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Factors associated with adolescent and caregiver reported problems in using asthma medications

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Abstract

Objectives: The purpose of this study was to: (a) describe the types of medication problems/concerns youth with asthma and their caregivers reported and (b) examine the association between

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Declaration of Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the article.

socio-demographic characteristics and youth and caregiver reported medication problems/concerns.

Methods: English-and Spanish-speaking youth ages 11–17 with persistent asthma were recruited at four pediatric clinics. Youth were interviewed and caregivers completed questionnaires about reported asthma medication concerns/problems. Multiple logistic regression was used to analyze the data.

Results: Three hundred and fifty-nine youth were recruited. Eighty percent of youth and 70% of caregivers reported one or more problems in using asthma medications. The most commonly reported problems by youth were: (a) hard to remember when to take the asthma medication (54%) and (b) hard to use asthma medication at school (34%). Younger children were significantly more likely to report difficulty in understanding their asthma medication's directions and difficulty reading the print on the medication's package. Caregivers' top-reported problem was that it is hard for their child to remember to take their asthma medications (49%). Caregivers without Medicaid were significantly more likely to express difficulty paying for their child's asthma medications.

Conclusions: Difficulty remembering to take asthma medication was a significant problem for youth and their caregivers. Providers should work with youth and their caregivers to identify asthma medication problems and discuss strategies to address those problems.

Keywords

asthma; medications; youth; caregivers; problems; adolescents

Introduction

Among children ages 5 to 17, asthma is the leading cause of school absences from a chronic illness[1]. Asthma accounts for an annual loss of more than 14 million school days per year and more hospitalizations than any other childhood disease[1]. Additionally, poorly controlled asthma can impair an adolescent's psychological, emotional, and social quality of life by limiting their ability to engage in normal daily activities[2, 3].

Asthma exacerbations can be prevented with appropriate care, which often involves the use of medications[4]. However, prior research has found that both youth and their caregivers have reported problems or concerns in using asthma medications[5–8]. Our prior research, conducted in 2005–2008 with 320 youth, found that 87% of youth reported one or more problems or concerns in using their asthma medications and the most commonly reported problems were difficulty remembering when to take the medication, side effects, and hard to understand the medication directions[5]

Little is known about whether these problems have changed over the past ten years. Additionally, North Carolina's Hispanic population has grown substantially, going from 75,000 to 800,000 residents between 1990 and 2010 and then increasing by 16.5% between 2010 and 2016[9]. We are interested in examining how family use of Spanish language at home might be associated with reported problems in using asthma medications because our prior work did not include Spanish-speaking families (charlotte cite ref 5).

One of the reported problems in using asthma medications that has been investigated the most is inhaler technique (charlotee cite 5, 10,11,12). In our previous study, females and non-Whites were more likely to report that they did not know how to use their inhaler (5). Prior work has found that using inhalers correctly can be a challenge for youth[10, 11] and that youth are often overconfident on their ability to use their inhaled asthma medications correctly[12]. Caregivers also are not confident that their children have correct inhaler technique, with close to 30% of caregivers reporting a concern that their child is not using them correctly[5].

Previous work has also found that younger children were more likely to report side effects, difficulty understanding medication directions and difficulty reading the print on the medication label (5). Females were more likely to report difficulty using their asthma medication at school than males (5). Caregivers with Medicaid were less likely to report difficulty paying for their child's asthma medications than those without Medicaid (5).

It is important to examine what socio-demographic factors are associated with different reported problems in asthma medication use so that interventions can be developed for the individuals who need them most. Therefore, the purpose of this study was to: (a) describe the types of medication problems/concerns youth with asthma and their caregivers reported and (b) examine the association between the youth and caregiver socio-demographic characteristics and youth and caregiver reported medication problems/concerns.

