



Inaccuracy of asthma-related self-reported health-care utilization data compared to Medicaid claims

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Self-reported (or parent/guardian-reported) health-care utilization is frequently used in childhood asthma intervention and observational studies to identify cases of poorly controlled asthma and as an outcome measure. The Asthma Outcomes: Exacerbations Workshop recommends that baseline eligibility criteria in clinical trials consist of having at least one of the following events in the 12 months prior to study entry: treatment with systemic corticosteroids for asthma, an asthma-specific hospital admission, or an asthma-specific emergency-department (ED) visit [1]. These same metrics are also used clinically as markers of asthma risk, which then contribute to severity classification and treatment [2]. A history of an exacerbation in the prior 12 months is one of the strongest predictors of a future exacerbation [3]. This history (via self-report) is relatively easy to obtain, yet it is not known if it is accurate. Herein we report that when it comes to a prior exacerbation, caregiver reports can differ from administrative or insurance-based claims data. The goal of this analysis was to compare caregiver-reported with claims-based asthma utilization data collected during a pilot school-based asthma intervention in Hartford, CT.

School-based asthma interventions have demonstrated mixed results with respect to reduced health-care utilization. Most of these studies have collected data on health-care utilization by caregiver report [4, 5]. The accuracy of self-reported health-care utilization is variable and can be affected by the recall time frame, type of utilization, and frequency of the event [6]. Our group recently piloted a school-centered asthma program, named Building Bridges for Asthma Care, with a primary goal of reducing overall school absences among urban children in Hartford, CT, and Denver, CO [7]. Students with diagnosed asthma were identified through school records. Eligibility criteria for students (5-14 years old) with asthma included a parent/caregiver-report of health-care utilization for asthma and frequency of symptoms within the past 12 months. Based upon *a priori* guidelines-based thresholds, students were considered at risk for an asthma exacerbation, and invited to participate in the study. Medicaid claims

data for study participants were only available for the Hartford sample. The study was approved by the Institutional Review Board at Connecticut Children's Medical Center.

We examined the concordance of caregiver-reported asthma hospitalizations, ED visits, or systemic corticosteroid courses in the past 12 months with claims data provided by Community Health Network of CT (CHNCT), Inc., Connecticut's sole Medicaid and Children's Health Insurance Program (CHIP) administrative services organization since 2012. Ninety percent of Building Bridges participants were covered by HUSKY Health (the Medicaid and CHIP programs in Connecticut) at the time of enrollment. Of 206 Hartford students enrolled in Building Bridges during the 2014-2015 school year, CHNCT claims data were obtained for 97 students (47%) (Table 1). Children who were part of the analytic sample ($n=97$) were slightly younger than the children for whom claims data were not available (mean age 7.6 years vs 8.4 years, respectively, $p = 0.03$). The unweighted Kappa (κ) coefficient was computed to examine how often caregiver-reported results agreed with actual Medicaid and CHIP claims data. Claims concordance was poor for both caregiver-reported ED visits and systemic corticosteroid courses, and fair for hospitalizations (Table 2). Using claims as the gold standard, caregivers over-reported ED visits, and under-reported systemic corticosteroid usage. Our results are consistent with a prior study which showed that asthma-related hospitalizations demonstrated the strongest agreement between sources, and systemic corticosteroid courses demonstrated the poorest agreement with claims data [8]. That our population tended to over-report ED visits may reflect the study population's health behaviors and demographics. The Latino population in Hartford is primarily Puerto Rican, for whom there is a documented fear of children dying from asthma, which may account for higher ED utilization rates, compared with other racial/ethnic groups and Latino subgroups [9, 10]. Puerto Ricans are more likely to make ED visits for asthma, and therefore, they may be more likely to over-report ED visits.

In asthma research, there is widespread use of parent/caregiver-reported and self-reported health-care utilization to categorize asthma severity, risk stratify for study eligibility, and assess outcome

measures in pediatric efficacy/effectiveness studies. In studies for which health-care utilization is an eligibility criterion, social desirability bias may influence reported utilization. For example, parents/caregivers may over-report ED visits to ensure their child's eligibility for study participation. Enrollment of children inaccurately described as at-risk may lead to decreased effect sizes for an intervention, because potentially less severe, well-controlled, ineligible participants would still be enrolled. Relying on self-reported health-care utilization may also introduce recall bias (telescoping and memory decay) that depends on the interval between healthcare use and data collection. In families with more than one child, it may be difficult to recall utilization for the index child.

