

TECHNICAL PAPERS ON HEALTH AND BEHAVIOR MEASUREMENT

TECHNICAL PAPER 76

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Reference Citation

Bender B, Bartlett SJ, Rand CS, Turner CF, Wamboldt FS, Zhang L. (2007) Impact of Reporting Mode on Accuracy of Child and Parent Report of Adherence with Asthma Controller Medication. *Pediatrics*, 120: e471 - e477.

Impact of Interview Mode on Accuracy of Child and Parent Report of Adherence With Asthma-Controller Medication

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The authors have indicated they have no financial relationships relevant to this article to disclose.

ABSTRACT

OBJECTIVES. Parents and children often overreport adherence to treatment regimens, which in turn complicates interpretation and application of clinical trial findings. The objective of this investigation was to test the effect of reporting mode on accuracy of inhaled corticosteroid-adherence reporting in children with asthma and their parents under conditions similar to those of an asthma clinical trial.

PATIENTS AND METHODS. Participants included 104 children who were being treated with an inhaled corticosteroid delivered by a metered-dose inhaler for asthma diagnosed by their health care provider. Each parent and child dyad was randomly assigned to 1 of 3 self-report adherence-assessment modes: (1) audio computer-assisted self-interviewing; (2) face-to-face interview with study staff; or (3) self-administered paper-and-pencil questionnaire. At the 4 monthly visits, the parent and child were interviewed separately and asked questions about adherence on the previous day and in the past week. Electronic devices were attached to the each participant's metered-dose inhaler to provide an objective record of actual daily medication activations.

RESULTS. Both children and parents greatly overreported their inhaled corticosteroid adherence when queried about either time frame (1 day or 1 week) in any of the 3 interview modes. One of 3 responses reported full adherence when no medication had been taken. Inconsistent with the study hypothesis, discrepancy between self-report and objectively measured adherence was greatest in the computer-interview condition. In the optimal circumstance where children were interviewed by study staff about their adherence within the previous 24 hours, reported adherence was within the $\pm 25\%$ accuracy range for only half of the participants. Larger discrepancy scores were observed for both parents and children when reporting by computer or questionnaire.

CONCLUSIONS. Under the best of conditions in this study, accuracy of self-report was insufficient to provide a stand-alone measure of adherence. Verification of treatment adherence by objective measures remains necessary.

www.pediatrics.org/cgi/doi/10.1542/peds.2006-3457

doi:10.1542/peds.2006-3457

Key Words

asthma, corticosteroids, patient nonadherence, interview mode

Abbreviations

ICS—inhaled corticosteroid
ACASI—audio computer-assisted self-interviewing
MDI—metered-dose inhaler

Accepted for publication Feb 16, 2007

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275). Copyright © 2007 by the American Academy of Pediatrics

SELF-REPORT IS THE most commonly used method for assessing parent and child health-related behaviors in clinical and research settings. Researchers and health care providers routinely rely on parent and patient reports of health-related behaviors, including health-promoting (eg, exercise, diet, and medication adherence) and health-jeopardizing (eg, smoking and illicit drug use) behaviors. Pediatric clinical trials rely on self-report, often including parent- and patient-provided information about symptoms, behaviors, quality of life, and treatment adherence. The accuracy of conclusions based on these data is dependent on the validity of the self-reported information.

The accuracy of self-reports of health-related behavior, in particular, medication treatment adherence, has been examined across a wide range of diseases and medical regimens and has been found to be highly variable and, in many instances, markedly inaccurate.¹ Children with asthma frequently take no more than half of their prescribed controller medication, whereas they report much higher levels of adherence. For example, electronic monitoring documented that children with asthma used only 50% of prescribed inhaled corticosteroid (ICS) over 6 months, whereas the patients and their mothers reported >80% adherence.²

