 0 to 27. A score of 20 or greater has been determined to be a good indication of controlled asthma, whereas a score of 19 or less suggests inadequately controlled asthma.

Participating camps were provided an honorarium from the CCAC to meet the additional expenses incurred in distributing and processing the UHH form, administering the C-ACT, and performing data entry. Each participating camp received camper gifts (activity packets and water bottles) to distribute to their campers as an additional acknowledgment of the camp's willingness to participate in the project. The camper gifts were provided by a second study sponsor (GlaxoSmithKline, Research Triangle Park, North Carolina).

Parental consent for the use of information contained in the UHH was obtained at the time the application was completed. Because camps were located in multiple states, individual institutional review board documents were completed when required. Each camp was responsible for entering data onto a password-protected, secure Web site using data entry screens established for this purpose. Camp personnel were trained in data entry procedures via a telephone conference call, and a project contact was available at all times to provide assistance if needed. Data entry progress was monitored, and reminder prompts were provided periodically. The Web site for data entry provided frequency distributions of entered data to each camp interactively. The individual camp's information was reported and displayed along with the accumulating data from all of the camps.

A single data download provided data for analysis. No personal identifying information was included in the download. A software program (SAS version 9.1; SAS Institute Inc, Cary, North Carolina) was used to calculate rates and other descriptive statistics and for statistical analyses. Bivariate comparisons were tested using χ^2 and Mantel-Haenszel χ^2 techniques. $P < .05$, 2-tailed, was considered statistically significant.

RESULTS

All 24 asthma camps completed data entry. The UHH forms were received from 1,783 campers 6 to 16 years of age. Incomplete UHH forms were excluded from further study,

resulting in a sample of 1,775. The campers participated in camp sessions at asthma camps in 17 different states. Demographic and asthma characteristics of the children are given in Table 2. The mean ± SD age of campers was 10.4 ± 1.9 years. By age group, 6% were 7 years or younger, 64% were 8 to 11 years, and 30% were 12 to 16 years. Girls composed 44% of the study group; slightly less than one-third (31%) were children who qualified for a Medicaid program in their state.

In addition to an evaluation of asthma severity parents were asked to provide information regarding 2 other aspects of asthma symptoms: nighttime wakening and exercise interference (Table 2). Nighttime wakening at least 1 night per week was reported by 52% of parents: awakening 1 to 2 nights a week was reported by 35% (n = 624), 3 to 4 nights a week by 13% (n = 230), and 5 to 7 nights a week by 4% (n = 67). Some level of exercise interference due to asthma was reported by 80% of parents: "some" interference was indicated by 51% (n = 899), a "moderate amount" of interference by 20% (n = 352), and "a lot" of interference by 9% (n = 159). Only 24% of children did not miss school during the previous school year due to asthma. A total of 811 of 1,492 children (54%) had 3 or more absences; 6% missed 16 or more school days. Three children missed more than 40 days of school.

Table 2. Camper Profile

Characteristic	Campers, % (n = 1,775)
Age, y[a]	
≤7	6
8–11	64
12–16	30
Sex	
F	44
M	56
State Medicaid qualified	31
No previous asthma camp experience	57
Asthma-related problems	
≥1 nighttime awakening per week	52
Exercise limitations	80
≥1 school absence due to asthma	76
≥3 school absences due to asthma[b]	54
Health care service use due to asthma	
Care by an asthma specialist	49
≥1 hospitalization in the previous year	10
≥1 emergency department visit in the previous year	44
≥1 office visit for acute asthma in the previous year	76
≥1 oral corticosteroid regimen in the previous year	60
Use of asthma management tools	
Written asthma action plan	25
Regular use of peak flow meter	20

[a] Mean ± SD age, 10.4 ± 1. 9 years.
[b] Based on 1,492 campers because not all parents responded and because some responses were uninterpretable.

