Congruence between Urban Adolescent and Caregiver Responses to Questions about the Adolescent's Asthma

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ABSTRACT *In clinical and research settings, it is increasingly acknowledged that adolescents may be better positioned than their caregivers to provide information in regard to their own health status, including information related to asthma. Very little is known, however, about the congruence between adolescent and caregiver responses to questions about asthma beyond reports of symptoms. We analyzed data for 215 urban, primarily African-American adolescent-caregiver pairs. Adolescents and caregiver reports concerning the adolescent's asthma-related medical history were moderately correlated and not found to differ at the aggregate level. Correlations between adolescent and caregiver reports of the adolescent's asthma symptoms and functional status were weak, although these differences deteriorated at the aggregate level. Adolescent-caregiver reports of symptoms and functioning were more likely to be in agreement if the adolescent was older, if school personnel were unaware of the child's asthma, and if the adolescent's asthma was classified as mild intermittent. For questions concerning the frequency of hospitalizations, emergency department visits, and physician visits, moderate correlations between adolescent and caregiver responses were noted, although with some differences at the aggregate level. Findings suggest that, when adolescents and their caregivers are asked about the adolescent's asthma in clinical and research settings, the extent to which the two perspectives are likely to agree depends on the type of information sought. Clinicians and researchers may obtain more accurate information if questions about symptoms and functional status are directed toward adolescents.*

KEYWORDS *Asthma, Adolescents, Proxy Reports, Congruence*

INTRODUCTION

When information about adolescent asthma is desired for clinical or research purposes, there remains uncertainty about whether to direct questions toward adolescents or their parental caregivers. In the absence of a "gold standard" validation measure, some researchers have concluded that convergence between

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informant reports is the best available or most practical means of assessing the quality of reports obtained.¹ Evidence accumulating over the past decade suggests that adolescent and parental perceptions of asthma-related phenomena often diverge.^{2,3} The preponderance of available studies, however, has focused on congruence between parental and child reports of asthma symptoms,² and few studies have examined minority populations most affected by asthma.⁴ Identifying the most valid method of assessing the perceptions and experiences of adolescents with asthma and their caregivers may be especially important in populations bearing a disproportionate burden of disease.

Reports from patients or family members regarding symptom type or frequency have been the primary means of identifying asthma in epidemiological studies⁵ and an essential component of diagnostic and therapeutic decision making in clinical settings.⁶ In addition to symptom reports, clinicians and researchers' understanding of asthma often requires information from families about a broader range of factors. Patient experiences of the impact of asthma on daily activities, for example, cannot be discerned entirely from responses to questions about symptoms.⁷ Further, morbidity associated with asthma is frequently measured in terms of health care use,⁸ which is often collected by self-report. Similarly, patient or caregiver reports provide the data for assessing a child's functional status and the events that comprise his or her medical history. Using data obtained from an urban, predominantly African-American population, the aims of this study were to assess the extent of agreement between adolescents and caregivers on responses for a range of asthma-related items and to determine whether differences in reporting are associated with personal, clinical, or household characteristics of the adolescent or adult caregiver (e.g., the adolescent's age, level of disease severity, household income).

METHODS

Our study used baseline survey data collected as part of a randomized controlled trial designed to test the effectiveness of a computer-based asthma management program for urban teens.⁹ The Institutional Review Boards of the Henry Ford Health System and the University of Michigan approved the methods for the original study. Approval was also obtained for the analysis associated with the present study.

Participants were identified based on their responses to a screening survey administered to all 9th to 11th graders of six Detroit public schools. Adolescents were considered eligible if they met the criteria for current asthma, defined as a report of physician diagnosis of asthma and at least one of the following: one or more emergency department visit(s) in the last 12 months, two or more doctor visit(s) for symptoms in the past 12 months, one or more hospital visit(s) for asthma in the past 12 months, refilled an inhaler one or more time(s) in the last 12 months, awakened one or more time(s) due to asthma symptoms in the past 30 days, or took medicine for symptoms four or more days in the past 30 days. Adolescents not reporting a physician diagnosis of asthma were also considered eligible if they responded positively to selected items from the International Study of Asthma and Allergy in Children questionnaire¹⁰ and reported a pattern of asthma symptoms consistent at minimum with the National Asthma Education Prevention Program Expert Panel Report II¹¹ classification of mild intermittent asthma. Adolescents participating in the program completed questionnaires through an audio computer

assisted self-interviewing (ACASI) system made available through their school. Interviewers administered baseline questionnaires to caregivers over the telephone.

