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Agreement Between Teenager and Caregiver Responses to Questions About Teenager's Asthma

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Abstract

It is unknown if teenagers and caregivers give similar responses when interviewed about the teen's asthma. We analyzed data for 63 urban African-American teen-caregiver pairs. Caregivers underestimated teen smoking by 30%, gave lower estimates for teen exposure to passive smoke, and disagreed with teens on controller medication usage. Teen-caregiver responses were not significantly different for estimates of symptom-days, activity limitations, or nights awakened; nor were they significantly different for report of emergency department visits or hospitalizations. Agreement was weak for perceived asthma control and severity. Teen-caregiver agreement on asthma depends on the type of information being sought.

Keywords

adolescents; asthma; kappa statistic; teenagers; urban

Introduction

Asthma is a chronic respiratory disease affecting over 30 million persons in the United States (1). According to the 2001 National Health Interview Survey, asthma is among the leading chronic diseases of childhood, with an estimated prevalence of 87/1000 for children 0 to 17 years of age (2). The burden from asthma in the US, as reflected by emergency department (ED) visits, hospitalizations, and deaths, increased dramatically during the period 1980 to 1999, but recently these rates seem to be on the decline (1,2). Despite these overall national declines, racial disparities in asthma-related morbidity and mortality persist, with 2001 hospitalization and mortality rates for African Americans that are 125% and 200% higher than that of Caucasians, respectively (1).

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Asthma remains a leading chronic disease throughout adolescence (1–3). The annual asthma death rate in 1999 for the age group incorporating teenagers ≥ 15 years (15–34 years) was four times that for children 0 to 4 and was 60% higher than that of 5- to 14-year olds (2). In Detroit, 2000 asthma death rates for teenagers 15 to 19 years of age were 3.5/100,000 compared with 1.9 per 100,000 for children 0 to 14 years (4). National and local data sources confirm that the majority of asthma deaths among teens have occurred in minorities and in those of lower socioeconomic status (1–6).

Research that would inform development of asthma management programs targeting urban teenagers is needed. In one study, urban children with asthma assumed the responsibility of managing their condition at or before the onset of adolescence (7). Information on the concerns and obstacles faced by teenagers with asthma, especially those residing in US urban communities, is limited.

Investigators targeting teenagers with asthma are faced with the decision of whether to interview the teenager, their caregivers, or both when collecting data for analysis. Researchers may be reticent to rely on information taken solely from the teenager. Adolescence is a difficult time for many teens as they struggle to develop personal identities and independence from parents (8). The desire to fit in may lead teens to under-manage their asthma and/or deny asthma symptoms (8). Teenagers are less likely than younger children to share experiences with caregivers, and this may limit caregiver knowledge of the teen's day-to-day asthma management.

Using data previously collected from urban African American teenagers with asthma, the objective of this analysis was to compare teen and caregiver responses to an interviewer-administered questionnaire about the teen's asthma. We hypothesized that responses of the teenager would not differ significantly from that of their caregiver regarding teen behaviors, functional status, and asthma-related morbidity. Results of this analysis can help researchers plan data collection strategies for studies involving urban teens with asthma.

Materials and Methods

The methods of this study were approved by the Institutional Review Boards of Henry Ford Health System (HFHS) and Children's Hospital of Michigan (CHM). This study population was initially recruited to pilot a randomized trial of an asthma management program designed for urban teenagers. A list of African American patients, born between 6/30/1980 and 12/31/1983, and making at least 1 ED visit for asthma to the HFHS Downtown Campus, between 1/1/1995 and 2/1/1998, was obtained using hospital billing databases. Introductory letters explaining the program were sent to the designated caregiver (parent or guardian) of each eligible patient. Letters were followed up with a telephone call to request participation and schedule a baseline appointment. Patients were recruited consecutively, beginning with those who had visited most recently. Recruitment began in November 1997 and continued through May 1998.

Baseline interviews for teens and caregivers occurred at HFHS. Transportation to and from the interview was provided as needed. Teenagers and their caregivers were interviewed separately; however, the same staff person conducted both interviews.

