

FOLLOW-UP CARE OF CHILDREN IDENTIFIED WITH ADHD BY PRIMARY CARE CLINICIANS: A PROSPECTIVE COHORT STUDY

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Objective To document follow-up care received by children identified with attention deficit hyperactivity disorder (ADHD) by primary care clinicians (PCCs).

Study design We surveyed families of children 4 to 15 years of age who had been diagnosed with ADHD. At an index office visit, parents and clinicians completed questionnaires. Six months after the index visit, parents completed a questionnaire (N = 659 returned surveys, 68% return rate). The main outcome measure was the number of visits with the patients' PCCs or mental health specialists during the 6 months after the index visit.

Results Children had a median of one visit PCC over a period of 6 months. Children who had prescriptions for psychotropic medications (78%) did not differ from others in the number of visits. Follow-up visits with the child's own doctor were more common when the PCC had completed mental health training. Only 26% of patients saw a mental health specialist. Children who were black, on Medicaid, or with higher levels of internalizing symptoms were more likely to see a mental health specialist.

Conclusions Children treated for ADHD need more follow-up visits to permit adjustment of medication and support continuation of patients in treatment. Systematic quality improvement efforts are warranted. (*J Pediatr* 2004;145:767-71)

Stimulant use for attention deficit hyperactivity disorder (ADHD) in the United States has increased rapidly in the last 15 years.¹⁻⁹ This increase is due in part to the development of new practice guidelines by professional organizations, including the American Academy of Pediatrics.^{10,11} Regular visits are crucial for optimizing efficacy, minimizing adverse events, and evaluating the continuing need for medication.¹²

In the Multimodal Treatment Study of Children with ADHD (MTA), the largest randomized controlled trial of ADHD treatment to date, medication and medication plus behavioral therapy demonstrated more improvement in ADHD symptoms than did usual care.¹³ One of the differences between usual care and these treatments was that usual care patients averaged only 2.3 follow-up visits per year with the primary care clinicians (PCC).¹⁴ In contrast, the more successful treatments included monthly follow-up visits and higher doses of medication given on a more frequent schedule. Olfson et al⁶ used the Medical Expenditure Panel Survey to estimate that children with ADHD have 3.5 outpatient visits per year for ADHD treatment.

The families studied came from a study of routine office care.¹⁵ Whereas Medical Expenditure Panel Survey involved a single interview, in this prospective design families were seen at an index visit and surveyed 6 months later.

Our primary questions were, first, what were the rates of contact with PCCs and mental health specialists for children identified with ADHD during the 6 months after an index visit? Second, which characteristics of the child, physician, or index visit influenced rates of follow-up visits? We examined several factors likely to be associated with the rates of follow-up visits: insurance status,¹⁶ ethnicity/race,¹⁷ and clinician factors (such as clinician sex¹⁸) in management decisions. Finally, we wanted to see whether the treatment that the family had received at the index visit (eg, whether medication had been prescribed) affected rates of follow-up visits.

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ADHD	Attention deficit hyperactivity disorder	PCC	Primary care clinician
CBS	Child Behavior Study	PSC	Pediatric Symptom Checklist

Table I. Distribution of variables at index visit and for missing and non-missing follow-up data