Measures

The adolescent and caregiver questionnaires included a number of equivalent questions about the adolescent's asthma. Respondents were asked about the adolescent's asthma-related medical history (age at symptom onset, whether the child had a physician diagnosis of asthma, child's age at diagnosis). Questionnaires also included two items related to asthma symptoms (the number of symptom days and symptom nights) and two items concerning functional status (days of restricted activity and changed plans due to asthma) during the past 30 days. Adolescents and caregivers were also asked to report the frequency of asthma-related health care use within the past 12 months, as well as visits made to a physician for any reason.

Demographic data collected from adolescent respondents included the child's age, race, and grade in school. Adolescents were also asked about their smoking status, whether school personnel were aware of their asthma status, if they believed their asthma was serious, and a series of Likert-type items used previously¹² to assess their perceptions regarding their parents' knowledge of their whereabouts ($\alpha = 0.75$). Information obtained from adult respondents included their relationship to the adolescent (e.g., mother, grandmother), level of education, smoking status, household income, and the presence of adults or other children with asthma living in the household.

ANALYSIS

We restricted congruence analyses to adolescent-caregiver pairs, excluding adolescent responses to items when there was not a corresponding response from the caregiver and vice versa. To assess the level of congruence between adolescent-caregiver pairs, a Spearman rho correlation statistic was calculated for continuous variables, and a kappa statistic was calculated for the binary variable (physician diagnosis). For continuous variables having a significant positive correlation, the mean directional differences between adolescents and caregivers reports were calculated, and paired *t* tests were performed. Congruence analyses included both correlation and examination of group difference, as the insufficiency of relying on one method alone has been noted;¹³ for example, while *t* tests can assess how closely informants agree on average, the results of these procedures can mask individual differences.

To examine bivariate associations between personal, clinical, and household factors and congruence between adolescent-caregiver responses, we constructed a composite variable representing agreement across the four items related to asthma symptoms and functioning. For each item, we calculated the absolute differences between adolescent and caregiver reports and then dichotomized the results into higher agreement and lower agreement by a median split. Adolescent and caregiver pairs were considered in agreement if the caregiver and his/her adolescent child were in the group with higher agreement across all four of the items. Bivariate associations between agreement and independent variables were explored using χ^2 tests and *t* tests. Multivariate logistic regression was then used to model the relationship between agreement of adolescent and caregiver symptoms and functioning reports and independent variables chosen on the basis of bivariate analyses.

RESULTS

Study Population

A total of 350 students (29% of eligible) provided assent and consent to participate in the asthma management program, of which 314 completed a baseline survey. Data from the screening survey showed that, compared to nonparticipating students, students participating in the program were significantly more likely to have a physician diagnosis of asthma, be female, have missed school in the last 30 days, as well as be significantly more likely to be classified as having mild, persistent asthma. A corresponding caregiver baseline survey was available for 215 of those students. Demographic characteristics of the study population are presented in Table 1.

Questions Related to the Adolescent's Asthma

Table 2 presents descriptive statistics and results of agreement analyses for equivalent questions about the adolescent's asthma. The level of agreement between adolescent and caregiver responses to questions about the adolescent's asthma varied across domains. Correlations between adolescent and caregiver reports related to medical history were moderate ($r_s=0.56-0.60$) and statistically significant. The kappa coefficient for the item concerning physician diagnosis was 0.31 ($p<0.001$), indicating a fair level of agreement. The correlations between self- and proxy-reports of daytime and nighttime asthma symptoms and functional status, however, were weak ($r_s=0.16-0.22$) but statistically significant. Results of paired t tests for the items concerning medical history, symptoms, and functional status were not significant. Moderate ($r_s=0.35-0.48$), statistically significant correlations were found between adolescent and caregiver reports of hospitalizations, emergency department visits, and physician visits. Results of paired t tests for indicated differences between caregiver and adolescent responses were significant only for responses to the question about asthma-related hospitalizations. We also assessed congruence in two subgroups—those meeting criteria for current asthma versus those with symptoms suggesting probable asthma, but no significant differences were found (results not shown).

Factors Influencing Congruence for Reports of Symptoms and Functioning

Descriptive statistics and bivariate associations between personal, familial, and clinical factors and congruence between adolescent-caregiver reports of asthma symptoms and functional status are presented in Table 3. Adolescent and caregiver reports of symptoms and functioning were more likely to be congruent if the adolescent was older, had less severe asthma, and if greater household income was reported. Greater congruence between reports was also significantly related to the adolescent not having an emergency department visit for asthma within the past 12 months, less frequent rescue inhaler use, the adolescent indicating their asthma is less serious, and reporting school personnel not being aware of the adolescent's asthma.

