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Communication about ADHD and its treatment during pediatric asthma visits

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Abstract

The objectives of the study were to examine provider-family communication about attention deficit disorder during pediatric asthma visits. Children with asthma, aged 8 through 16 and their parents were recruited at five pediatric practices. All medical visits were audio-taped. There were

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296 asthmatic children enrolled into the study and 67 of them also had ADHD. ADHD communication elements suggested by national guidelines were discussed infrequently. Providers were more likely to discuss, educate, and ask one or more questions about ADHD medications if the visit was non-asthma related. Providers included child input into the ADHD treatment regimen during 3% of visits and they included parent input during 4.5% of visits. Only one child and three parents asked questions about ADHD. Providers may neglect essential aspects of good ADHD management and communication in children who have ADHD plus another chronic condition such as asthma. Providers should set appropriate treatment expectations, establish target symptoms, and encourage children and parents to ask questions so mutual decision-making can occur.

Keywords

pediatrics asthma; communication; ADHD

Introduction

Relatively little is known about how children, caregivers, and providers communicate when a child has multiple co-morbidities. Attention deficit hyperactivity disorder (ADHD) is one of the most common psychiatric disorders of childhood (Rey & Sawyer, 2003) and asthma is a chronic disease that can influence the social, physical, and psychological status of children (Yuskel et al. 2008). It is thought that both the nature of asthma and the medications used to treat it can increase the frequency of ADHD symptoms, but the studies that have attempted to examine the association between asthma medications and ADHD symptoms are inconclusive (Yuskel et al. 2008; Fowler et al. 1992; Lindgren et al. 1992, Creer et al. 1989; Daly et al. 1996; Nall et al. 1992). Little is known about the extent to which providers communicate about ADHD when a child has a co-morbid condition, like asthma.

The American Academy of Pediatrics (AAP) (2001) recommends the following when treating children with ADHD: (1) a treatment program that recognizes ADHD as a chronic condition, (2) the provider, parents, and child, in collaboration with school personnel, should specify appropriate outcomes, (3) the provider should recommend stimulant medication and/or behavioral therapy as appropriate to improve target outcomes, (4) when target outcomes are not met, providers use all appropriate treatments and evaluate adherence to the treatment plan, and (5) the provider provides a systematic follow-up for the ADHD child. In addition, the Institute of Medicine has emphasized that shared decision-making should occur during pediatric visits (IOM, 2009; Berwick, 2002).

Three prior studies have audio-taped primary care visits to examine communication about ADHD, but they did not examine the extent to which shared decision-making occurred and they did not examine how well communication matched with the American Academy of Pediatrics' (AAP) ADHD guidelines (2001). This prior work was also limited by its use of very small samples (n= 22 to 32 children) (Mattingly et al. 2011; Findling et al. 2009; Brown et al. 2007). Finally, these studies failed to include the impact of co-morbidities within their study population. Two-thirds of pediatric patients with ADHD suffer from co-morbidities (Larson et al. 2011). Additionally, pediatric patients with asthma are more likely to suffer from ADHD and other behavioral disorders, with a strong correlation between the severity of asthma symptoms and the severity of ADHD symptoms (Blackman & Gurka (2007). Blackman & Gurka (2007) have recommended that asthma treatment programs specifically address co-morbidities to achieve better outcomes, yet prior studies have failed to incorporate this finding into their sampling schemes.

ADHD is commonly treated with medications, which are often prescribed during primary care visits (Harpez-Rotem & Rosenheck, 2006; Winterstein et al. 2008; Chen et al. 2009). If a child has asthma and ADHD, it is important to examine whether providers adequately discuss ADHD and its treatment, especially medications, with patients. Therefore, within a sample of children with asthma, the purpose of this study was to examine: (a) whether providers discuss key areas recommended by the AAP ADHD guidelines, (b) the extent to which providers discuss, educate, and ask questions about ADHD medications during pediatric visits, (c) the extent to which children and parents ask questions about ADHD and its treatment, and (d) the extent to which the provider asks for and includes child input into the ADHD treatment regimen.

2. Methods

Participants

The cross-sectional study was approved by the University of North Carolina Institutional Review Board. Providers were recruited at five pediatric practices in North Carolina and provider consent was obtained. Children and their caregivers seeing these participating providers were recruited. The children were being seen by their regular pediatricians, and they were not seen at a special asthma management clinic. Children were eligible if they: (a) were ages 8 through 16 years, (b) were able to speak English, (c) could read the assent form, (d) had been seen at the clinic at least once before, (e) were present at the visit with an adult caregiver who could read and speak English and who was at least 18 years of age, and (f) had persistent asthma.