Accuracy of parent and child self-reported adherence may be influenced by a number of variables, including content, memory ability, social desirability, characteristics of the respondent, and assessment mode. Content that is potentially embarrassing to parents, such as failure to vaccinate their child,³ may lead to underreporting. Younger children have less developed cognitive skills and, therefore, may do less well than older children on tasks that demand memory ability.⁴ Parents who are strongly influenced by the social desirability effect, reflecting the desire to present a positive impression to the health care provider or researcher, will tend to underreport undesirable behaviors, such as excessive eating,⁵ or overreport desirable behaviors, such as exercise.⁶ Information accuracy also depends on the respondent. Parents and children may produce differing accounts of the child's medication adherence,² and children may underreport behaviors such as alcohol use if a parent is present.⁷ Finally, variation in assessment mode, including questionnaire, direct interview, or computer responding, can influence reporting bias.⁸

Pediatric researchers seeking to maximize self-report accuracy to obtain valid information should consider the variables that influence accuracy. For example, patient recall accuracy improves when possibility of embarrassment is reduced and recall is limited to events that occurred in the last 24 hours.^{9,10} Multiple 24-hour interviews can be combined to produce a comprehensive estimate of treatment adherence.¹⁰⁻¹² Mode of reporting is another determinant of accuracy but seems to interact with other variables, most particularly content and risk

of embarrassment. Face-to-face inquiry about stigmatized behaviors may lead to less forthcoming responses. For example, compared with face-to-face inquiry, interviews using audio computer-assisted self-interviewing (ACASI) in assessing parent reports of infant feeding practices found that ACASI seemed to decrease socially desirable responses and improve information quality.¹³ However, in these studies, whereas relative rates of reported events were compared between inquiry conditions, no objective behavior measure was included to determine actual accuracy of each self-report condition.

The admission of treatment nonadherence is a source of potential embarrassment and, therefore, may account for the tendency of parents and children to largely overreport their use of medications. However, it is not known whether nonadherence is stigmatized to a degree so that increased anonymity improves reporting accuracy. The purpose of this investigation was to test the effect of reporting mode on accuracy of ICS adherence reporting in children with asthma under conditions similar to an asthma clinical trial. We hypothesized that adherence report accuracy would be highest where parent and child interviews were conducted by a computer with no other person present and lowest when conducted in a face-to-face interview with study personnel. Study design included random assignment of participants to 3 assessment modes reflecting differing levels of potential exposure to interpersonal embarrassment. Multiple respondents (children and parents) and questions were included to contrast additional variables that might impact recall accuracy. Objective measurement of adherence was included to allow for the determination of relative discrepancy among the 3 self-report conditions.

METHODS

Participants were recruited through advertising and referrals from multiple practices and clinics in the Denver, Colorado, area and met the following inclusion criteria: (1) aged 8 to 18 years; (2) current diagnosis of asthma by a health care provider; (3) currently under a health care provider's care for asthma; (4) currently prescribed ICS delivered by metered-dose inhaler (MDI); (5) otherwise in good general health; and (6) no known significant learning or psychological problems.

One parent was required to participate with their child. Children <18 years of age provided informed assent; parents of these children and participants who were 18 years of age provided informed consent. Each parent and child dyad was randomly assigned to 1 of 3 self-report adherence-assessment modes: (1) ACASI; (2) face-to-face interview with study staff; or (3) self-administered paper-and-pencil questionnaire. Research assistants who conducted each visit were unblinded, but the investigators remained blind to condition until completion of data collection. Visits occurred at baseline, 1

month, 2 months, 3 months, and 4 months. The 4-month study period with monthly visits was included to provide a sufficient length of time to document the comparative validity of the adherence measures. At each 45-minute clinic visit, the participant's MDI was equipped with a newly initialized MDIlog (WestMed, Englewood, CO) or Doser (Meditrack, Hudson, MA), which are electronic devices that attach to the side of a plastic MDI or the top of the canister and record daily activations of the MDI on a microchip. To track device failures and prevent data contamination, all of the devices were tested immediately before they were given to participants and again after they were returned at monthly visits.