The UHH form included questions related to the use of health care services for asthma (Table 2). At least 1 hospitalization in the previous year due to acute asthma was reported by 10% of parents, an emergency department (ED) visit by 44%, and 3 or more office visits to a physician for acute asthma by 37% (≥1 office visits by 76%). Overall, 49% of the children (n = 724) were seen by an asthma specialist (allergist or pulmonary specialist). Controller medication use was reported by 83% (n = 1,470), but only 25% (n = 445) indicated that there was an asthma action plan, 41% (n = 724) that a spacer was used in conjunction with an inhaler, and 20% (n = 353) that a peak flow meter was used on a regular basis.

Asthma severity was evaluated from the UHH based on the question, "How bad is your child's asthma?" Camp attendees generally had moderately severe asthma, as indicated by a mean ± SD parent-reported severity rating of 4.86 ± 2.10 on an 11-point scale (0 = no asthma and 10 = severe asthma). Approximately 44% of the parents rated the asthma 1 to 4, 52% responded with a score of 5 to 9, and 3% indicated a score of 10 (severe asthma).

Activities at asthma camps have, historically, emphasized asthma self-management. Therefore, asthma camp attendance the previous year was hypothesized to be associated with better use of asthma management tools (regular use of a peak flow meter, having a written asthma action plan, and use of a spacer or assisting device), increased responsibility for medication use by the child, use of a controller medication, reduced use of health care services for acute asthma management (physician office visits, hospitalizations, and ED or urgent care clinic visits in the previous year), lower parent-reported asthma severity, and lower school absenteeism. Table 3 indicates that children who attended asthma camp the previous year reported better use of asthma management tools (ie, having a written asthma action plan [$P = .02$] and using a spacer or assisting device in conjunction with their inhaler [$P = .03$]) and were more likely to be receiving controller therapy ($P < .001$) compared with children who had never attended camp. They also reported having fewer physician office visits ($P < .001$), hospitalizations ($P = .02$), and ED or urgent care clinic visits ($P < .001$).

Responsibility for asthma medication was also analyzed using the Mantel-Haenszel χ^2 test. Except for children 7 years or younger, children who had previously attended asthma camp had a higher likelihood of having some or all of the responsibility for their asthma medication (children 8–11 years, $P = .01$; children 12–16 years, $P = .02$) compared with children who had not previously attended camp. No children 7 years or younger had sole responsibility for their medications, and a similar number had shared responsibility for their asthma medication.

Table 3. Frequency of Asthma Characteristics Overall and Based on Previous Camp Experience

Characteristic	Campers, No./total No. (%)			*P* value
	Previously attended camp	Did not previously attend camp	Overall	
Peak flow use (use regularly)	169/770 (21.9)	184/1,005 (18.3)	**353/1,775** (19.9)	NS
Asthma action plan (having a written plan)	214/770 (27.8)	231/1,005 (23.0)	**445/1,775** (25.1)	.02
Controller therapy (use of controller therapy)	667/770 (86.6)	803/1,005 (79.9)	**1,470/1,775** (82.8)	<.001
Spacer/assisting device (regular use)	344/770 (44.7)	398/1,005 (39.6)	**742/1,775** (41.8)	.03
Medication responsibility (some or all by child)	601/717 (83.8)	656/926 (70.8)	**1,257/1,643** (76.5)	<.001
Physician office visits (≥3 in the previous year)	201/627 (32.1)	334/827 (40.4)	**535/1,454** (36.8)	<.001
Hospitalizations (≥1 in the previous year)	61/770 (7.9)	113/1,005 (11.2)	**174/1,775** (9.8)	.02
ED/urgent care (≥1 in the previous year)	202/527 (38.3)	342/719 (47.6)	**544/1,246** (43.7)	<.001
Asthma severity (high severity)	166/728 (22.8)	206/929 (22.2)	**372/1,657** (22.5)	NS

Abbreviations: ED, emergency department; NS, not significant ($P > .05$).