Clinic staff referred potentially eligible and interested patients to a research assistant, who explained the study; obtained caregiver consent and child assent, and administered the eligibility screener (Sleath et al. 2011). Providers and families were told that the study was examining communication during pediatric visits. Children were interviewed after their medical visits while caregivers completed self-administered questionnaires. Data was collected between 2005 and 2008. The patients' medical records were reviewed

Audio-tape coding

All of the medical visit audio-tapes were transcribed, and a detailed coding tool was developed. This tool was refined and tested over a one-year period. The categories used to code for communication about ADHD medications were adapted from the categories used in prior research (Sleath et al. 1999; Sleath et al. 2007; Young et al. 2006; Scherwitz et al 1985) and the categories for child and caregiver input into the ADHD management treatment plan were created based on existing literature on shared decision-making (Berwick et al. 2002; IOM 2001; Charles et al 1997). The transcripts were reviewed by two research assistants who met twice a month with the investigators to develop and refine the coding rules until saturation of themes was achieved.

Coders recorded the following: was there any discussion of ADHD medications, did the provider give any education about ADHD medications, and how many questions did the provider ask the child and caregiver about ADHD medications. The research assistants then coded whether discussion, education, and question-asking occurred in each of the following areas: adherence, amount/dose, cost/insurance, fears/concerns, frequency/timing, generic/brand, how well it works/benefit, purpose, risks/side effects, supply, and when to use.

Two research assistants coded 20 of the same transcripts throughout the study period to assess inter-coder reliability, which was calculated using correlations. Inter-rater reliability was 0.88 or above for the coded variables.

Measures

Sociodemographic and visit-related characteristics—Child and caregiver age, caregiver education, and years the child had asthma were measured as continuous variables. Child and caregiver gender were also recorded. For descriptive purposes, child race was re-coded into four categories: White, African American, Native American/American Indian, or Other. However, for the bivariate analyses, child race was re-coded into a dichotomous variable (White versus non-White). The child's insurance status was assessed using the following categories: none, private insurance, Medicaid, the State Children's Health Insurance Program (CHIP), and other. Length of visit was measured in minutes. Whether the patient had a diagnosis of ADHD was measured as a dichotomous variable.

Statistical Analyses—All analyses were conducted using SPSS v. 14. First, we present descriptive statistics for all variables. Second, we examine bivariate relationships between these variables. Next, we used multivariable logistic regression to examine how patient gender, age, race, caregiver education, reason for visit, and provider gender were associated with discussion of ADHD medications during the visit, provider education about ADHD medications during the visit, and whether the provider asked one or more questions about ADHD medications during the visit. Only provider gender was used in the multivariable analyses because it was the only provider characteristic significantly associated with ADHD communication in the bivariate analyses.

3. Results

The five clinics were all primary care pediatric practices. Forty-one providers agreed to participate in the study; two providers refused to participate. Providers completed a short demographic questionnaire. Clinic staff referred eligible families to research assistants. Three hundred and thirty-three of the 377 families (88%) who approached the research assistant to learn more about the study agreed to participate in the study. Two-hundred and ninety six patients of the 333 participating patients (89%) had useable audio-tape data and these patients were seen by 35 of the 41 providers who agreed to participate in the study. Twenty-three percent of the 296 children had a diagnosis of ADHD in their medical chart.

Four of the 35 providers were nurse practitioners or physician assistants. Fifty-one percent of the providers were female. Twenty-seven of the providers were White, two were American Indian, three were African American, one was Asian, and two classified their race as other. Providers ranged in age from 30 to 70 years (mean = 44.8 years, standard deviation = 9.4).

Table 1 presents the demographic characteristics. Boys in the sample were significantly more likely to have a diagnosis of ADHD (Pearson chi-square=9.6, $p=0.002$). Child race was not significantly associated with whether or not a child had an ADHD diagnosis.

Teacher and school-based functioning issues were discussed during 35.8% of the visits, home functioning was discussed during 11.9% of the visits, and social and community functioning was discussed during 1.5% of the visits. Providers asked about school functioning during 23.9% of the visits. They asked about home functioning during 9% of visits and social and community functioning during one visit. Providers educated families about school functioning during 9% of visits and they educated about home functioning in one visit and social and community functioning in one visit.