Parents were physically separated from the child for the period when they were reporting adherence. The ACASI technology was developed by researchers at Research Triangle Institute (Research Triangle Park, NC) and City University of New York to administer complex questionnaires in personal interview surveys.¹⁴ Interview procedures were piloted on the first 20 children meeting study inclusion criteria to determine that the children understood the questions and were able to respond using the ACASI system. Adherence questions were adapted from the Adherence in Clinical Trials Questionnaire¹⁵ and focused on puffs of ICS taken on the previous day and in the past week. Adherence questions were identical across the 3 interview modes. At the baseline visit, questions were reviewed to assure that they were clearly understood by both parent and child. Procedures were explained for those in the ACASI condition, in which the participant wore headphones connected to the computer, heard each recorded question, responded by pushing a numbered button on the computer keyboard, and could elect to hear the question repeated.

Consistent with most clinical guidelines for the management of asthma, participants received asthma education and educational materials at study visits and were encouraged to adhere to their prescribed treatment protocol. All of the children received the same educational content in the 5 asthma education modules, which were culturally sensitive, required low literacy, and included (1) establishing a partnership to manage asthma, (2) asthma basics, (3) asthma medicines, inhaler/spacer skills, and using a peak flow meter, (4) action plan to manage asthma, and (5) triggers of asthma. This study was approved by the institutional review boards at National Jewish Medical and Research Center, Research Triangle Institute, and the City University of New York.

Data Analysis

Objective and self-reported adherence were determined separately for each of the 2 respondents (child and parent) and for each of the time periods (yesterday and last 7 days). Percentage of adherence was determined by

dividing the number of puffs taken (reported or recorded) by the number prescribed. Self-report discrepancy was the primary outcome variable and was obtained by subtracting each participant's self-report percentage of adherence from their objective measure percentage of adherence. Thus, positive discrepancy scores represent underreporting, whereas negative discrepancy scores represent overreporting of adherence. A 0 discrepancy indicates exact agreement between objective and self-report measures of adherence. A $\pm 25\%$ accuracy range was chosen for this analysis because, first, a precedent has been established of using a 25% drop in adherence as the cutoff between adequate and inadequate adherence¹⁶⁻¹⁸ and, second, because that range is below the average discrepancy scores reported previously for parents and children self-reporting adherence.²

All of the statistical analyses were conducted with SAS 9.1 (SAS Institute Inc, Cary, NC). Percentage of adherence of both the self-report and objective measures was truncated to 100% if it was $>100\%$ to prevent artificially elevating mean adherence. The nonparametric Kruskal-Wallis test was used to compare discrepancy scores. A generalized linear regression model (SAS Proc Genmod, SAS Institute Inc) was used to compare ordinal discrepancy scores among reporting modes with and without covariates (age, race, and gender). The ordinal discrepancy scores were assumed to have multinomial distributions with a cumulative logit link. The footnotes in Table 2 provide the categorization of ordinal discrepancy scores. For all of the analyses, 2-tailed tests were used, and *P* values of $\leq .05$ were determined to be statistically significant.

RESULTS

Subjects

Participants included 104 children and 104 parents. The parent group included 94 mothers, 8 fathers, and 2 guardians. Mean child age was 11.75 years (SD: 2.73; range: 8-18 years old). Boys comprised 53.9% of participants. Race of participants included 37.5% white, 26.0% black, 21.2% Hispanic, and 15.3% other (including Native American, Asian, and multiracial). The maximum attained education level of 75% of the parents included college attendance.