Variable	CBS cohort at index visit (N = 21,065)*	Follow-up survey returned (N = 659)	Follow-up survey not returned (N = 317)	P value, returned vs not returned
Child demographics, insurance coverage, and problem severity				
Child age	$\bar{X} = 8.4, SD = 3.3$ years	$\bar{X} = 9.3, SD = 2.9$ years	$\bar{X} = 9.2, SD = 3.0$ years	.61
Male child	50%	78%	78%	.97
Single parent	22%	40%	56%	<.0001
Black race	6%	10%	24%	<.0001
Hispanic ethnicity	8%	4%	8%	.028
Managed care	55%	53%	46%	.14
Uninsured	5%	8%	6%	.46
Fee for service	37%	32%	43%	.008
Medicaid	18%	21%	39%	<.0001
PSC-17 Internalizing	$\bar{X} = 1.9, SD = 1.9$ points	$\bar{X} = 3.2, SD = 2.4$ points	$\bar{X} = 3.3, SD = 2.4$ points	.66
PSC-17 Externalizing	$\bar{X} = 3.9, SD = 2.9$ points	$\bar{X} = 6.2, SD = 3.2$ points	$\bar{X} = 6.9, SD = 3.2$ points	.002
PSC-17 Attention	$\bar{X} = 2.9, SD = 2.5$ points	$\bar{X} = 6.5, SD = 2.3$ points	$\bar{X} = 6.5, SD = 2.3$ points	.82
Primary care clinician characteristics				
Male clinician	53%	65%	57%	.10
Clinician age	$\bar{X} = 42.5, SD = 8.2$ years	$\bar{X} = 43.7, SD = 8.2$ years	$\bar{X} = 42.7, SD = 8.5$ years	.13
Mental health fellowship	4%	7%	5%	.64
Specialist onsite	32%	36%	44%	.14
Patient treatment status at index visit				
Patient on medication	5%	78%	72%	.07
Patient referred to specialist	3%	15%	26%	.0001
Counseled family	7%	34%	43%	.046
My patient	60%	82%	75%	.02

*The CBS cohort sample that was not followed differs from the sample that was followed with significance $P < .0001$ for every variable, except for clinician age, where the difference is significant at $P < .001$.

METHODS

Sites and Settings

The patients were participants in the Child Behavior Study (CBS).^{15,19} Several primary care research networks participated in the CBS: Ambulatory Sentinel Practice Network, Pediatric Research in Office Settings, the Wisconsin Research Network, and the Minnesota Academy of Family Physicians. CBS patients and clinicians resemble those in national samples.^{15,20-23}

Sample

Each clinician enrolled a consecutive sample of approximately 55 children 4 to 15 years of age being seen for nonemergency care with a parent or primary caretaker. There were 24,183 eligible children, of whom 21,065 participated in the study and contributed sufficient data for analyses.

PCCs identified 3934 patients as having a psychosocial problem. From that group, we recruited 1970 families to participate in a 6-month follow-up study (Table I). For the analyses reported, we selected the 976 children in the follow-up sample whom clinicians had identified as having ADHD at the first interview. For these children, we had 659 returned surveys (68% return rate).

Procedure

PCCs signed an agreement to participate, an institutional review board–approved alternative to standard informed consent, and completed the Practice Questionnaire. At first visit, parents gave informed consent and filled out a Parent Visit Questionnaire. The clinician completed a Clinician Visit Questionnaire following the visit and did not see the parent data.

For the follow-up study, we selected all minority patients, all uninsured patients, every fourth managed-care patient, and every fourth fee-for-service patient. Testing for disparities in the quality of care associated with race/ethnicity and insurance was a primary goal of the CBS. We oversampled uninsured and minority patients to have sufficient numbers to test for these disparities.

MEASURES

Practice Questionnaire

The practice questionnaire included questions about the clinician's sex, age, whether she had completed a mental health fellowship, and whether there was a mental health specialist onsite.

Table II. Follow-Up Visits by Type of Clinician Visited

Type of Clinician Visited	0 Visits	0 or 1 Visits	Median	Mean	SD
Own doctor	12%	52%	1	2.0	2.3
Other Non-Mental Health Doctors	83%	91%	0	0.4	1.5
Mental Health Specialists	73%	81%	0	1.8	5.2
All Visits	7%	36%	2	4.2	6.3

Parent Visit Questionnaire

The parent visit questionnaire included questions about the child's age, sex, race, ethnicity, and whether the child lived in a single-parent household. It also included the Pediatric Symptom Checklist (PSC).²⁴ We used three PSC subscales²⁵: (1) Attention problems, (2) externalizing problems (conflicts with others), and (3) internalizing problems (child's inner distress). These subscales have high internal consistency ($\alpha \geq 0.79$) and good agreement with criterion instruments.²⁵

Clinician Visit Questionnaire

The PCC checked whether the child "is my primary care patient" and reported the child's insurance, if any. The survey also included a checklist of child psychosocial problems. The clinicians checked "attention deficit/hyperactivity problems" for all children in this report. It also asked what treatment was provided (specialist referral, counseling, or prescription of medication).

