A multi-method assessment of treatment adherence for children with cystic fibrosis

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Abstract

Background: Adherence rates for chronic pediatric conditions are approximately 50%. The primary objective of the study was to assess rates of adherence using four different measurement methods for children with cystic fibrosis (CF).

Methods: Participants included 37 children with CF between 6 and 13 years of age and their primary caregivers. Adherence measures included parent and child self-reports, diary data, pharmacy refill history, and electronic monitors.

Results: Results suggested that rates of adherence varied by treatment component and across measurement methods. However, when examining more objective measures, rates of overall adherence were below 50% for children with CF, indicating generally poor adherence to the treatment regimen. For example, rates of adherence to enzyme medications, using electronic and diary measures, ranged from 27% to 46%.

Conclusions: The multi-method measurement approach provided unique information regarding rates of adherence for each disease condition by type of treatment component. Accurately measuring rates of treatment adherence for children with CF is an important step in developing effective interventions to influence these behaviors.

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1. Introduction

Medical treatments for chronic conditions, such as cystic fibrosis (CF) can be burdensome, time-consuming, and costly. Given the long-term and arduous nature of these regimens, poor adherence is commonly reported, with average rates of adherence generally below 50% [1]. Specifically, studies of children with CF have reported adherence rates of 40–47% for chest physical therapy, a form of airway clearance [2,3], while adherence to dietary recommendations have been lower, ranging from 16% to 20% [3–5]. Two recent pediatric studies suggest that...
adherence rates for dornase alpha ranges from 67% to 84% [6,7], while the adult literature cites adherence rates between 24% and 82% [8]. However, these adherence estimates are typically based on self-report measures or vial counts (dornase alpha). New measurement methods and technologies are now available that may be used individually or in combination to more reliably measure adherence behaviors.

In addition, little information is available on rates of adherence for children to new medications, such as nebulized antibiotics (e.g., tobramycin) or medications critical to nutritional outcomes, such as pancreatic enzymes. Lack of information regarding adherence makes it difficult for physicians to determine the impact of these treatments on health status or weigh the cost/benefit ratio for prescribing these costly medications for their patients. Poor adherence can have serious consequences, including increased morbidity and mortality, reduced quality of life, and greater health care costs [9–11]. Therefore, it is critically important to accurately measure adherence in order to identify and target factors that may positively influence these behaviors. The purpose of the current study is to document rates of adherence to medical regimens for CF using four different measurement methods.

1.1. Measuring adherence

One reason for the wide range of adherence rates across studies is the lack of a consistent measurement approach. Several methods of assessment have been used, including self-report, pharmacy refill data, diary methods, and electronic monitoring [12–14]. However, each method has its own strengths and weaknesses, suggesting a need for a multi-method assessment of adherence [13,14]. To date, no studies have documented rates of adherence using all four methods in children with CF.

1.2. Self-report

Patient self-report is the most common adherence measurement approach because it is practical and inexpensive [1]. Burkhart and Dunbar-Jacob found that 71% of studies examining pediatric adherence from 1987 to 1996 utilized self-report measures [15]. Of those studies, more than one-third (36%) utilized self-report as the only measure. However, self-reported adherence can be seriously inflated. For example, research has documented 95% adherence to inhaled corticosteroids for self-report versus 54% for electronic monitoring [16]. These studies highlight the social desirability and recall biases that may be associated with self-report, as well as the problems of relying exclusively on this type of measurement.

1.3. Prescription refill history

Prescription refill histories are another useful method for measuring adherence. Pharmacy databases provide information on the type and amount of medication that is dispensed, as well as the dates of refills. However, pharmacy data cannot determine whether the medications were consumed or taken appropriately [12]. Further, they do not capture samples dispensed at physician offices or emergency rooms. Thus, this measure provides global estimates of medication adherence that are useful for identifying patients who clearly fail to refill prescriptions [17,18]. To date, no studies have reported rates of adherence for CF patients using pharmacy data.