Methods

Procedure

This study was approved by the Institutional Review Board at the University of North Carolina. Forty-six providers from four pediatric primary care practices (one academic and three private) in North Carolina agreed to participate in the study. Clinic staff briefly explained the study to all families present for a medical visit whose child was between the ages of 11 and 17 and had an asthma diagnosis in their medical record. The clinic staff referred interested families to a research assistant to learn more about the study. We focused on adolescents because they most likely are managing their asthma medications at this developmental age. During pre-visit wait time, the research assistant explained the study, obtained caregiver consent and teen assent, and administered an eligibility screener[10, 11]. All caregivers completed the eligibility screener with the research assistant. To assess asthma severity, the research assistant asked about: (a) asthma medication use while showing laminated photos of asthma medications, (b) eight questions about asthma symptoms and frequency of symptoms, and (c) one question about sleep disturbance due to asthma symptoms. Using information from the eligibility screener, persistent asthma was defined as experiencing asthma-related daytime symptoms more than twice a week, asthma-related nighttime symptoms more than twice a month, or receiving one or more long-term controller therapies for asthma[5, 10].

Youth were eligible if they were: ages 11 to 17 years; spoke and read English or Spanish; had persistent asthma; were present for an acute or follow-up asthma visit or a well-child visit; had previously visited the clinic at least once for asthma; and the caregiver present

with them at the office visit was a legal guardian who had knowledge of their asthma. All youth were interviewed after their medical visits by a research assistant while their caregivers completed questionnaires. The caregiver questionnaire was written at a sixth-grade reading level. Youth and caregivers each received \$25 for their time.

Measurement

Socio-demographic characteristics—Teen age, years the teen has been living with asthma, and caregiver years of education were measured as continuous variables. Teen and caregiver gender were measured as dichotomous variables. Teen race was coded into five categories: Caucasian, African American, Native American/American Indian, Hispanic, or Other. Teen race was recoded into a dichotomous variable (White, non-White) for the multivariable analyses. Caregiver race was coded as White and non-White. Asthma severity was classified as mild persistent versus moderate/severe persistent according to the National Heart Lung and Blood Institute's guidelines[13, 14]. Whether the child had Medicaid for insurance was measured as a dichotomous variable (has Medicaid as their insurance, does not have Medicaid as their insurance). Total household annual income was measured with the following response categories: less than \$10,000, \$10,000–\$19,999, \$20,000–\$29,999, \$30,000–\$49,999, \$50,000–\$69,999, and \$70,000 or more. Primary language spoken at home was measured as a dichotomous variable (English, Spanish). Reason for medical visit was measured as for asthma or for another reason (well child visit, physical, etc.).

Youth and caregiver reported problems in using asthma medications—The primary outcome variables for this study were youth- and caregiver-reported problems or concerns with medication use which was adapted from the Brief Medication Questionnaire[15]. Problems or concerns were assessed on the youth interview and caregiver questionnaire. Youth were asked how much they had a problem or concern in using asthma medications in each of the following areas: side effects, hard to remember when to take, hard to use medicines at school, not sure they are using their inhalers like they are supposed to, hard to understand the directions on the medicines, and hard to read the print on the package. Caregivers were asked how much they perceived a problem or concern in using asthma medications in each of the following areas: child has side effects, hard for child to remember when to take, not sure they are using their inhaler correctly, hard to understand the directions, hard to read the print on the package, hard to pay for, and hard to get refills on time. Response options included none, a little, or a lot. Each of the youth and caregiver reported problems were recoded into dichotomous variables (none versus a little or a lot of a problem) for the multivariable analyses because we were interested in whether the youth or caregiver reported any level of problem.

Analysis—All analyses were conducted using IBM SPSS Statistics (Version 24). First, we computed descriptive statistics for the youth and caregiver socio-demographic characteristics and youth and caregiver reported problems or concerns in using asthma medications. Next, we conducted multivariable logistic regression to examine the relationship between youth gender, age, race, asthma severity, years living with asthma, on a control medication, primary language spoken at home, reason for visit, and the following youth-reported problems/concerns in using medications: side effects, hard to remember when to take, hard

to use at school, not sure how to use an inhaler, hard to understand the directions, and hard to read the print on the package.