Baseline interviews included questions on basic demographics, teen smoking ("Do you currently smoke cigarettes?"), teen exposure to environmental tobacco smoke (ETS) in the home ("Do one or more persons living in your home smoke cigarettes?"), perceived control (controlled versus not controlled), perceived severity of teen's asthma (mild, moderate, severe), teen's functional status (symptom-days, days of restricted activity in the last 2 weeks, and nights of disrupted sleep due to asthma symptoms), and teen's asthma morbidity (ED visits

and hospitalizations). Respondents were asked to list all of the asthma medications currently being used by the teen for asthma. This line of questioning focused on prescriptions for controller or anti-inflammatory medications. Respondents were asked specifically about each of the controller medications listed. Pictures of controller medications were available to aid respondent identification. Controller medications included inhaled corticosteroids, nedocrimil, cromolyn, and leukotriene modifiers.

To estimate the socioeconomic level of our study population, a geographic information system (GIS), a computer mapping and analysis technology capable of linking geographic with demographic information, was used in conjunction with patient address and census data. Each study participant was assigned the average household income based in the block-group of residence (a subdivision of a census tract representing a city block) (9).

Analysis

The strength of agreement between teen and caregiver responses to categorical variables was compared by calculating a kappa statistic and computing the corresponding 95% confidence interval (95%CI). McNemar's test was used to test for symmetry in 2 × 2 tables, and Bowker's test was used to check for symmetry in 3 × 3 tables (10). To assess agreement on controller medications, we determined the percentage of teen-caregiver pairs that agreed on the exact controller medication(s) used in the past year and when the medication was last used (i.e., within the last 7 days or more than 7 days ago). A 95% confidence interval was calculated for these percentages. A paired *t* test was used to test agreement between teen and caregiver reports for continuous variables (functional status and asthma morbidity), and the difference in means was computed. The association of teen/caregiver report of functional status and asthma morbidity to perceived severity was determined using a Wilcoxon or Kruskal-Wallis rank sum test for non-normal data.

We restricted all analyses to teen-caregiver pairs, excluding teen responses when there was not a corresponding response from the caregiver and vice-versa. "Don't know" responses were not included in the statistical testing. For the purposes of our analysis, we considered agreement to be excellent when kappa ≥ 0.75; very good when kappa = 0.40–0.75; and poor when kappa ≤ 0.40.

Results

A total of 74 African American teenagers were contacted, of which 63 (85%) completed a baseline interview. The majority (82.5%) of caregivers participating were mothers. Table 1 shows the demographic characteristics of the 63 teens completing a baseline interview. With the exception of Medicaid enrollment and median household income, variables in this table were based on the teenager's report. A total of 68.2% of the study population were between the ages of 15 to 16 years, with a mean age at baseline of 16.5 (S.D. 0.7). Almost 48% of participants were male. A total of 43.3% of participating teens were Medicaid enrollees. The mean median income for participants completing the baseline was $28,877 ($6,134), range $17,893 to $45,053. According to GIS coding, the median annual household income category for the majority of teenagers in our study was $25,000 to $34,999 (Table 1). Smoking was reported by 14.3% of teens, and 58.7% reported living in a household with at least one smoker. Over 75% of teens reported an ED visit, and 19% reported a hospitalization for asthma in the past 12 months. Only 17.5% of teens reported seeing a specialist in the past 12 months.

Table 2 presents agreement between teen and caregiver for study variables. About 15% of teens responded "yes" to the question about currently smoking cigarettes, compared with 10.2% of caregivers, kappa = 0.62 (0.32–0.92);$p < 0.01$. A total of 6.8% of caregivers responded negatively about their teen's smoking, despite a positive response from the teen, McNemar's

$p = 0.18$. For ETS, 58.1% of teens reported at least one adult smoker at home compared to 41.9% of care-givers, kappa = 0.43 (0.22–0.64); $p < 0.01$.