1.4. Daily phone diary

Daily phone diary methods have also been used in several studies of adherence [2,19,20]. The daily phone diary (DPD) has been utilized with CF populations and has demonstrated good reliability and validity [21]. The DPD uses a cued recall procedure to track parents through their activities over the past 24 h [21,22], eliciting information about all activities lasting more than 5 min, including the type of activity, its duration, companions, and a rating of mood. Although diaries are a form of self-report, the unobtrusive nature of the 24-h recall process (i.e., all activities, not just adherence behaviors are reported) reduces social desirability responding and its immediacy reduces memory and recall problems. This potentially increases the accuracy of the respondent’s report and its temporal precision [2]. The disadvantages of the DPD method include its time-intensive nature, the amount and complexity of the data that is obtained, and its limited usefulness for younger children [13]. Phone diary methods may be uniquely beneficial in allowing researchers to gather information about the processes related to poor disease management. For example, phone diaries can reveal that a child missed treatment because of a sports activity that occurred during the usual treatment time [20]. Thus, the reasons underlying poor adherence may be best identified through diary methods.

1.5. Electronic monitoring

With the advent of new microchip technologies, electronic monitoring devices have now been developed to assess a subset of adherence behaviors, including use of metered dose inhalers (MDIs), opening pill bottles, and use of nebulizer machines [23,24]. Several electronic monitoring devices are available to measure adherence behaviors in children with CF, including MEMS caps, MDI monitors, and vest monitors. These monitoring devices allow for precise recording of the date, time and duration of treatments. They also allow for continuous, long-term measurement that is unaffected by response biases [13]. Electronic monitors can identify a variety of adherence problems, including under- and over-use of medications, improper technique in taking medications, delayed dosing, and drug “holidays” [1,13,14]. Unfortunately, as with all mechanical
devices, electronic monitors can malfunction and data can be lost. Furthermore, they are expensive and may not be feasible for clinical use [1]. Although electronic monitors have some limitations, as they are “debugged,” they may become the future “gold standard” of adherence measurement [25]. In the current study, convergence among these four types of measures (e.g., self-report, prescription refill data, daily diaries, and electronic monitoring) was compared.

1.6. Current study

The first objective of this study was to document rates of adherence to medical regimens for children with CF using four methods of measurement. Rates of adherence to different components of the regimen were expected to vary, with average rates of adherence less than 50%. The second objective was to assess convergence across the different adherence measurement methods and identify the measure that correlated most strongly with electronic monitoring. Greatest concordance was expected between the diary measure and electronic data as shown in a prior study [20].

2. Materials and methods

2.1. Participants

Participants were recruited from two pediatric pulmonary clinics in the southeastern United States. Eligibility criteria included: 1) aged between 6 and 13 years, 2) a documented diagnosis of CF by a physician for at least the prior year, and 3) no major comorbid diagnoses (e.g., cerebral palsy, cancer). Potential participants were mailed information letters and brochures explaining the study. Participants were then contacted by phone or during routine clinic visits to review the study.

2.2. Procedure

The protocol and consent forms were approved by the appropriate Institutional Review Boards/Human Research Ethics Committee. Potential participants were identified from the schedule of upcoming, routine clinic visits. Participants were initially mailed information letters and brochures explaining the study prior to their clinic visit and then approached in clinic by a member of the research team to answer questions about the study and obtain consent/assent. After obtaining consent, primary caregivers and children participated in a clinical interview with trained graduate students or research assistants and then completed several questionnaires, including a demographics form and self-report measures of adherence (parents and children over 10 years of age). They were also scheduled to complete a daily phone diary over 2 days prior to their next clinic visit and utilize electronic monitors (e.g., MEMS cap) for enzymes over a 3-month period. Pharmacy refill history was also collected at the end of the study for this 3-month study period. In order to decrease social desirability responding, participants were told that information from the interviews would not be shared with the health care team. Pulmonary function tests were also conducted to assess the respiratory health status at each visit. Participants were offered a $5 gift certificate to local stores for their participation, $10 for completing daily phone diaries, and $10 gift certificates for returning electronic monitors.