Table 4 describes the results of the logistic regression analysis. Adolescent-caregivers dyads were more than six times as likely (odds ratio [OR] 6.01; 95% confidence interval [CI] 2.41, 14.98) to be in agreement in cases where the severity of the adolescent's asthma was classified as mild intermittent. Adolescents and caregivers were also more likely to agree if the adolescent was 15 years of age or

TABLE 1 Respondent sociodemographic characteristics

Adolescent mean age in years (SD), <i>n</i> =213	15.3 (0.97)
Adolescent gender, <i>n</i> =215 (%)	
Girls	137 (63.7)
Boys	78 (36.3)
Adolescent grade in school, <i>n</i> =220 (%)	
Grade 9	84 (39.8)
Grade 10	74 (35.1)
Grade 11	55 (24.1)
Grade 12	2 (1.0)
Adolescent race, <i>n</i> =211 (%)	
African-American	192 (91.0)
Other	19 (9.0)
Adolescent smoking status, <i>n</i> =212 (%)	
Current smoker	11 (5.2)
Former smoker/tried smoking	79 (37.2)
Never smoked	122 (57.6)
Physician diagnosis of asthma, <i>n</i> =212 (%)	
Yes	141 (66.5)
No	71 (33.4)
Adolescent asthma severity, <i>n</i> =212 (%)	
Mild intermittent	115 (54.3)
Mild persistent	32 (15.1)
Moderate persistent	25 (11.8)
Severe persistent	40 (18.9)
Caregiver relationship to child, <i>n</i> =212 (%)	
Mother	172 (81.1)
Grandparent	17 (8.0)
Other	23 (10.9)
Caregiver education, <i>n</i> =214 (%)	
Did not complete high school	33 (15.4)
Completed high school	81 (37.8)
Some college	65 (30.4)
Completed college	35 (16.4)
Caregiver current smoker, <i>n</i> =214 (%)	
Yes	71 (31.4)
No	155 (68.6)
Household history of asthma, <i>n</i> =215 (%)	
Adults with asthma in the household	
Yes	81 (37.7)
No	134 (62.3)
Multiple children with asthma in the household	
Yes	69 (32.1)
No	146 (67.9)
Household income, <i>n</i> =198 (%)	
\$0–15,000	60 (30.3)
\$15,001–20,000	32 (16.1)
\$20,001–30,000	35 (17.7)
\$30,001 and above	71 (35.9)

Asthma diagnosis information based on parent report

TABLE 2 Descriptive statistics and response agreement for items concerning the adolescent’s asthma

Item	n (pairs)	Adolescent response	Caregiver response	Agreement between responses	
		M (SD)	M (SD)	Spearman rho	Paired t test ^c
Asthma medical history					
Age asthma symptoms began	193	6.68 (5.4)	6.76 (4.9)	0.56***	−0.07
Physician diagnosis ^a	191	143 (73.7) ^b	141 (66.5) ^b	0.31***	—
Age at diagnosis	120	5.86 (5.4)	5.92 (4.3)	0.60***	−0.06
Asthma symptoms past 30 days					
Daytime asthma symptoms	213	6.01 (7.2)	5.87 (8.0)	0.22**	0.14
Nighttime asthma symptoms	207	3.38 (6.0)	3.70 (6.6)	0.16**	−0.32
Functional status past 30 days					
Slowed down/stopped activities	206	5.64 (7.7)	5.28 (7.8)	0.19**	0.35
Changed plans due to asthma	212	1.92 (4.5)	1.32 (3.6)	0.17*	0.59
Health care use past 12 months					
Asthma-related hospitalizations	167	0.63 (2.0)	0.16 (0.6)	0.40***	0.48***
Asthma-related ER visits	213	1.00 (2.7)	0.75 (1.5)	0.48***	0.25
Asthma-related doctor visits	194	1.68 (3.0)	2.01 (2.8)	0.48***	−0.34
All doctor visits	212	3.72 (4.6)	3.71 (4.4)	0.35***	0.00

* $p \leq 0.05$; ** $p < 0.01$; *** $p < 0.001$
^aAgreement assessed using kappa
^bn (%) reporting “yes”
^cMean(diff) = mean(adolescent report – caregiver report)

older (OR 4.62; 95% CI 1.59, 13.32) and if school personnel were not aware of the child’s symptoms (OR 2.34; 95% CI 1.05, 5.17).