The CASF

A total of 1,653 parents completed the CASF. Of these, 1,649 parents provided an adequate number of responses to score the daytime symptom scale, 1,645 provided responses to score the nighttime symptom scale, and 1,607 provided responses to score the functional limitations scale. Compared with results published by the authors of the CASF, the HRQL scores obtained from the asthma camp attendees are slightly higher but not statistically significantly different from those reported.[12] The results demonstrate a moderate symptom burden and are consistent with the parent-reported severity results (Table 4).

The C-ACT

Responses to the C-ACT were received from 782 children aged 4 to 11 years. The mean ± SD score was 20.0 ± 4.4. Using the categories of inadequately controlled (scores ≤19) and controlled (scores ≥20) asthma, 37% of the children were found to have inadequately controlled asthma (Table 5). The results of the C-ACT are consistent with the profile of health care service use for asthma reported for this group of asthma camp attendees. Among the children reporting on use of health care services in the past year, 44% required ED admissions; 10% had at least 1 hospitalization, and 76% had unscheduled office visits for acute asthma, events typically considered to be indicators of poor asthma control.

Comparison of the CASF and the C-ACT

It was hypothesized that there would be a direct association between the CASF score and the C-ACT score. The association was tested using the χ^2 test, which required the subscale scores from the CASF to be categorized into 3 groups (severe impact, ≤25; moderate impact, 26–75; and mild impact, 76–100). The dichotomized C-ACT scores (≤19, inadequately controlled; ≥20, controlled) remained as previously defined. The results indicate that children who are classified as having controlled asthma (C-ACT scores ≥20) also have higher (better) scores on all 3 of the subscales of the CASF ($P \leq .05$) (Table 6).

Table 4. Child Asthma Short Form (CASF) Scores

Scale	CASF score, mean ± SD	
	Asthma camp sample	Validation sample[a]
Daytime symptoms	64.61 ± 22.58	62.2 ± 27.5
Nighttime symptoms	67.43 ± 24.26	60.5 ± 28.3
Functional limitations	77.62 ± 20.88	75.7 ± 24.4

[a] From Bukstein et al.[12]

Table 5. Childhood Asthma Control Test (C-ACT) Scores in 782 Campers Aged 4 to 11 Years

C-ACT score	Campers, No. (%)
Inadequately controlled asthma	
1–10	37 (5)
11–19	250 (32)
Subtotal	**287 (37)**
Controlled asthma	
20–23	335 (43)
24–27	160 (20)
Subtotal	**495 (63)**

DISCUSSION

To our knowledge, the present study is the first to collect and publish cross-sectional data regarding asthma morbidity, HRQL, and asthma control from a large sample of children with asthma. The clinical information provided in a common health application used by 24 US asthma camps in 2005 resulted in a large survey (N = 1,783) that allowed a review of the current state of childhood asthma management in this country. The children attending asthma camps had a diagnosis of asthma that was confirmed by the child's physician. In fact, a physician was required to complete portions of the application so that it can be safely said that all the children in this survey were being followed up by a physician. Despite this, overall the campers had a surprising degree of asthma morbidity and overall impairment of daily life. More than one-fourth of the children had missed excessive amounts of

Table 6. Comparison of the Child Asthma Short Form (CASF) and the Childhood Asthma Control Test (C-ACT)

Variable: C-ACT and…	χ^2_2 value	*P* value	Result: Children who reported controlled asthma also reported…
CASF daytime symptoms	46.60	<.001	Higher (better) daytime symptom scores
CASF nighttime symptoms	41.59	<.001	Higher (better) nighttime symptom scores
CASF functional limitations	30.02	<.001	Higher (better) functional limitation scores

school, with 6% having missed more than 2 weeks of school in the past year; many reported nighttime awakenings and exercise limitations of some degree. In terms of health care use, 44% had been to the ED for acute asthma in the past year, whereas 10% of all the children had at least 1 hospitalization in that same period.