A current prescription for at least one asthma controller medication was reported by 29 teen-caregivers pairs or 52.4% of teens and 41.9% of caregivers. Of these, 9 pairs agreed on the exact medication used (e.g., Azmacort, Kos Pharmaceuticals, Inc., Cranbury, NJ) and agreed within 7 days as to when the teen last took the medication. Considering the 24 teen-caregiver pairs that agreed the teen was not on controller medication, the overall percentage of teen-caregiver pairs in agreement for this item was 33/63 or 52.4% (95%CI = 40.1%–64.7%).

More teens felt that their asthma was well-controlled compared to their caregivers, 77.4% for teens versus 67.7% for caregivers, kappa = 0.28 (0.03–0.53);$p = 0.02$. Almost 20% of caregivers felt the asthma was not controlled, while their teen felt otherwise (McNemar's $p = 0.16$).

Perceived severity was assessed as a 3 × 3 table with response categories of mild, moderate, and severe. In general, the teen's perceived their asthma to be milder than what their caregivers perceived; 57.4% of teens felt their asthma was mild, compared to 45.9% of caregivers, kappa = 0.19 (0.0–0.39); $p < 0.07$. The percentage of caregivers reporting moderate severity for the teen's asthma when the teen reported mild was 19.7%, whereas 3.3% of the caregivers reported severe when the teen reported mild (Bowker's $p = 0.08$).

Table 3 shows the teen-caregiver agreement for the teen's functional status and asthma- related morbidity. Mean differences for these variables were relatively small and all p values were more than 0.05. Number of symptom-days in the past 2 weeks had the largest mean difference of −1.0 with a corresponding p value of 0.08. Since ED visits and hospitalizations are fairly rare, we also assessed teen-caregiver agreement for these items as categorical variables (data not shown). The kappa for teen-caregiver agreement for ≥1 ED visit in the last 12 months was 0.50, 95%CI = 0.25–0.76; $p < 0.01$ and 0.73 for ≥ 1 hospitalization in the last 12 months, 95% CI = 0.51–0.95; $p < 0.01$.

We also examined controller medication use, functional status, and asthma morbidity in relation to perceived severity (Table 4). These assessments were limited due to small sample size, i.e., only 1 teenager perceived their asthma as severe, and was not included in this portion of the analysis. Agreement for prescribed controller medication and last use of medication did not differ by perceived asthma severity (data not shown). For teen respondents, report of symptom-days increased with increasing perceived severity ($p = 0.01$). Increases in days of restricted activity and nights of disrupted sleep increased when progressing from mild to moderate perceived severity ($p = 0.11$ and 0.06, respectively). No significant trends for ED visits and hospitalizations were observed with progressing perceived severity among teenagers. For caregivers, reports of days of restricted activity ($p = 0.04$) and nights of disrupted sleep ($p = 0.04$) increased significantly when progressing from mild to moderate perceived severity. Significant increases in ED visits ($p < 0.01$) and hospitalizations ($p < 0.001$) were also observed for caregiver perceptions of progressing asthma severity (Table 4).

Discussion

We report teen-caregiver agreement for information collected about the teen's asthma during an interviewer-administered questionnaire. We hypothesized that adolescents 15 to 18 years of age would have responses that were similar to that of their caregivers. We found this to be generally true for estimates of functional status and morbidity, but not true for medication use and for perceived severity and control.

Although agreement for teen smoking was very good, as might be expected, some caregivers were apparently unaware of their teen's smoking. Our results suggest that asking parents about their teen's smoking may result in an underestimate by about 30%.

The prevalence of smoking among youth in grades 9 to 12 has declined in the past 8 years, but smoking among teenagers with asthma has emerged as a potentially important disease management issue (11–14). Several publications cite smoking prevalence rates among adolescents with asthma higher than that of their non-asthma counterparts (13,14). One US study found that students 15 to 18 years of age with asthma were 1.5 times more likely to smoke than peers without asthma (12).