Adherence Discrepancy Scores According to Mode and Respondent

Sixty-four subjects had a Doser and 40 subjects had an MDIlog. Adherence-monitoring-device failures were detected at 25 visits, or 6% of total visits. These measurement intervals were omitted from all of the data analyses. Because discrepancy scores were not normally distributed, a nonparametric Kruskal-Wallis test was used to compare the 3 group median discrepancy scores

TABLE 1 Self-Report Discrepancy Scores

Self-Report Discrepancy Scores	ACASI	Clinical Interview	Self-Administered Questionnaire	<i>P</i> , Kruskal-Wallis Test
Child				
Yesterday	−50.0 (100.0)	−12.5 (50.0)	−29.1 (100.0)	.0145
Past 7 d	−42.9 (68.9)	−14.3 (42.9)	−17.3 (57.1)	.0002
Parent				
Yesterday	−50.0 (100.0)	−25.0 (100.0)	−50.0 (100.0)	.1433
Past 7 d	−46.4 (53.1)	−28.6 (51.8)	−30.3 (64.3)	.0040

Data are presented as median (interquartile range); interquartile range is the range between the 25th and 75th quartile of the variable.

and interquartile ranges (range between the 25th and 75th quartiles; Table 1). For child self-reports, the discrepancy scores were significantly different among the 3 interview modes on both the yesterday and last-7-days questions, with greatest discrepancy in the ACASI mode. For parent self-reports, the discrepancy scores were significantly different among the 3 interview modes on the last-7-days question, where ACASI mode produced the lowest median and the largest discrepancies. Mode differences were not found for the yesterday question, although the data trend followed a pattern similar to the last-7-days question where ACASI mode had the least number of accurate scores and the most −100% scores, suggesting that parents were least accurate in the ACASI mode (Table 1).

Self-report discrepancy frequencies were compared for both the yesterday and past-week questions (Figs 1 and 2). More than half of children and parents overreported adherence by $\geq 25\%$ and, in the ACASI mode, more than one third reported 100% adherence when no ICS had been used. Underreporting of adherence occurred very infrequently. Child self-re-

ported adherence was in the $\pm 25\%$ accuracy range for 50% and 48.7% of those children in the clinical interview condition for the yesterday and last-7-days questions, respectively. In contrast, child reports had 39.2% and 32.8% of responses in the $\pm 25\%$ accuracy range for the ACASI condition for the yesterday and last-7-days questions, respectively. Results were similar for parents, where 47.8% and 41.4% were in the $\pm 25\%$ accuracy range when interviewed with the 2 kinds of questions in contrast to 29.4% when responding to both questions via computer. Increasing the accuracy range to $\pm 35\%$ or decreasing it to $\pm 15\%$ predictably resulted in greater or fewer numbers of accurate reports, respectively. Nonetheless, where group differences emerged, the ACASI group produced the least proportion of accurate responses (data not shown).

Effect of Subject Characteristics on Discrepancy Scores

To determine whether mode differences were influenced by age, gender, or race, a generalized linear regression model on the discrepancy scores was used.

TABLE 2 Comparison of Ordinal Discrepancy Scores Among Interview Modes Using Generalized Linear Regression Models Adjusted for Age, Race, and Gender

Outcome Variable	Report	Mode	OR	95% Confidence Limits		<i>P</i> for Testing Whether OR = 1	<i>P</i> for Comparing Modes
				Lower	Upper		
ODS for yesterday's adherence	Child	ACASI	1.553	0.893	2.699	.1191	.0430
		Clinical	0.735	0.434	1.243	.2504	
		SAQ	1.000	1.000	1.000	–	
	Parent	ACASI	1.460	0.833	2.560	.1862	
		Clinical	0.915	0.531	1.577	.7484	
		SAQ	1.000	1.000	1.000	–	
ODS for adherence in past 7 d	Child	ACASI	2.001	1.091	3.668	.0250	.0163
		Clinical	0.774	0.417	1.437	.4171	
		SAQ	1.000	1.000	1.000	–	
	Parent	ACASI	1.984	1.077	3.653	.0279	
		Clinical	1.101	0.583	2.079	.7673	
		SAQ	1.000	1.000	1.000	–	

OR indicates odds ratio; clinical, clinical face-to-face interview; SAQ, self-administered paper-and-pencil questionnaire; ODS, ordinal discrepancy score; – indicates reference data. For discrepancy scores on yesterday's adherence, ODS = 1 if discrepancy scores = −100; ODS = 2 if −100 < discrepancy scores < 0; ODS = 3 if discrepancy scores = 0; and ODS = 4 if discrepancy scores > 0. For discrepancy scores on past 7 days' adherence, ODS = 1 if discrepancy scores = −100; ODS = 2 if −100 < discrepancy scores less than or equal to −75; ODS = 3 if −75 < discrepancy scores less than or equal to −50; ODS = 4 if −50 < discrepancy scores less than or equal to −25; ODS = 5 if −25 < discrepancy scores < 0; ODS = 6 if discrepancy scores = 0; and ODS = 7 if discrepancy scores > 0.