DISCUSSION

We examined congruence between the responses of urban adolescents and their caregivers to questions about the adolescent’s asthma in this study. Congruence between adolescent and caregiver reports related to the adolescent’s asthma-related medical history was moderate and did not differ significantly at the individual or aggregate level. The generally weak correlations between adolescent and caregiver reports of asthma symptoms and functional status support the notion that adolescents and caregivers report different information in these domains. Significant associations between adolescent and caregiver reports of health care use were found, although differences were noted at the aggregate level for asthma-related hospitalizations.

The moderate correlations around the asthma-related medical history items were somewhat higher than expected. Generally occurring during early childhood, symptom onset or diagnosis may be a perceptually distinct event for caregivers and therefore easier to recall with accuracy. Researchers have suggested that the accuracy of children’s reports of their medical history is questionable.¹⁴ It is possible that completion of the screening questionnaire and/or some aspect of the informed

TABLE 3 Correlates of adolescent–caregiver congruence for symptoms and functional status items

Variable	Agree, <i>n</i> = 50 (24.6%)	Disagree, <i>n</i> = 153 (75.3%)	χ^2
Adolescent age			5.53*
<15	6 (12)	43 (28.5)	
≥15	44 (88)	108 (71.5)	
Adolescent gender			0.06
Boys	17 (34.5)	55 (36)	
Girls	33 (65.5)	98 (64)	
Adolescent race/ethnicity			0.97
African-American	7 (94)	133 (89.3)	
Other	3 (6.0)	16 (10.7)	
Asthma diagnosis			0.01
Physician diagnosis	33 (67.4)	101 (66.4)	
No diagnosis, but current symptoms	16 (32.6)	51 (33.6)	
Asthma severity classification			27.04***
Mild intermittent	43 (86)	67 (43.8)	
More severe	7 (14)	86 (56.21)	
Adolescent grade in school			2.62
<Grade 10	15 (30)	64 (43)	
≥Grade 10	35 (70)	85 (57)	
Adolescent smoking status			3.46
Current/former smoker or tried smoking	15 (30.6)	69 (45.7)	
Never smoked	34 (69.4)	82 (54.3)	
Caregiver education			2.39
≤High school	22 (44)	66 (43.4)	
>High school	28 (56)	86 (56.6)	
Caregiver current smoker			0.30
Yes	15 (30)	52 (34.2)	
No	35 (70)	100 (65.8)	
Adults with asthma in the home			0.06
Yes	19 (38)	55 (36)	
No	31 (62)	98 (64)	
Other children with asthma in home			0.03
Yes	16 (32)	47 (30.7)	
No	34 (68)	106 (69.3)	
Household income			4.41*
<\$20,001	15 (32.6)	72 (50.4)	
≥\$20,001	31 (67.4)	71 (49.6)	
Household size			1.21
<5 members	31 (62)	78 (53)	
≥5 members	19 (38)	69 (47)	
Parental knowledge of whereabouts			0.01
Low/moderate	26 (55)	78 (51)	
High	24 (48)	75 (49)	
Caregiver relationship to child			0.13
Mother	30 (73.2)	123 (75.9)	
Other	11 (26.8)	39 (24.1)	
ER visits during past 12 months			7.89**
Yes	9 (18.4)	61 (40.4)	
No	40 (81.6)	90 (59.6)	

TABLE 3 (continued)

Variable	Agree, <i>n</i> = 50 (24.6%)	Disagree, <i>n</i> = 153 (75.3%)	χ^2
Rescue medicine use			11.27***
≥2 times per week	7 (14.6)	62 (41.1)	
<2 times per week	41 (85.4)	89 (58.9)	
Beliefs about asthma seriousness			9.32**
Very serious/serious	11 (22)	71 (46.4)	
Other	39 (78)	82 (53.6)	
School aware of adolescent's asthma			7.18**
Yes	13 (26.5)	73 (48.3)	
No/do not know	36 (73.5)	78 (51.7)	

Asthma diagnosis information based on caregiver report
p*<0.05; *p*<0.01; ****p*<0.001

consent process may have prompted discussion of the adolescent's medical history within the family and encouraged agreement between their responses.