There also are limitations for administrative claims data, including out-of-plan usage, non-covered services, and failure to properly document or code an exacerbation. In our study, out-of-plan usage would not be a factor, as all participants were insured by Medicaid or CHIP. Patients often lose their Medicaid/CHIP eligibility and then re-enter the system when they are seen in the ED or are hospitalized. Another limitation of claims data is the lag between services rendered and data availability, ranging from six to 12 months [11]. Administrative claims data are also limited because, as seen in previous studies, patients may not take the systemic corticosteroids that they picked up from the pharmacy [12, 13].

These study findings are an important contribution to a growing body of evidence showing that claims-based data and self-reported medical services utilization are not interchangeable [8, 14-16]. On the individual level, self-reported ED visits and systemic corticosteroid courses are not always reliable, when using claims data as the gold standard. On the population level, the mean number of events appears to be relatively similar between self-report and administrative data [8]. The decision, thus, to rely upon self-reported or administrative claims data for asthma healthcare utilization may depend upon the study objective. For clinical trials, self-report seems reliable, because participants' consistent reporting of healthcare utilization may be improved due to greater awareness of the child's current

health from participation in the study, or shorter duration between study visits. In a pragmatic study, however, caregiver-reported utilization data, particularly ED visits and systemic corticosteroid use, may not be reliable, and might result in biased outcomes measures.

Declaration of Interest Statement

S.J. Szeffler has consulted for Aerocrine, Astra Zeneca, Boehringer-Ingelheim, Daiichi Sankyo, Glaxo Smith Kline, Genentech, Novartis, Roche, and Teva and has received research support from the National Institutes of Health, the National Heart, Lung and Blood Institute, GlaxoSmithKline, and the Colorado Cancer, Cardiovascular and Pulmonary Disease Program. He is also a former member of the Global Initiative for Asthma Scientific Committee and the National Asthma Education and Prevention Expert Panel 3.

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Table 1. Sociodemographics of study population, comparing participants with Medicaid claims with those without claims data.

	Unmatched to Claims (N=109)	Matched to Medicaid Claims (N=97)	Total (N=206)	<i>P</i>
Gender				0.22 ¹
Female	56 (52%)	42 (44%)	98 (48%)	
Age (at enrollment)				0.03 ²
Mean (years) (SD)	8.4 (2.5)	7.6 (2.3)	8.1 (2.5)	
Grade				0.24 ¹
PK	1 (1%)	3 (3%)	4 (2%)	
K	8 (8%)	8 (8%)	16 (8%)	
1	21 (20%)	22 (23%)	43 (21%)	
2	17 (16%)	17 (18%)	34 (17%)	
3	10 (9%)	17 (18%)	27 (13%)	
4	15 (14%)	15 (16%)	30 (15%)	
5	11 (10%)	4 (4%)	15 (7%)	
6	11 (10%)	4 (4%)	15 (7%)	
7	8 (8%)	3 (3%)	11 (5%)	
8	5 (5%)	3 (3%)	8 (4%)	
Race/Ethnicity				0.81 ¹
Black/African American	27 (25%)	20 (21%)	47 (23%)	
Hispanic/Latino	74 (69%)	69 (72%)	143 (70%)	
Other	1 (1%)	2 (2%)	3 (2%)	
White	5 (5%)	5 (5%)	10 (5%)	

¹Chi-Square ²Kruskal Wallis

Table 2. Agreement between parent/caregiver reports and Medicaid administrative claims.

Medicaid Claim Outcome	Parent Under-Reported	Parent Accurately Reported	Parent Over-Reported	Kappa (Strength of Agreement)
Emergency-department visit	15%	25%	60%	0.04 (poor)
Hospitalization	69%	25%	6%	0.21 (fair)
Systemic corticosteroid use	68%	16%	16%	0.02 (poor)

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