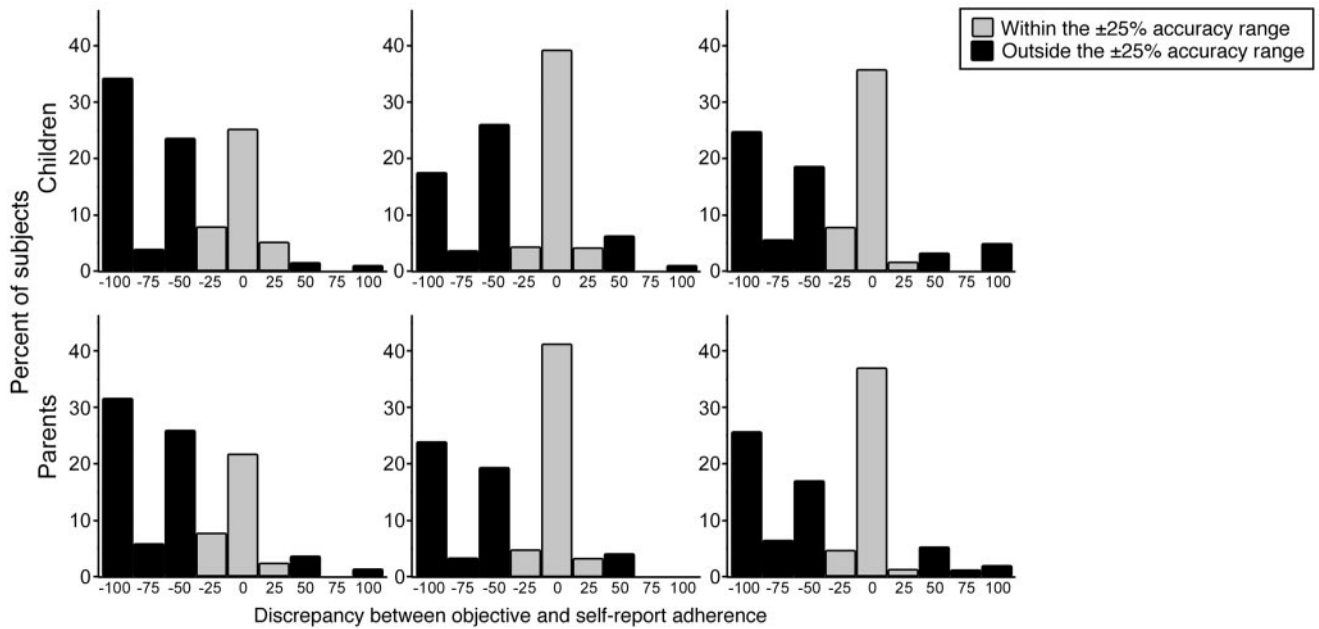


FIGURE 1
Self-report discrepancy frequencies for yesterday questions: ACASI (left), clinical (middle), and questionnaire (right).