Teen smoking patterns exhibit more variability in rate and frequency when compared to that of adults (15). Accuracy of data on teen smoking behavior can be improved by requesting the number of cigarettes smoked over a specific period of time. This would also allow better comparison across studies (11). More information is needed to determine the effect of teen smoking behavior on the teen's asthma morbidity.

Our results suggest that caregivers may be reluctant to admit to household ETS. Caregivers may underreport ETS due to feelings of guilt about this behavior as a likely cause of symptoms (16,17). Exposure to ETS has been cited as a major trigger of acute exacerbations, and previous estimates suggest that 60% of Detroit elementary school children with asthma are exposed to ETS at home (18,20). Teens may be less affected by societal and medical disapproval of ETS, but we cannot rule out the possibility that teen reports are inaccurate. When validation with biological specimens is not within the scope of the study, our data suggest that the source of information on household smoking should be considered (19).

In our study, only about half of teens and their caregivers were able to agree on the exact controller medication prescribed (or no prescribed controller medication) and the last time the medication was used. Without other studies for comparison, these results are difficult to interpret but suggest that medications are difficult for teens and caregivers to remember or identify, even with color memory aids. Shorter recall may improve agreement on usage. Recall periods of 2 weeks and 30 days have been used previously (20–23). As mentioned previously, caregivers may be unaware of teen use of medication.

Functional status is one measurable aspect of quality of life (23). Teen and caregiver reports of functional status were similar, but teens estimated slightly fewer symptom-days and nights of disrupted sleep in the last 2 weeks than caregivers. Teens may underestimate symptoms because of denial or perceived stigma (9). Alternatively, caregivers may overestimate symptom frequency when questioned. In an Italian study of adolescent (13 to 14 years) and parent responses to the international study of asthma and allergies in childhood (ISAAC) questionnaire, it was the parent responses, not those of the teenager, that were more likely to be influenced by family history, socioeconomic status, and diagnosis of asthma (24). The authors concluded that obtaining information directly from adolescents was acceptable for an accurate evaluation of respiratory disorders (24).

Teens and caregivers also gave similar estimates for ED visits and hospitalizations due to asthma, although teen estimates again were slightly lower. Although researchers try to avoid using health care utilization as a measure of asthma severity due to potential confounding with disease management, the frequency of attacks requiring medical attention are often used as an indicator of asthma that is uncontrolled (25). Since ED visits and hospitalizations are fairly rare events, a dichotomized measure (e.g., ≥ 1 ED visit versus none) may be appropriate for some projects.

Agreement was weak for teen-caregiver perceptions of asthma severity and control, indicating potential dissimilarities in illness perception. Classification by asthma severity is used in epidemiologic research to describe the study population, and risk estimates are often stratified by some indicator of severity (20,26–28). Providers also have difficulty translating Expert Panel II guidelines, and must interpret terms such as “frequent” and “continual” (25). One-or two-day discrepancies in estimates of daily symptoms can result in a classification shift (25, 29). One suggestion for better agreement on severity would be to ask more direct questions such as number of prescription refills and days in which rescue medication was needed (e.g., Rules of Two™, Baylor Health Care System, Dallas, TX) (30).

We noted that in describing the teen’s asthma severity, care-givers were more likely to select the extremes (mild or severe), while teens were more likely to select mild or moderate. Whether teens avoided the category of severe because of perceived stigma associated with asthma or because they underestimate the true seriousness of the condition cannot be determined in this analysis. Denial of disease severity by teens may lead to poorer asthma management, which contributes both directly and indirectly to asthma morbidity (9,26,27).

Perceptions of severity were significantly related to reported functional status and morbidity for caregivers, with the exception of symptom-days. A trend toward increasing functional impairment and morbidity with increasing severity was suggested for teens, but was not significant for three of the five variables. Elimination of the “severe” category due to small sample size hampers interpretation of teen responses for perceived severity. For both respondent groups, distinctions in levels of morbidity were less evident between the moderate and severe categories, indicating that boundaries for these categories are difficult for respondents to conceptualize. The similar reports of morbidity and functional status for teens and caregivers seem to suggest that the problem lies with respondent difficulty in determining what constitutes “moderate” or “severe”, as opposed to the respondent’s ability to accurately recall symptom-days, etc.