Follow-Up Questionnaire

Six months after the index visit, parents were asked how many times their child had seen the child's own doctor and how many times they had seen a mental health specialist.

Analysis Plan

Whether families returned surveys was a factor of interest. Therefore, we conducted regressions that used the Heckman method²⁶ (as implemented in Stata²⁷) to correct for the nonrandom survey return. We corrected for the index visit variables that predicted nonreturned surveys (Table I): single-parent status, black race, Hispanic ethnicity, being on Medicaid or not having fee-for-service insurance, high PSC-17 externalizing score, not having a "my patient" relationship with the PCC, receipt of a specialist referral, and receipt of counseling.

We used the Heckman method to compute a regression in which the log-transformed count of PCC visits was the dependent variable and child, clinician, and visit factors were the independent variables. We also examined the factors associated with mental health specialist visits. Because such visits were less common, we looked at whether children had any specialist visits using probit regression, again corrected for selection bias using Heckman Method.

All tests were corrected for the clustering of patients by clinician²⁸, and we corrected for multiple comparisons using the Bonferroni technique.

RESULTS

Attention Problems and Medication in Index Visits

Clinicians identified children as having an attention problem in 9.2% of visits in the CBS sample (95% CI = [8.8%, 9.6%], N = 21,065 visits). Medications were prescribed for 52.3% of identified children (95% CI = [50.1%, 54.6%], N = 1,947 visits), who comprised 4.8% of visits (95% CI = [4.6%, 5.1%], N = 21,065 visits). Clinicians identified 94.2% of medications for children identified with attention problems as stimulants (95% CI = [92.6%, 95.6%], N = 1109 visits).

Follow-Up Visits by Families with Children Identified with Attention Problems

Table II shows that few patients received continuous care from their PCCs. Table III shows that follow-up visits were more common only when the clinician had completed a fellowship including mental health training. Finally, Table IV shows that children were more likely to see a mental health specialist when they came from black families, were on Medicaid, had a high level of internalizing symptoms, and had been referred to a specialist at the index visit. Rates of specialist use were higher for black children among children not receiving medication prescriptions (29% versus 23%), but the difference was greater among children who did receive prescriptions (41% versus 27%; $P = 0.04$).

DISCUSSION

Children identified with ADHD, including those prescribed medication, had a median of only one follow-up visit. This is too few visits to permit adjustment of medication or support adherence to treatment. This gap in care was not filled by mental health specialty referral, since less than one child in three had such contact. Children receiving Medicaid were more likely to see a specialist, suggesting that this coverage improves access of families to follow-up care. Medicaid does not include any patient cost-sharing for mental health care. We were surprised to find that black families were more likely to visit a mental health specialist, given that black adults appear to be less likely to receive several kinds of specialist care and procedures.²⁹ The higher rate of specialist use by black families was most pronounced when children received prescriptions of medications at the index visit. One possible explanation is that black families are more concerned about psychotropic medications, and these concerns prompt follow-up visits.