The degree of asthma severity suggested by the school absences and health care use results are supported by the self-reported asthma severity, the CASF scores that are consistent with a group of children moderately impaired by their asthma, and the C-ACT results. These findings are also similar to those of a random, but smaller, sample of children (N = 801) surveyed in the *Children and Asthma in America* project.[8] In that survey 42% of the children had used acute care services in the past year, and almost two-thirds had some degree of limitation on various physical activities, results not unlike those of the present study. The findings are, however, higher than those reported[13] in schoolchildren in Chicago with asthma, where only 12% reported wakening due to wheezing, 11% had missed school due to asthma, 9% visited the ED during the past year for asthma or wheezing, and 6% had been hospitalized. A possible explanation for this difference is that children with greater severity of asthma and overall poor adherence/perception of control are referred to asthma camp. However, CASF results suggest that children sent to asthma camp are comparable with children considered moderately impaired by their asthma.

Because asthma camp is intended for children to learn better management skills, one might expect the population of children attending asthma camp to have more significant asthma severity than the average child with asthma and greater morbidity from their disease. On the other hand, almost half of the children attending camp reported care by an asthma specialist (allergist or pulmonologist), which was expected to have resulted in better asthma control and, therefore, less morbidity. The results indicate that even under the care of a general physician, sometimes even an asthma specialist, children with asthma are not achieving the goals of asthma therapy.[13,14]

This UHH project allowed for the collection of cross-sectional HRQL and asthma control data from a large sample of children with asthma. Average daytime and nighttime symptom scores of 65 and 67, respectively, and a functional limitation score of 78 of a possible 100 using the CASF were found. These scores were similar to those of children with asthma reported by Bukstein et al[12] and suggest a group of children moderately burdened by their asthma symptoms. The C-ACT is a newly available validated tool for use by researchers and practitioners in the clinic to quantify the degree of asthma control. The average C-ACT score for age-appropriate children in this survey was 20.0, the published cutoff point for controlled asthma. Most striking was the finding that 37% of the children aged 4 to 11 years had a score of 19 or less, an indication that many children attending asthma camp have inadequately controlled asthma. The C-ACT results provide further evidence that even with excellent established treatment guidelines children with asthma are falling short on reaching the goals of successful asthma treatment.

The C-ACT score correlated well with a child's score on the CASF. Children with poor asthma control were found to also have higher daytime and nighttime symptom burdens and more functional limitations due to their asthma. The C-ACT seems to be a useful measure of asthma control in children and, in conjunction with the CASF, provides information that can be used with patients and families to reinforce the importance of good asthma control.

Results of the analysis comparing children who had previously attended an asthma camp vs those who had not suggest that the camp experience is a positive one. Compared with children who had not attended camp previously, camp returnees reported better asthma management skills (eg, have a written asthma action plan, have sole or shared responsibility for their medication use, and use a spacer or peak flow meter), were more likely to be using a controller medication, and had reduced health care use (fewer physician visits for acute asthma and fewer ED visits and hospitalizations in the past year). These findings speak to the value of children going to camp.

However, even the children who had previously been to asthma camp had less-than-optimal functional status, HRQL, and asthma control. There still is a great opportunity for asthma camps to improve the lives of children attending an asthma camp program. It was reassuring and satisfying to see that 83% of all the children reported using controller therapy, but the somewhat disappointing results about their asthma control, as a whole, makes one question whether the controller therapy was being used by the child or whether more aggressive treatment was needed.

Data obtained from the asthma camp experience are important for the physician managing the child's asthma. In knowing, there is a chance that the child's asthma management can be altered for the better. In the next phase of this project the CCAC plans to introduce a detailed feedback or

"asthma report card" system whereby the referring physician is made aware of the child's various measurements obtained during the camp application. The CCAC also intends to evaluate whether the report card resulted in a change in the child's asthma treatment program. In establishing this feedback loop asthma camps will have a better chance of making a positive impact during the typical short period the child is involved in the camp experience.

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