Disagreement between patient report of symptoms and measures of airway obstruction has been reported (31,32). In a small study of 52 children and their parents, correlations between the child’s global rating of change in symptoms, airway caliber and asthma control were higher for children 11 to 17 years of age than that of their parents’ global ratings (31). In a Chinese study of almost 2,000 children, 8 to 12 years of age, there was little difference between reports of respiratory illness experiences (diagnosis of asthma or bronchitis, and frequency of cough, phlegm, and wheeze in the past 12 months) between parents and children in terms of their association with lower lung function. The authors recommended that administering respiratory questionnaires to children 10 years of age and older would be appropriate (33).

The major limitation of this analysis is that respondent reports from either source cannot be validated (34). In addition, “excellent” agreement (kappa ≥ 0.75) was not observed for any item, and our interpretation of good or poor agreement may differ from that of other researchers (10). Our sample size and method of recruitment limit generalizability of our results to urban African American teenagers with asthma who share the same sociodemographic characteristics and health care utilization patterns as that of our study participants. Also, since teenagers in our study were recruited from ED listings, they are more likely to have persistent disease. Results may differ for teens with mild, intermittent asthma.

Our results are similar to previous publications on child-parent agreement for factors related to the child’s chronic illness, in that strength of agreement depends on the type of information sought (31–34). Information on teen smoking should be collected from the teen, as caregivers may be unaware of this behavior. Researchers should consider short recall periods and confirmation of medications prescribed and used. Information collected from the teen on

asthma-related functional status and health care utilization should not differ appreciably from that of caregivers, but teen estimates will be more conservative. Finally, where social acceptability is likely to influence caregiver answers, teen responses may reduce the probability of exposure misclassification. Our findings also underscore the importance of exploring the adolescent's concept of severity and control when designing education programs with the goal of improving asthma self-management.

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Table 1

Demographic characteristics of a sample of urban African American teenagers with asthma (n = 63).

Characteristic	N	(%)
Age		
15–16	43	(68.2)
17–18	20	(31.8)
Sex		
Male	30	(47.6)
Female	33	(52.4)
Medicaid Enrollee	26	(43.3)
Median household Income		
≤ 24,999	17	(27.0)
25,000–34,999	37	(58.7)
≥ 35,000	9	(14.3)
≥ 1 ED visit in last 12 months	48	(76.2)
≥ 1 Hospital visit in last 12 months	12	(19.0)
Report using controller medication*	33	(52.4)
Smoker	9	(14.3)
Living with ≥ 1 smoker	37	(58.7)
Seen specialist for asthma in last 12 months	11	(17.5)

* Controller medications include anti-inflammatory medication, including leukotriene inhibitors; does not include methylxanthines.

Table 2

Teen-caregiver responses to selected questions about teen's asthma in a sample of urban African American teenagers with asthma.

	Caregiver response									
	Yes		No		Total					
Teen response	**n**	**(%)**	**n**	**(%)**	**N**	**(%)**	**Kappa**	**95% CI**	***P****	***P*+**
Teen smoker (59 pairs)										
Yes	5	8.5	4	6.8	9	15.3	0.62	0.32–0.92	<0.01	0.18
No	1	1.7	49	83.0	50	84.7				
Total	6	10.2	53	89.8	59	100.0				
ETS exposure (62 pairs)										
Yes	22	35.5	14	22.6	36	58.1	0.43	0.22–0.64	<0.01	0.02
No	4	6.4	22	35.5	26	41.9				
Total	26	41.9	36	58.1	62	100.0				
Asthma controlled (62 pairs)										
Yes	36	58.0	12	19.4	48	77.4	0.28	0.03–0.53	0.02	0.16
No	6	9.7	8	12.9	14	22.6				
Total	42	67.7	20	32.3	62	100.0				
	Mild		Moderate		Severe		Total			
	n	(%)	*n*	(%)	*n*	(%)	*N*	(%)		
Asthma severity (61 pairs)										
Mild	21	34.4	12	19.7	2	3.3	35	57.4	0.19	0.0–0.39	0.07	0.08†
Moderate	7	11.5	12	19.7	6	9.8	25	41.0				
Severe	0	0	1	1.6	0	0	1	1.6				
Total	28	45.9	25	40.8	8	13.1	61	100.0				

* *p* value for Kappa statistic.