Table III. Factors associated with log-transformed count of visits to own doctor

Variable	B	95% CI	P value
Age	-0.015	(-0.028, -0.002)	.026
Male child	-0.002	(-0.093, 0.09)	.972
Single parent	0.036	(-0.052, 0.124)	.422
Black	0.05	(-0.161, 0.261)	.644
Hispanic ethnicity	0.231	(-0.011, 0.473)	.062
Managed care	-0.116	(-0.31, 0.077)	.238
Uninsured	-0.244	(-0.477, -0.011)	.041
Fee for service	-0.112	(-0.318, 0.094)	.285
Medicaid	0.083	(-0.04, 0.206)	.185
PSC-17 Internalizing	0.006	(-0.013, 0.026)	.519
PSC-17 Externalizing	0.000	(-0.017, 0.018)	.968
PSC-17 Attention	0.018	(-0.005, 0.041)	.121
Male clinician	0.097	(0.013, 0.182)	.024
Clinician age	-0.002	(-0.008, 0.003)	.45
Mental health fellowship	0.154	(0.032, 0.277)	.014*
Specialist onsite	-0.056	(-0.139, 0.026)	.182
Patient on medication	0.004	(-0.114, 0.123)	.942
Referred to specialist	0.047	(-0.063, 0.157)	.403
Counseled family	0.044	(-0.049, 0.136)	.355
My patient	0.031	(-0.073, 0.135)	.564

*Statistically significant, using Bonferroni correction to control for multiple comparisons.

Strengths of our study include its large, representative sample and its prospective design. A weakness is that our decision to obtain a large sample of office visits from a national sample of primary care offices required that we use brief surveys and prevented us from obtaining independent diagnoses of the children. In addition, we did not collect data on other ways that PCCs may have followed their patients, such as telephoning. Finally, our follow-up procedure oversampled minority groups and some insurance types, which may limit the generalizability of our findings.

Our findings about the rates of follow-up visits are similar to those found by Olfson et al⁶ and somewhat higher than those reported by the MTA group.¹⁴ Because children in the MTA usual care group received five study assessments, parents may have felt less need for physician visits than if they had not been in the trial.

Follow-up care for children identified with attention-deficit/hyperactivity problems falls below the standards described in professional guidelines. A recent study concluded that American adults receive 56.5% of the follow-up health care appropriate for their medical conditions.³⁰ Our results suggest that follow-up care for children identified with ADHD is at least this poor.

Although fellowship training in mental health for PCCs appeared to improve care, simply changing the skill set of PCCs is unlikely to be sufficient. Most effective chronic illness management programs are multidisciplinary and involve changes in the organization of service delivery such as the

Table IV. Factors associated with having a visit to a mental health specialist

Variable	B	95% CI	P value
Age	-0.007	(-0.028, 0.013)	.471
Male child	-0.037	(-0.186, 0.112)	.626
Single parent	0.200	(0.039, 0.361)	.015
Black	0.351	(0.082, 0.620)	.010*
Hispanic ethnicity	0.326	(-0.117, 0.770)	.149
Managed care	0.160	(-0.078, 0.398)	.188
Uninsured	0.230	(-0.074, 0.534)	.138
Fee for service	0.243	(-0.036, 0.523)	.088
Medicaid	0.286	(0.064, 0.509)	.012*
PSC-17 Internalizing	0.041	(0.011, 0.071)	.008*
PSC-17 Externalizing	0.038	(0.006, 0.070)	.020
PSC-17 Attention	0.042	(0.008, 0.075)	.015
Male clinician	-0.106	(-0.236, 0.023)	.108
Clinician age	0.001	(-0.008, 0.010)	.815
Mental health fellowship	0.022	(-0.173, 0.216)	.828
Specialist onsite	-0.017	(-0.145, 0.110)	.793
Patient on medication	0.017	(-0.111, 0.145)	.796
Referred to specialist	0.371	(0.150, 0.591)	.001*
Counseled family	0.070	(-0.111, 0.252)	.448
My patient	-0.110	(-0.277, 0.058)	.200

*Statistically significant, using Bonferroni correction to control for multiple comparisons.

use of non-physician care managers.³¹ Systematic practice improvements such as collaborative care management models used to improve the care of depressive illness in adults³² deserve careful study.³³

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