2.3. Measures

2.3.1. Background information form

Parents completed a Background Information Form at the initial visit which asked about the child’s date of birth, gender, parent’s age, socioeconomic status, occupation, and composition of the family. Information about the child’s medical history was also collected from the parent, including date of diagnosis, presence of siblings with chronic illnesses, and comorbid diagnoses.

2.3.2. Prescribed treatment plan

The Prescribed Treatment Plan (PTP) is a brief instrument completed by physicians that documents the current treatment regimen [13]. Each component of the child’s regimen (e.g., medication, type, dosage, timing, method of administration) is listed and is circled by the physician. The PTP was completed at each clinic visit and took less than 2 min to complete.

2.3.3. Disease management interview

The Disease Management Interview-CF (DMI-CF) is a 51-item self-report measure of adherence for patients with CF [13]. Before the interview, the challenges of managing the child’s regimen were normalized for the family in order to promote honest responding [26], using the following statement “Most parents find it difficult to do all of the treatments each day that are required for good CF care. We are interested in knowing what you are currently doing with your child for their care.” Parents were asked to consider the disease management regimen completed over the past 2 weeks, with the exception of medications utilized on an aperiodic basis, such as oral antibiotics and aerosolized antibiotics. For these medications, parents were asked to describe their use over the past 3 months.

For each component of the regimen, children (over 10 years of age) and parents were asked separately about the frequency and duration of each treatment performed (e.g., chest physical therapy for 30 min, twice a day). Children were shown pictures of possible medications to assist them in reporting.

2.3.4. Prescription refill data

Consent to obtain prescription refill data from the patient’s pharmacy was obtained at the initial visit. Each
pharmacy was asked for comprehensive refill histories over the 3-month period of the study. However, due to implementation of new HIPPA guidelines, pharmacy refill history could not be obtained for 49% of patients.

2.3.5. Daily phone diary (DPD)

The DPD uses a cued recall procedure to track parents through their activities over the past 24 h [20–22]. For all activities lasting 5 min or longer, mothers reported the type of activity, duration, and who was present. The interviewer initiated all phone calls and assisted each caregiver in reconstructing their day as accurately as possible by providing prompts, such as the time of day or information about the previous activity (“after you finished dinner, what did you do next?”). Each activity is recorded by the interviewer on a computer screen with clock hands which rotate through a 24-h clock, a set of activities, companions, and a rating scale for mood ranging from 1 (Extremely Negative) to 5 (Extremely Positive). A set of 2 DPDs (1 weekday and 1 weekend day) was conducted with the primary caretaker by phone. The DPD procedure took approximately 20–30 min to complete. The DPD has yielded reliable stability coefficients over a 3-week period ($r$ values = .61–.71, $p < .01$) and high levels of interrater reliability (>90%) in a CF population [27]. Furthermore, strong convergent validity was found for parental differential treatment between the DPD and both home interview and nightly rating scale measures for parents of toddlers [22] and between daily routines and the Self Observation Report Technique [28] (77–80% [27]). Overall, DPDs were completed for 31 patients with CF.

2.3.6. Electronic monitoring/counter method

Electronic monitoring provides an “objective” method of measuring adherence. However, due to the high costs of these devices, only enzyme medications were monitored.

The Medication Event Monitoring Systems (MEMS®) made by AARDEX Corporation was used to monitor adherence to enzyme medications. It stores dates and times for over 2000 doses. These data were downloaded to a central docking station via computer when patients returned the devices at the end of the study. Patients were asked to bring their enzyme medications in for their next clinic appointment and the medication was placed in the MEMS® bottle with the cap. The MEMS® cap did not account for the number of capsules taken at each snack or meal; it was assumed that patients extracted the correct number of capsules.