Finally, we conducted logistic regression models to examine the relationship between youth gender, age, race, asthma severity, years living with asthma, on a control medication, caregiver years of education, child has Medicaid for insurance, family income, primary language spoken at home, reason for visit, and the following caregiver-reported problems/concerns in using medications: side effects, hard to remember when to take, not sure child knows how to use an inhaler, hard to understand the directions, hard to read the print on the package, difficulty paying for the medicines, and difficulty getting refills on time. Alpha was set at the 0.05 significance level. However, to deal with the fact that we were testing the effect of the same set of independent variables on different dependent variables, an independent variable was considered statistically significant if the p-value was $<.01$ or if the p-value was less than .05 in two or more models.

Results

Youth were enrolled from June 2015 to November 2016. One hundred and ten youth did not meet inclusion criteria. The main reasons for not meeting inclusion criteria included: had not been seen at clinic before for asthma, no legal guardian present, and adolescent did not have persistent asthma. Of the 412 eligible youth, 359 agreed to participate and 53 refused (87% participation rate). Reasons for not participating included: lack of time (N= 27), caregiver is not interested because child's asthma is under control (N=8), child does not believe they have asthma (N=2), caregiver does not believe child has asthma (N=3), child going away to college (N=3), child refused and no reason given (N=6), caregiver not interested and no reason give (N=3), and father said that he needs to consult with mother first (N=1).

Table 1 presents the youth and caregiver characteristics. Thirty-six percent of the youth were Caucasian, 37% African American, 13% Hispanic, and 11% Native American. Fifteen caregivers completed the questionnaires in Spanish and seven youth were interviewed in Spanish.

Eighty percent of the youth reported one or more problems or concerns in using their asthma medications (mean=1.7, standard deviation=1.4, range=0 to 6). Table 2 presents the youth reported problems/concerns in using their asthma medications. The most commonly reported problems reported by the youth were (a) it was hard to remember when to take the asthma medication (53.5%) and (b) it was hard to use asthma medication at school (34.3%). Twenty-seven percent of youth reported a problem with the side effects of their asthma medications. Twenty-five percent of youth reported having a problem/concern with not being sure how to use their inhalers.

Seventy percent of caregivers reported one or more problems or concerns with their child using asthma medications (mean=1.4, standard deviation=1.3, range 0 to 7). Table 2 also reports the caregiver reported problems/concerns with their child using their asthma medications. Being hard for their child to remember to take their asthma medications was caregivers' top-reported problem (48.7%). Twenty-seven percent of caregivers reported that

their child was unsure how to use their inhaler. Twenty-one percent of caregivers reported having difficulty paying for their child's medications. Eleven percent of caregivers reported having difficulty getting their child's asthma medication refilled on time.

Table 3 presents the logistic regression results predicting youth reported problems of hard to remember to take the medication, not being sure how to use their inhaler, hard to understand the medication directions, and hard to read the print on the package. Youth present for an asthma visit were significantly less likely to believe it was difficult to remember to take their asthma medications than youth present for another reason (odds ratio=0.5, 95% confidence interval=0.3, 0.7). Females were twice as likely as males to report not knowing how to use their inhaler (odds ratio=2.0, 95% confidence interval=1.3, 3.3). Older children were less likely to report having difficulty understanding the medication directions (odds ratio=0.80, 95% confidence interval=0.7, 0.9) and difficulty reading the print on the package (odds ratio=0.8, 95% confidence interval=0.7, 0.9) than younger children. None of the demographic characteristics were significantly associated with side effects and difficulty using medications at school (results not shown).