Other elements of guideline-suggested communication about ADHD were discussed infrequently: (a) target outcomes were discussed during one visit, (b) a treatment plan was established during only one visit, (c) the relationship between ADHD and asthma was

discussed during two visits, and (d) the provider explained that ADHD was a chronic condition during one visit. Follow-up visits were scheduled for 15% of the children.

The provider suggested that the child receive counseling during 7.5% of the visits (N=5) and barriers to counseling were discussed during three visits. Examples of barriers to counseling included both: cost and the parent not liking the idea of counseling.

Providers discussed ADHD medications during 37.3% of encounters. The average number of topic areas discussed was 1.27 (standard deviation= 1.98; range 0 to 7 areas). Table 2 shows the ADHD medication areas that providers discussed most often during the medical visits: (a) generic versus brand medications (25.4%), (b) amount/dose (17.9%), (c) how well the medication is working/benefits (17.9%), (d) risks/side effects (16.4%). Adherence was only discussed during 3% of visits. The majority of benefits providers discussed related to taking medications focused on task completion and the ability to focus, particularly in school. "You're supposed to observe that he is more focused doing his work," said one provider. The risks focused on two major areas, either the physical effects of taking a medication, or personality and mood changes. In the former category, providers most often referred to stomach issues such as nausea or loss of appetite, and difficulties sleeping. In terms of personality or mood, providers used the word "zombie" on multiple occasions to indicate the importance of achieving the correct dosages for children without over-medicating them. "The zombie business is on simply too much, too strong... no doctor taking care of kids with ADHD is ever gonna advocate for a child to be a zombie." They also discussed how some children experienced increased moodiness on different medications.

Table 3 presents the multivariable logistic regression results predicting whether ADHD medications were discussed during the visit. ADHD medications were significantly more likely to be discussed if the provider was male ($p < 0.05$) and if the visit was non-asthma related ($p < 0.01$).

Providers educated patients about ADHD medications during 19.4% of encounters. The average number of topics educated about were 0.56 (standard deviation=1.34; range 0 to 6 areas). Table 2 displays the ADHD medication areas that providers educated about the most during medical visits: (a) benefits/how well the medication works (11.9%), (b) risks/side effects (10.4%), and (c) amount/dose (7.5%). Education about adherence or the importance of adherence only occurred during one visit. Table 3 presents the multivariable logistic regression results predicting whether providers educated about ADHD medications during the visit. Providers were significantly more likely to educate about ADHD medications if the provider was male ($p < 0.05$) and if the visit was non-asthma related ($p < 0.01$).

Providers asked one or more questions about ADHD medications during 23.9% of the visits. The average number of questions asked was 0.86 (standard deviation=2.11; range 0 to 10). Providers were most likely to ask children questions about ADHD medications in the following areas: (a) frequency of use (11.9%), (b) risks/side effects (9.0%), (c) amount/dose (7.5%), and (d) how well the medication is working/benefits (7.5%).

Providers only asked about adherence to ADHD medications during one visit. Here is the passage from the transcript of the visits where the provider asked about adherence:

Doctor: Have you been taking your Adderall? Child: Just on the math EOG

Doctor: So you don't take your Adderall every day?

Child: No

It is interesting that in the above passage the child is just taking the medicine for the end of grade tests. Below is another example. This type of communication is concerning because it discusses medication as a performance improving drug, rather than as a treatment regimen.

Doctor: Okay tell me about tennis and Concerta? Do you take your medicine when you play tennis?

Child: Yes

Parent: We just started and I've actually thought about it ..you know you gave us a little Ritalin and I thought we might just try that for tennis

Table 3 presents the multivariable logistic regression results predicting whether providers asked families one or more questions about ADHD medications. Providers were significantly more likely to ask one or more questions about ADHD medications if the provider was male ($p < 0.05$) and if the visit was non-asthma related ($p < 0.01$).

The provider asked for child input into the ADHD treatment regimen during 6% of the visits and they included it during 3% of the visits. The provider asked for parent input into the ADHD treatment regimen during 7.5% of visits and they included it during 4.5% of visits. One example is below:

Provider: You work really hard at it for something that shouldn't be hard for you because we know you are really smart, right? I would like to make your work easier. Not giving you easier work but making the work that you are doing easier to do. The way this medicine works is that it makes your brain focus more.....So what do you think about that? Do you think that is something you'd be willing to take a pill for once a day in the evening after supper? Do you want to give that a try?

Child: Yeah

Provider: I would ask you to bear with me for about a month because it doesn't happen like bam but it takes a few weeks to see the difference with this medication. Is that a fair thing to try?