2.3.7. Health status

Pulmonary function tests are the gold standard for measuring respiratory functioning and lung damage for patients with CF. Forced expiratory volume in one second (FEV$_1$ % predicted) is used as the primary indicator of health status, using the Knudson equations for age, sex and weight [29]. Illness severity ratings are based on established cutoffs for mild (>70%), moderate (40%<$x$<69%), and severe (<39%) disease [30].

2.4. Statistical analyses

2.4.1. Calculating adherence scores

For each behavior that was monitored electronically, the number of treatments performed each day divided by the number of treatments prescribed was multiplied by 100 to determine percent adherence (e.g., % of enzymes taken each day). These percentages were calculated across the 3-month time period. This procedure was used to calculate rates of adherence from the self-report and diary measures. Truncated adherence rates for each treatment component (e.g., maximum of 100%) were utilized to reduce inflation due to overuse. This method has been utilized successfully in studies assessing adherence with electronic monitoring [31]. Rates of adherence for several components of the child’s treatment regimen (e.g., airway clearance, enzymes, inhaled corticosteroids, nebulized medications) were calculated. In addition, an overall adherence score was calculated across all treatments for each child. Overall adherence was calculated by summing all treatment adherence rates for treatments and dividing this by the number of treatments prescribed (e.g. 50% for enzymes, 100% for inhaled tobramycin, 75% airway clearance, 50% vitamins; [(50 + 100 + 75 + 50)/4 = 68.8%]). It is important to note that rates of adherence could not be calculated for medications that were PRN (e.g., as needed).

Prescription refill data was calculated for each medication prescribed. Rates of adherence for a single medication taken continuously were calculated by dividing the medication obtained during a 3-month interval by the total number of days in that interval (90 days). For example, if 30 days of medication were obtained over a period of 90 days, the prescription refill rate was 33%.

Descriptive analyses, including means, medians, and standard deviations, were calculated for rates of adherence across the four methods of assessment for each component of the treatment regimen and for overall adherence. Wilcoxon Signed Ranks Tests were conducted to examine convergence between the four measurement methods. Significance was identified as $p < .05$.

3. Results

3.1. Participants

Study participants included 37 children between the ages of 6 and 13 with a primary diagnosis of CF and their parents. Forty-three consecutive, potential participants were eligible for the study. Six eligible participants were not included for the following reasons: (a) five parents declined to participate (e.g., too busy) and (b) one patient was moving. No demographic or medical information was
available for those who declined to participate due to the new Health Insurance Portability and Accountability Act (HIPAA) regulations, which limits access to patient health information.

Twenty-six patients in the current study were part of a larger, longitudinal adherence intervention trial funded by the National Institutes of Health (NIH) [32]. Only self-report data were available for four children because they had begun an adherence intervention study, which could impact their subsequent adherence scores over the 3-month study period. Thus, no data were included in analyses from participants after they started the intervention.

Two children with CF dropped out of the study due to busy schedules or family illness prior to the 3-month assessment; however, self-report data were available for all of these participants. No significant differences were found between patients who dropped out of the study compared to those who completed on the following variables: disease severity, age, gender, parent-reported adherence or income ($p$ values=n.s.).