Table 4 presents the logistic regression results predicting caregiver reported problems. Caregivers whose children were on Medicaid were significantly less likely to report having difficulty paying for their child's asthma medications than caregivers not on Medicaid (odds ratio=0.2, 95% confidence interval=0.01, 0.4). None of the demographic characteristics were significantly associated with side effects, not sure how to use an inhaler, difficulty remembering, hard to understand the directions, hard to read the print on the package, and difficulty getting refills on time (results not shown).

Discussion

Even though many youth and caregivers did not report certain types of problems in using asthma medication, 80% of youth reported one or more problems or concerns in using their asthma medications and 70% of caregivers reported one or more problems. The most common problem that both youth and caregivers reported was having difficulty remembering when to take the medication. In our prior study that was conducted almost 10 years ago, only 12% of caregivers reported difficulty remembering when their child should take their asthma medication compared to 48% of caregivers in the current study (5). Sonney et al. found that caregivers expressed concerns about their children taking daily asthma control medications[6]. Our finding suggests that providers need to make sure to educate caregivers on when control medications should be taken. Providers can also give caregivers strategies on how to remember when to have the child take the control medication. This might involve storing the control medication in a place that would prompt the family to remember to have the child take it, such as near their toothbrush. Interventions should be developed to help families with remembering to take control medications regularly.

We found that approximately 25% of youth reported not being sure whether they were using their inhalers correctly which is similar to previous findings that were reported using data that were almost ten years old[5]. Unlike our prior work, non-White youth were not more likely than White youth to report not being sure how to use their inhalers (5). However,

similar to our prior work, females were more likely to report not being sure how to use their inhalers (5). Health care providers should assess inhaler technique of all youth and especially females. It is concerning that these numbers have not changed over a decade. The guidelines of the National Asthma Education and Prevention Program of the National Heart Lung and Blood Institute state that providers should teach patients and their families medication skills such as inhaler technique[13, 14]. The guidelines also emphasize that the providers should demonstrate proper inhaler technique and have the child return the demonstration[13, 14].

Youth might be embarrassed to admit to their providers that they do not know how to use their inhalers. If providers ask youth to demonstrate inhaler technique during visits, providers can assess and then correct the technique if needed. However, provider education on how to assess and provide feedback on technique may be needed first. Intervention studies could be developed and implemented to improve youth inhaler technique.

One third of youth reported difficulty in using their asthma medications at school. Unlike our prior work, females were not more likely to report difficulty in using their asthma medications at school (5). Previous research found that parents expressed concerns about youth using their asthma medications at school and that parents felt as though teachers and staff did not have the needed knowledge and did not provide support to youth with asthma[7]. Future work should investigate why youth report difficulty using their asthma medications at school.

Providers should talk with youth about asthma medication use at school, so they can detect if the teen is experiencing problems in using medications at school. Providers could then work with the family and/or school to figure out a way that would make it easier for the child to use the medications at school. School nurse interventions could be used to help youth overcome certain problems in using asthma medication such as using an inhaler correctly[12, 16]. Unfortunately, funding for school nurses has been cut over time which limits their ability in many school districts to work with youth with chronic conditions such as asthma[17, 18]. School nurse staffing is not meeting national recommendations[19]. Future research should examine whether youth who attend schools that have nurses are less likely to report difficulty using their medications at school.

Youth who were present for an asthma visit were less likely to report difficulty remembering to take their asthma medication. Perhaps youth who return more often for regular asthma visits have less difficulty remembering to take their asthma medications because they are being followed more closely. Whether Spanish was the primary language spoken at home was not significantly associated with youth or caregiver reported problems in using asthma medications. However, less than 10% of our patients reported speaking Spanish at home. Future research needs to be done in populations with a great percentage of Spanish-speaking families.

Younger youth were significantly more likely to report difficulty in understanding their asthma medication's directions and difficulty reading the print on the medication's package, which is like the findings of our prior study (5). The youth in this study were ages 11 to 17.

Providers should educate younger youth to help them better understand how to take their asthma medications. They should encourage younger youth to ask questions that they have about using their medications. Providers should use the teach back method in which the provider asks the teen how they will use their medication so that the provider can correct any misunderstandings in how to use the medications[20].