Child: Yeah

Only one child asked a question about ADHD or ADHD medications during their visit and only three parents asked a question. One child asked "What's that called?" after the provider asked "do you have ADHD?". A caregiver asked "Now are you gonna put him on the medication for ADHD because that's what his teacher has been hassling me about?".

4. Discussion

This study focused on communication about ADHD medications in a sample of children that had asthma as a comorbid condition. We found that, in this context, communication about ADHD and its treatment was poor. There tended to be more communication if a visit was not an asthma visit but some other type of visit such as a physical or sports physical. Providers should assess how well a child is doing with their ADHD even when the child's main reason for the visit is related to another comorbidity, because it may be one of the few times the child is at the provider's office and can be assessed. From a community health perspective, when a child or teen comes into a physician's office for a visit, this could be a unique and rare opportunity to care for the whole child and cover multiple health issues even

if they are presenting with just one issue (e.g. asthma), as this population may not always be receiving routine care.

We also found that providers did not follow the suggested AAP guidelines (2001) for discussing ADHD with families. Specifically, we found that target outcomes were discussed during only one visit, a treatment plan was established during only one visit, and the provider explained that ADHD was a chronic condition during one visit. We also found that follow-up visits were only scheduled for 15% of the children. Providers should make sure to educate families about the fact that ADHD is a chronic condition. This is important because in several of the visits, the families openly discussed that the child simply took the medicine for a tennis game or for an end of grade test, which is not how these medications should be taken. Providers should also discuss target outcomes for the child's ADHD and they should make sure follow-up visits are scheduled.

We found that providers rarely asked parents and children for their input into the ADHD treatment regimen. The Institute of Medicine has emphasized that shared decision-making among the provider, parent, and child should occur during pediatric visits (IOM, 2009). Fiks et al. (2011) found that parents viewed shared decision-making as a partnership between equals, whereas providers understood it as a means to encourage families to accept provider recommendations. Honeycutt et al. (2005) found that providers rated themselves as using shared decision-making or being more participatory with parents of children with ADHD than with the children themselves. We actually found little difference between providers involving parents and children in deciding the ADHD treatment regimen.

Shared decision-making involves families working with providers to develop a treatment plan for their child (IOM, 2001; Berwick, 2002). Brinkman et al. (2013) conducted a randomized trial of a shared decision-making intervention with seven providers and 54 families who had a child with ADHD in a pre/post trial of decision aids. The researchers found that their decision aid intervention improved shared decision-making during ADHD visits (Brinkman et al. 2013; Brinkman et al. 2011). Primary care practices could consider using these decision aids in their practices to encourage shared decision-making. In addition, caregivers and children asked very few questions about ADHD and its treatment. Providers should encourage both parents and children to ask questions about their ADHD and its treatment so that they can be more active participants in their care. Providers also asked few questions about how well the ADHD medications were working and whether the child was experiencing side effects. If providers want to detect and prevent problems with ADHD medication use and adherence, they should consider asking at least one open-ended question about how the medications are working and a second question about any side effects or barriers to use.

Future research should examine how to help providers better manage ADHD in primary care. Power et al. (2008) found that primary care providers believe it is appropriate for them to have a role in the management of ADHD. They also found a need for practice-based resources to assist with school communication and collaboration with mental health agencies. We did find that providers asked more about school functioning than they did home or community functioning. Part of this might be from the pressure that providers feel from parents and school personnel to prescribe ADHD medications for disruptive classroom behavior. Future research should explore this in more detail.

Our data suggest that there is a need for providers and families to be further educated about ADHD and that the desire to start treatment should be based on more than teacher recommendations. Primary care practices should partner with mental health agencies and mental health professionals to further educate providers, families, and teachers/schools

about the American Academy of Pediatrics ADHD clinical practice guidelines and when treatment is and is not needed (AAP, 2011) Also, providers should educate families about the value of mental health care to help them overcome the stigma that they might feel about getting their child counseling. Providers could encourage children, teens, and parents to be proactive with their health and direct them to those services.

In addition, caregivers and children asked very few questions about ADHD and its treatment. Providers should encourage both parents and children to ask questions about their ADHD and its treatment so that they can be more active participants in their care. Providers also asked few questions about how well the ADHD medications were working and whether the child was experiencing side effects. If providers want to detect and prevent problems with ADHD medication use and adherence, they should consider asking at least one open-ended question about how the medications are working and a second question about any side effects or barriers to use.