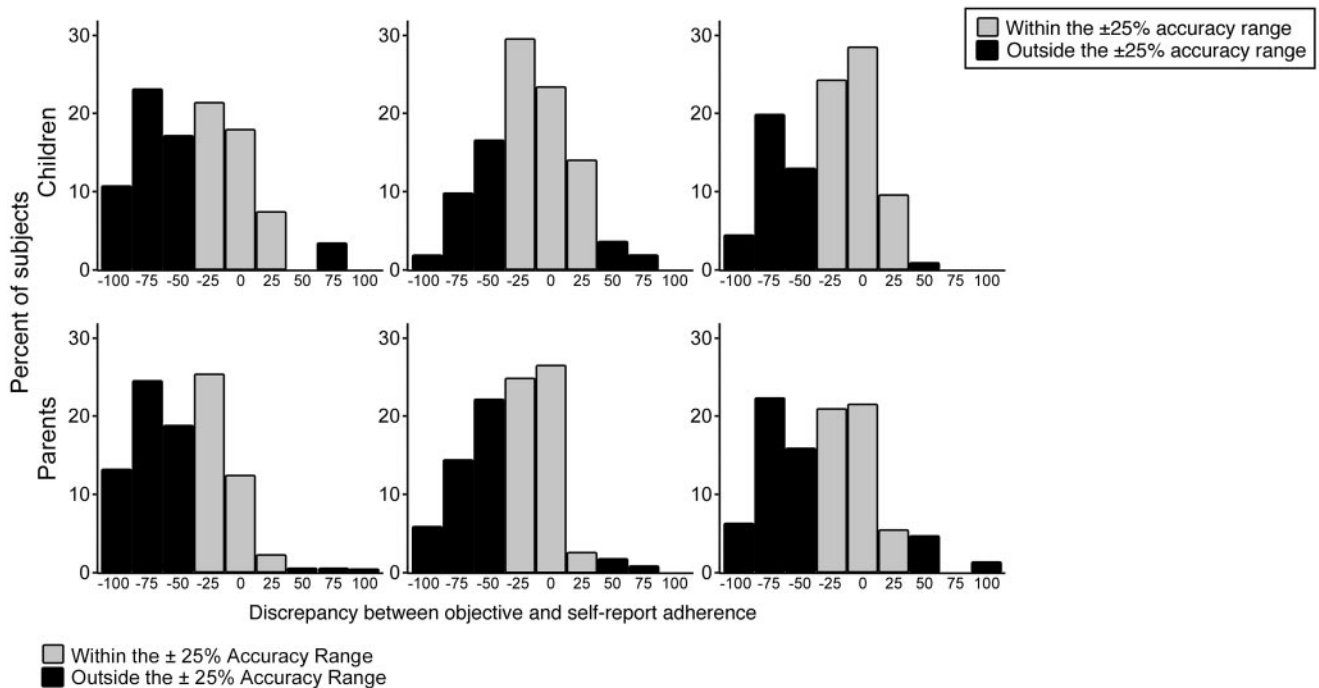


FIGURE 2
Self-report discrepancy frequencies for past-week questions: ACASI (left), clinical (middle), and questionnaire (right).

Because the discrepancy scores were not normally distributed and tended to cluster, the scores were converted to an ordinal variable. The fact that each subject had ≤ 4 measurements was accounted for in the model. As in the nonparametric comparison of medians, this model revealed self-report discrepancies that

were greatest in the ACASI condition for both questions (yesterday and past 7 days) when the child was queried and a trend ($P = .068$) indicating a similar pattern when parents were queried about adherence over the past 7 days. These results were not affected when age, gender, and race were added as covariates

into the model (Table 2). Device (Doser versus MDILog) was also entered as a covariate but, because it was nonsignificant, was not included in the final model.