One out of five caregivers reported difficulty paying for their child's asthma medications. Caregivers who had Medicaid as their insurance were significantly less likely to report difficulty paying for their child's medication, which is similar to the results of prior research[5]. Fung et al. (2014) found that almost 16% of caregivers borrowed money or cut back on necessities to pay for their children's medications[8]. Providers should make sure to ask caregivers if cost is a barrier to asthma medication use so they can help patients obtain lower cost medications. This is especially important to address with families given the uncertainty regarding Medicaid insurance and medication reimbursement that has been covered recently in the popular press.

The caregiver asthma medication problems that were not reported often included hard to understand the directions (6%) and hard to read the print on the package (10%). Similarly, only 16% of youth reported difficulty understanding the directions and 16% reported difficulty reading the print on the package. Fewer youth reported these problems compared to those in our prior study where 39% of youth reported difficulty understanding the directions and 36% reported difficulty reading the print on the package (5). It is encouraging that more youth understand the directions on how to use their asthma medications and can read the print on the package. As mentioned above, the areas where providers can help families the most is remembering when to take asthma medications and using asthma medications at school.

The study is limited in generalizability in that it was conducted in four pediatric clinics in North Carolina. The study is also limited in that we do not have specific details on the copayments paid by families on different types of insurance plans. Another limitation is that we did not assess the literacy level of the caregiver or youth. We recruited youth from primary care clinics, the results might have differed if youth were recruited from specialty clinics or non-clinic settings. Despite the limitations of the study, it provides new information on the types of asthma medication problems and concerns that children and their caregivers report.

Conclusions

The number and types of medication problems that youth with asthma and their caregivers report has not changed much over the past ten years. This suggests that there are still opportunities to improve communication about asthma medications in pediatric practice settings. Providers should make sure to discuss with youth and caregivers the types of problems/concerns that they may have in using their asthma medications. Providers should help families come up with strategies on how to remember when to take their asthma medications. Interventions that allow practices to address these problems/concerns in a manner that can be feasibly integrated into their workflow are critical.

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Table 1:

Youth and caregiver demographic and youth asthma-related characteristics (N=359)

Characteristics	Percent (N)
Youth Gender	
Male	57.1 (205)
Female	42.9 (154)
Youth Race/Ethnicity	
Caucasian	36.2 (130)
African American	37.2 (134)
Hispanic	12.5 (45)
Native American	11.4 (41)
Other	2.5 (9)
Asthma Severity	
Mild	46.8 (168)
Moderate/Severe	53.2 (191)
Caregiver Gender	
Male	13.6 (49)
Female	86.4 (310)
Caregiver Race	
Caucasian	46.0 (165)
Non-Caucasian	54.0 (194)
On control medication	
Yes	88.9 (319)
No	11.1 (40)
Primary language spoken at home	
English	91.5 (292)
Spanish	8.5 (27)
Reason for visit	
Asthma	66.6 (239)
Other	33.4 (12)
Household total annual income	
Less than \$10,000	16.4 (59)
\$10,000–\$19,999	15.3 (55)
\$20,000–\$29,999	18.7 (67)
\$30,000–\$49,999	13.1 (47)
\$50,000–\$69,999	13.1 (47)
\$70,000 or more	23.4 (84)
Has Medicaid as health insurance	
Yes	54.6 (196)

Characteristics	Percent (N)
No	45.4 (163)
	Mean (SD), Range
Youth Age	13.2 (1.9), 11–17
Years Living with Asthma	9.5 (4.1), 1–17
Caregiver Age	42.6 (8.6), 19–76
Caregiver Education (in years)	13.6 (3.3), 4–26

SD=standard deviation

Table 2:

Youth and caregiver reported problems/concerns in using asthma medications (N=359)