<table>
<thead>
<tr>
<th>Medication</th>
<th>Parent self-report</th>
<th>Child self-report</th>
<th>Diary</th>
<th>Pharmacy refill history</th>
<th>Electronic monitoring</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (S.D.)</td>
<td>Mean (S.D.)</td>
<td>Mean (S.D.)</td>
<td>Mean (S.D.)</td>
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<td></td>
<td>Median</td>
<td>Median</td>
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<td>Sample size</td>
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<tr>
<td>Enzymes ($n=36$)</td>
<td>89.5 (21.7)</td>
<td>90.0 (25.5)</td>
<td>27.4 (22.9)</td>
<td>46.4 (32.5)</td>
<td>42.5 (32.4)</td>
</tr>
<tr>
<td>Airway clearance ($n=36$)</td>
<td>74.4 (35.3)</td>
<td>66.9 (30.2)</td>
<td>51.1 (40.2)</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Frequency</td>
<td>73.5 (30.2)</td>
<td>69.4 (35.4)</td>
<td>64.2 (50.5)</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Duration</td>
<td>75.0</td>
<td>75.0</td>
<td>75.0</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Combined nebulized medications* ($n=21$)</td>
<td>82.4 (31.6)</td>
<td>80.0 (36.9)</td>
<td>47.6 (41.0)</td>
<td>68.3 (40.7)</td>
<td>100</td>
</tr>
<tr>
<td>Dornase alpha ($n=16$)</td>
<td>90.4 (25.9)</td>
<td>77.8 (44.1)</td>
<td>56.7 (45.8)</td>
<td>71.7 (41.7)</td>
<td>100</td>
</tr>
<tr>
<td>Inhaled tobramycin ($n=10$)</td>
<td>85.0 (33.7)</td>
<td>83.3 (25.8)</td>
<td>36.1 (35.6)</td>
<td>25.0</td>
<td>100</td>
</tr>
<tr>
<td>Vitamins ($n=34$)</td>
<td>88.4 (27.6)</td>
<td>93.8 (17.1)</td>
<td>22.2 (34.2)</td>
<td>33.71 (45.6)</td>
<td>100</td>
</tr>
</tbody>
</table>

* Combined nebulized medications included dornase alpha, inhaled tobramycin, and albuterol.

Adherence rates were not reported for measurement methods in which five or fewer participants provided data (e.g., nebulized bronchodilators).
Mean age of participants with CF was 10.1 years (S.D. = 2.5), 49% were females and 89% were Caucasian, 3% African American, 3% Hispanic, and 5% Others. Average FEV₁ % predicted and FEF₂₅–₇₅ for the sample was 79.6 (S.D. = 20.8) and 72.2 (S.D. = 32.8), respectively. About 66% of the sample was classified as having mild disease, 28% moderate disease, and 6% severe disease. Median family income for the CF sample was $30,000–49,999 US dollars, which is in the lower, middle income bracket.

3.2. Rates of adherence for CF

Descriptive data regarding rates of adherence for CF are presented in Table 1. For example, rates of adherence for duration of airway clearance in CF ranged from 64% to 74% depending on the measure. For nebulized medications, which included a combination of nebulized bronchodilators (e.g., Albuterol), dornase alpha, and inhaled tobramycin, adherence rates ranged from 48% (diary) to 82% (parent self-report). However, examination of specific nebulized medications indicated that adherence rates ranged from 57% to 90% for dornase alpha and from 36% to 85% for inhaled tobramycin. Adherence for vitamins, which included ADEK, multivitamins, and specific vitamins (e.g., Vitamin K) was quite variable and ranged from 22% (diary data) to 94% (child self-report). Similarly, great variability in adherence rates was found for enzymes, from 27% (diary data) to 90% (child self-report).

Overall rates of adherence were calculated across all treatments, with the exception of electronic monitoring because it was only assessed for one treatment component (e.g., enzymes) (see Fig. 1). As predicted, overall mean rate of adherence for CF using objective measures (e.g., pharmacy refill history, diary data, and electronic monitoring) was below 50%. In comparison, self-reported adherence by both parents and children was approximately 80%. These data confirmed the hypothesis that rates of adherence, on average, would be less than 50% for children with CF.

3.3. Convergence between measures of adherence

Because electronic monitoring was available for enzymes, convergence between the measures was examined with this particular medication. A subsample of patients, for whom data was available across all four methods, was utilized in these analyses. Pairwise comparisons of adherence rates were conducted using a Wilcoxon Signed Ranks test. A significant difference was found between parent-reported adherence and more objective measures, with parents reporting higher adherence rates compared to pharmacy refill history, diary data, and electronic monitoring (p values < .05) (see Fig. 2).