\+ *p* value for McNemar's test.

† *p* value for Bowker's test.

Table 3

Teen-caregiver responses to selected questions about teen's asthma morbidity for a sample of urban African American teenagers with asthma.

	Teen-Caregiver pairs	Teen response			Caregiver response					
	N	Mean	(S.D.)	Range	Mean	(S.D.)	Range	Mean diff.	(S.D.)	p
Functional status										
Symptom-days (2 weeks)	61	2.6	(3.5)	0–14	3.6	4.4	0–14	−1.0	(4.4)	0.08
Days restricted activity (2 weeks)	61	1.7	(3.0)	0–14	1.3	1.8	0–7	0.4	(3.0)	0.28
Nights disrupted sleep (2 weeks)	57	0.9	(1.7)	0–7	1.2	2.8	0–14	−0.3	(3.2)	0.51
Utilization										
ED visits (12 months)	61	2.2	(3.1)	0–20	2.5	3.9	0–28	−0.2	(2.5)	0.45
Hospitalizations (12 months)	61	0.3	(0.7)	0–4	0.4	1.1	0–7	−0.1	(0.9)	0.32

Table 4

Teen-caregiver reports of functional status and asthma morbidity by perceptions of severity for a sample of urban African American teenagers with asthma.

	Teen Perception of Severity						
	Mild (*n* = 37)		**Moderate (*n* = 25)**		**Severe (*n* = 1)**		
	Mean (S.D.)	**Median**	**Mean (S.D.)**	**Median**	**Mean (S.D.)**	**Median**	***p*[a]**
Teen response							
Functional status							
Symptom-days (2 weeks)	1.9 (3.1)	1.0	3.5 (3.8)	2.0	5.0	—	0.01
Days restricted activity (2 weeks)	1.4 (2.7)	0.0	2.4 (3.4)	2.0	2.0	—	0.11
Nights disrupted sleep (2 weeks)	0.5 (1.4)	0.0	1.3 (1.9)	0.0	1.0	—	0.06
Utilization							
ED visits (12 months)	2.2 (3.6)	1.0	2.2 (2.2)	2.0	5.0	—	0.46
Hospitalizations (12 months)	0.2 (0.5)	0.0	0.5 (1.0)	0.0	0.0	—	0.35
	Caregiver Perception of Severity						
	Mild (*n* = 28)		Moderate (*n* = 25)		Severe (*n* = 8)		
	Mean (S.D.)	Median	Mean (S.D.)	Median	Mean (S.D.)	Median	*p*[a]
Caregiver response							
Functional status							
Symptom-days (2 weeks)	2.6 (3.8)	1.0	4.2 (4.6)	3.0	3.8 (3.9)	2.5	0.10
Days restricted activity (2 weeks)	0.8 (1.5)	0.0	1.4 (1.7)	1.0	2.6 (2.6)	2.0	0.04
Nights disrupted sleep (2 weeks)	0.3 (0.8)	0.0	1.8 (3.3)	0.0	1.1 (1.8)	0.0	0.04
Utilization							
ED visits (12 months)	1.3 (1.4)	1.0	3.6 (5.8)	2.5	3.5 (1.8)	3.0	<0.01
Hospitalizations (12 months)	0.1 (0.5)	0.0	0.2 (0.5)	0.0	1.9 (2.4)	1.5	<0.001

[*] *p* values based on Wilcoxon rank sum test for non-normal data and is based on mild vs. moderate due to inadequate sample size (n = 1) for the severe category.

[†] values based on Wilcoxon rank sum test for non-normal data.