	None Percent (N)	A Little Percent (N)	A Lot Percent (N)
Youth reported problems/concerns			
Side effects	72.4 (260)	24.2 (87)	3.3 (12)
Hard to remember when to take	46.5 (167)	42.9 (154)	10.3 (37)
Hard to use at school	65.7 (236)	25.3 (91)	8.9 (32)
Not sure how to use inhaler	74.9 (269)	18.4 (66)	5.6 (20)
Hard to understand directions	83.6 (300)	13.9 (50)	2.5 (9)
Hard to read print on package	83.8 (301)	14.5 (52)	1.4 (5)
Caregiver reported problems/concerns			
Side effects	79.9 (287)	17.5 (63)	2.5 (9)
Hard for child to remember when to take	51.3 (184)	36.2 (130)	11.7 (42)
Not sure how to use inhaler	72.7 (261)	21.7 (78)	4.2 (15)
Hard to understand directions	93.6 (336)	4.7 (17)	1.1 (4)
Hard to read print on package	90.0 (323)	7.5 (27)	2.2 (8)
Hard to pay for	78.6 (282)	15.0 (54)	5.8 (21)
Hard to get refills on time	88.9 (319)	8.9 (32)	1.9 (7)

Table 3:

Logistic regression results predicting youth reported problems with asthma medications (N=359)

	Hard to remember OR (95% CI)	Not sure how to use inhaler OR (95% CI)	Hard to understand directions OR (95% CI)	Hard to read print on the package OR (95% CI)
Youth gender-female	1.1 (0.7, 1.6)	2.0 (1.3, 3.3) **	0.6 (0.3, 1.1)	0.9 (0.5, 1.6)
Youth age	1.0 (0.9, 1.1)	1.0 (0.9, 1.2)	0.8 (0.7, 0.9) *	0.8 (0.7, 0.9) *
Youth race-White	0.8 (0.5, 1.3)	0.8 (0.5, 1.4)	1.1 (0.6, 2.2)	1.3 (0.7, 2.5)
Asthma severity-moderate/severe	1.0 (0.7, 1.6)	0.9 (0.5, 1.5)	0.6 (0.3, 1.0)	1.4 (0.8, 2.6)
Years living with asthma	1.0 (0.9, 1.1)	1.0 (0.9, 1.1)	1.0 (0.9, 1.1)	1.1 (0.9, 1.2)
On control medication	1.1 (0.6, 2.2)	1.4 (0.6, 3.3)	0.9 (0.3, 2.2)	1.3 (0.4, 4.1)
Primary language spoken at home-Spanish	1.3 (0.6, 2.8)	0.9 (0.3, 2.4)	2.4 (0.9, 6.2)	1.4 (0.5, 4.3)
Reason for visit-asthma	0.5 (0.3, 0.7) **	0.9 (0.5, 1.5)	1.0 (0.5, 2.0)	0.9 (0.5, 1.8)

OR=Odds Ratio, 95% CI=95% Confidence Interval

*
p < 0.05**
p < 0.01***
p < 0.001

Table 4:

Logistic regression results predicting caregiver reported difficulty paying for asthma medications (N=359)

Independent variables	Difficulty Paying OR (95% CI)
Youth gender-female	1.0 (0.6, 1.7)
Youth age	1.1 (0.9, 1.3)
Youth race-White	1.0 (0.6, 2.0)
Asthma severity-moderate/severe	0.6 (0.3, 1.0)
Years living with asthma	1.0 (0.9, 1.1)
On a control medication	0.6 (0.3, 1.4)
Family income	1.0 (0.8, 1.3)
On Medicaid	0.2 (0.1, 0.4) ***
Caregiver years of education	0.9 (0.8, 1.1)
Primary language spoken at home-Spanish	1.5 (0.5, 4.5)
Reason for visit-asthma	1.0 (0.5, 1.7)

OR=Odds Ratio, 95% CI=95% Confidence Interval

*
p < 0.05**
p < 0.01***
p < 0.001