Providers may neglect essential aspects of good ADHD management and communication in children who have ADHD plus another chronic condition such as asthma. Providers should follow guidelines of ADHD care, set appropriate treatment expectations, establish target symptoms, encourage questions and mutual decision-making by involving parents and children in the process, regardless of what other chronic conditions they may have. The study is limited in generalizability in that it was conducted in five pediatric clinics. The study is also limited in that this is a secondary analysis of a dataset of all asthmatic children. Another limitation is that clinic staff referred potentially eligible patients to the research assistant, and we do not know how many patients that the clinic staff referred chose not to talk with the research assistant. Another limitation is that we did not know if the child was receiving treatment for their ADHD from a mental health clinic. Also, we did not know if the child was receiving treatment for their ADHD from a mental health clinic. Additionally, the data were collected and coded before the new American Academy of Pediatrics clinical practice guidelines were published in November of 2011 (AAP, 2011). Despite the limitations of the study, it presents new information on communication about ADHD and its treatment when children have a comorbid diagnosis of asthma.

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Table 1

Child and Caregiver Demographic Characteristics

Characteristic	All Children (N=296) Percent (N)	Children with an ADHD Diagnosis (N=67) Percent (N)
Child Age Mean (SD) Range	11.1 (2.4) 8-16 years	11.3 (11) 8-16 years
Child Gender Male Female	53.7 (159) 46.3 (137)	70.1 (47) 29.9 (20)
Child Race White African American Native American/American Indian Other	61.5 (182) 30.1 (89) 10.1 (30) 6.1 (18)	65.7 (44) 25.4 (17) 16.7 (5) 1.5 (1)
Number of Years Living with Asthma Mean (SD) Range	6.0 (3.9) 9-16 years	5.4 (5.0) 0-15 years
Caregiver Education (in years) Mean (SD) Range	12.8 (2.5) 2-20 years	12.6 (12) 2-19 years
Insurance Type None Private Medicaid State Children's Health Insurance Program Other	1.0 (3) 26.4 (78) 51.7 (153) 17.6 (52) 2.7 (8)	2.0 (2) 28.3 (19) 52.2 (35) 14.9 (10) 1.5 (1)
Reason for Visit Asthma related Non-asthma related	51.4 (152) 48.6 (144)	55.2 (37) 44.8 (30)

Table 2

Communication about ADHD medications during pediatric asthma visits where children have and ADHD diagnosis (N=67)

	Any discussion Percent (N)	Any education Percent (N)	Any question Percent (N)
Adherence	3.0 (2)	1.5 (1)	1.5 (1)
Amount/dose	17.9 (12)	7.5 (5)	7.5 (5)
Cost/insurance	3.0 (2)	3.0 (2)	0 (0)
Fears/concerns	4.5 (3)	1.5 (1)	1.5 (1)
Frequency/timing	14.9 (10)	4.5 (3)	11.9 (8)
Generic/brand	25.4 (17)	4.5 (3)	6.0 (4)
How well it works	17.9 (12)	11.9 (8)	7.5 (5)
Purpose	4.5 (3)	6.0 (4)	1.5 (1)
Side effects/risks	16.4 (11)	10.4 (7)	9.0 (6)
Supply	10.4 (7)	1.5 (1)	4.5 (3)
When to use medicine	7.5 (2)	4.5 (3)	1.5 (1)

Table 3

Multivariable logistic regression predicting provider discussion, education, and question asking about ADHD medications (N=67)

Independent Variable	Any Discussion OR (95% C.I.)	Any Education OR (95% C.I.)	Any Question OR (95% C.I.)
Child age in years	0.8 (0.6, 1.0)	1.0 (0.7, 1.4)	0.8 (0.6, 1.1)
Child gender- female	1.1 (0.3, 5.3)	3.4 (0.5, 23.9)	2.2 (0.4, 11.0)
Child race- White	1.4 (0.3, 5.7)	0.2 (0.1, 1.8)	1.2 (0.2, 6.4)
Caregiver years of education	0.8 (0.7, 1.0)	1.0 (0.7, 1.3)	1.0 (0.8, 1.2)
Provider gender- female	0.2 (0.1, 0.8)*	0.04 (0.1, 0.5)*	0.3 (0.1, 1.4)
Reason for visit-non-asthma related	6.7 (1.8, 25.1)**	19.7 (2.4, 157.4)**	8.3 (1.8, 38.3)**

OR=odds ratio, 95% C.I.-95% confidence interval,

*
p <0.05,

**
p < 0.01