The differences between the reports of asthma symptoms and functioning at the individual level indicate adolescent and caregiver reports are not interchangeable, consistent with the results of previous studies.¹⁵ A number of factors were found to influence the level of congruence between these reports, such as older age of the adolescent. Some research has suggested that relationships between older adolescents and their parents become more intimate and less conflicted than those of younger adolescents and parents, i.e., easier flow of communication.¹⁶ Much of parents' knowledge of their adolescent's day-to-day experience with asthma is likely to depend not on direct observation but on word-of-mouth communication. Additionally, the quality of data has been shown to increase with the cognitive growth of respondents.¹⁷ Greater communication between older adolescents and caregivers coupled with increasing similarity of their cognitive abilities may account for the improved convergence of reports found in this study.

Congruence between reports was strongly related to the adolescent having a severity classification of mild, intermittent asthma and was improved when the adolescents reported their teachers did not know about their disease, which may also reflect infrequent symptoms. We hypothesize that, compared to adolescents with persistent asthma, symptoms experienced by those with less severe asthma or whose asthma that is generally well controlled may be more salient and could prompt increased levels of discussion with caregivers when symptoms occur.

Previous research has demonstrated that caregivers have good recall for acute health care events involving their children.¹⁸ Caregivers and adolescents likely

TABLE 4 Multivariate logistic regression for odds of agreement between responses to symptoms and functional status items (*n*=196)

Variable	OR	<i>p</i>	95% CI
Adolescent ≥15 years old	4.62	0.005	1.59, 13.32
School personnel unaware of child's asthma	2.34	0.04	1.05, 5.17
Asthma severity = mild intermittent	6.01	0.000	2.41, 14.98
Rescue inhaler use ≤2 times per week	2.32	0.08	0.89, 6.05

experience some aspect of health care use events together, which may contribute to the greater convergence of reports we found for these items. Survey methodology research has shown that, as the level of joint participation in an event increases, the convergence between self- and proxy-reports increases.^{1,19} Information based on an individual's actual experiences receives more elaboration during the memory encoding process, resulting in easier retrieval relative to knowledge acquired secondhand.^{20,21} Furthermore, episodic information for less frequent "stand-out" events (e.g., health care use) is likely more accessible to memory, resulting in more accurate (or more congruent) reporting.^{22,23}

An important question for both clinicians treating asthma and asthma researchers is who holds the most accurate information about an adolescent's experience. Present results suggest that when clinicians or researchers require information regarding an adolescent's experience of asthma symptoms and functioning, the reports of adolescents and their caregivers are not equivalent. Adolescents may be uniquely positioned to provide information in these domains, given that with age comes greater independence and less obligation to "report" to caregivers about events and circumstances, including those related to asthma. Previous small studies found that child or adolescent reports of symptoms correlated with physiological measures of lung function, whereas parent reports did not.^{4,24} More research, however, seems needed to understand the relationship between adolescent and caregiver proxy-reports and the relative accuracy or predictive value of the reports obtained. Identification of ways to frame questions to adolescents that can result in accurate descriptions of their asthma-related health status or the degree to which asthma impinges on daily functioning is also an important avenue for future research.

The most notable limitation of this study is that only measured agreement was used, and outside validation measures, such as lung function, were not. Additionally, since this study was based on secondary analysis of existing data, variables not collected from participants (e.g., whether adolescents and caregivers interpreted questions similarly to each other) may have provided insight into the quality or congruence between their reports. Furthermore, different modes of interviewing were used to gather data from adolescents (ACASI) and caregivers (telephone). Among the differences that may be attributed to mode of interview, a general finding across a wide variety of studies is that self-administered questionnaires obtain increased levels of reporting of sensitive information (e.g., smoking) when compared to interviewer-administered questionnaires.²⁵ Finally, given that adolescents represent only 29% of those eligible for the educational program and differ from nonparticipants in reported symptom frequency, results are generalizable only to populations with characteristics similar to those included in our analysis.

Conclusion

Findings from this study suggest that when adolescents and their caregivers are asked about the adolescent's asthma in clinical and research settings, the extent to which their reports diverge depends on the type of information sought. Adults and youth are less likely to agree when asked about the adolescent's asthma-related symptoms and functioning, compared to the adolescent's health care use or asthma-related medical history. Clinicians and researchers may obtain more accurate information if questions about symptoms and functional status are directed toward adolescents. Congruence between reports of symptoms and functioning was associated with personal and other factors (e.g., adolescent age, disease severity),

and these factors may guide the selection of informants for research and be considered by clinicians in history taking and patient counseling.

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