DISCUSSION

Both children and parents greatly overreported their ICS adherence. Approximately 1 of 3 responses reported full adherence when no medication had been taken (ACASI mode, yesterday's adherence). Under the best of conditions in this study, accuracy of self-report was insufficient to provide a stand-alone measure of adherence. In the optimal circumstance where children were interviewed by study staff about their adherence within the previous 24 hours, reported adherence was within the accurate range for only half of the observations. Of the remaining participants, 46% exaggerated their adherence by >25%. The mode of self-reporting influenced parent and child accuracy but not in the direction hypothesized. Contrary to our prediction, computerized adherence self-reporting was less accurate than face-to-face interview or questionnaire; both children and parents in the ACASI condition produced the largest average overreporting of adherence. The reason for increased discrepancy in the ACASI condition is not evident. The ACASI procedure was more technically demanding than the other conditions and required use of the computer keyboard. The possibility that the cognitive demands of the ACASI condition may have resulted in more errors, however, is inconsistent with the finding that age did not alter the mode effect and that there was little underreporting, both of which should have occurred if the ACASI condition was a cause of confusion. It seems that either the ACASI condition did not decrease the embarrassment of admitting nonadherence or that embarrassment is not a primary reason for exaggerating adherence. In most of our analyses, face-to-face interviews with parents and children yielded the least discrepancy between self-report and objective adherence measure. This result supports the conclusion that embarrassment was not a determining factor influencing mode differences and stands in contrast to adult studies demonstrating that ACASI reporting of risky sexual behavior or illicit drug use increased over face-to-face¹⁹ or telephone²⁰ interviews. The reduced sense of shame, which may have accounted for increased reporting of those stigmatized behaviors, seems not to be a determining factor in the case of medication adherence reporting in parents and children.

Inadequate accounting of adherence may compromise clinical trials and the treatment guidelines that they inform. Data from clinical trials provide the evidence base for pediatric treatment guidelines. When information about dose-response sensitivity does not take into account variability in adherence of trial participants, the possibility of recommending unnecessarily high drug

dose increases.²¹ Diary-card reporting of medication in clinical trials, long the standard for establishing adherence sufficient to support a trial's validity, has been shown repeatedly to overestimate adherence. For example, diaries resulted in overreporting of adherence by 67% in a trial of treatment for chronic obstructive pulmonary disease²² and by 60% and 68% in studies of children² and adults²³ with asthma. Evidence from this study, in combination with previous research, indicates that no self-report methodology has yet been demonstrated to match objective adherence measures, yet self-report measures of adherence continue to be used in pediatric clinical trials more frequently than electronic adherence measures.

Patient or parent misrepresentation of medication adherence in the pediatrician's office may also result in unnecessary escalation of treatment while failing to remediate an important factor underlying poor illness control, medication nonadherence. Although this study was not designed to evaluate adherence reporting in pediatric offices, it nonetheless suggests that accuracy of self-report in clinical settings is of concern and warrants further investigation, particularly in light of findings that patients frequently provide inaccurate information on medication adherence to their physicians.²⁴⁻²⁵

Limitations to this study should be considered. The relative accuracy of 24-hour and 7-day adherence queries may not be best established through simultaneous questioning. The $\pm 25\%$ accuracy range chosen for this analysis may not represent an acceptable margin of accuracy for all physicians and researchers. The 5-module patient education program may have increased adherence of participants, although it is likely that such effects would have been distributed equally across conditions. Measurement of patient or parent embarrassment, not included in this study, should be incorporated in future investigations of self-report accuracy. The interview methodology used in this study did not include the use of telephone-based adherence inquiry, which may provide a greater degree of anonymity and, therefore, greater encouragement of disclosure than seen in the 3 conditions included here. Pediatricians who invest time and effort communicating effectively with families may obtain more accurate adherence information than seen in this investigation.²⁶ Objective adherence measures, although more accurate than self-report, may still introduce measurement error, which must be managed by judicious data inspection and management, including truncation of daily adherence scores.²⁷⁻²⁹

CONCLUSIONS

Additional manipulation of the conditions under which self-reporting is conducted may produce more accurate methods for measuring adherence through patient reports. Until that time, however, using electronic devices, weighing or counting returned medication, and tracking

pharmacy refills remain superior to patient reports for measuring adherence.

ACKNOWLEDGMENTS

This work was supported by General Clinical Research Centers grant M01-RR00051 and National Heart, Lung, and Blood Institute grant 5R01HL64199.

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Pediatrics 2007;120:e471-e477; originally published online Aug 13, 2007;
DOI: 10.1542/peds.2006-3457

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