4. Discussion

Tremendous variability in rates of adherence was found across measurement methods. Diary data indicated that adherence to airway clearance was approximately 51% for frequency and 64% for duration of treatment. These results are better than those reported in other studies [2,3], which is encouraging since this is a critically important aspect of treatment for CF. In contrast, diary and electronic monitoring data indicated poor adherence to enzymes (27%–43%), which is a serious problem given the importance of nutrition and weight gain for health outcomes in children with CF [33]. Low adherence to pancreatic enzymes can result in both short-term symptoms, such as gas, diarrhea, and cramping, as well as long-term consequences, such as poor growth and increased rates of pulmonary exacerbations [34]. In addition, low adherence was found for vitamins based on

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1 Child self-reported adherence was not included due to small sample size.
more objective measures, suggesting that children with CF may be lacking the vitamins and minerals necessary for optimal health. These data underscore the importance of examining adherence to each treatment component. Future intervention studies may want to emphasize the importance of enzyme medications for children with CF, given the positive relationship between good nutrition and maintenance of lung functioning. Overall, these results suggest that adherence to one component of treatment does not necessarily equate to all components of the regimen.

When examining overall rates of adherence, significant differences were found by measurement method. Self-report measures substantially inflated rates of adherence, whereas more objective measures (e.g., diary data, pharmacy refill history) revealed rates of adherence below 50% for children with CF. Low rates of adherence in CF are most likely due to the time-intensive, complex nature of the regimen, with children in the current study completing approximately seven treatments daily. Concerns about adherence have spurred new efforts to reduce the time and complexity of medical regimens for patients with chronic illnesses. For example, dry powder formulations of antibiotics and new nebulizers are in development which can deliver medications in 2 to 5 min, instead of the usual 15 to 20 min.

A single, primary medication (e.g., enzymes) was used to examine convergence between the four measures of adherence, with electronic monitoring identified as the “gold” standard. Results indicated that both pharmacy refill history and diary data were comparable to electronic measures. Conversely, parent-reported adherence was markedly inflated compared to these more objective measures. These data indicated that in the absence of electronic data, diaries and pharmacy refill history generally provide a good estimate of adherence.

The multi-method measurement approach provided unique information regarding rates of adherence by treatment component. As in prior studies [13], parent and child self-reported adherence was consistently higher than adherence documented with other measurement methods. These findings suggest that reporting biases and recall problems may strongly influence self-report methods. For example, parents may want to “please” their health care team by appearing to follow the treatment regimen and they may also have difficulty remembering exactly what treatments they have performed. Physicians may also be reluctant to probe patients/parents more deeply about their actual adherence because it can jeopardize their patient-physician relationship. Similar dilemmas face the healthcare team collecting pharmacy records or electronic data in the context of routine clinical care. In our experience, across several large adherence trials [32,35], families have been willing to accept both pharmacy data collection and electronic monitoring in the context of research. However, before implementing these measures in routine CF clinical care, healthcare teams may want to openly discuss adherence and barriers to effective disease management with patients and family members [20]. Ideally, these discussions should be part of every clinic visit to normalize difficulties with adherence and to facilitate physician referrals to appropriate specialists with training in behavioral techniques. To date, little is known about how patients with CF would respond to these discussions during routine clinic visits, however, in other chronic conditions, such as diabetes, adherence monitoring is part of standard clinical care (i.e., downloading of blood glucose meters) [36].

In this study, parents of children with CF reported rates of adherence that were double of those obtained with electronic monitors. Although self-report was inflated compared to other measurement methods, good convergence was found between parent and child reports of overall adherence, suggesting that parents and children tend to agree about the management of their treatment regimen. One potentially important next step is to improve self-report measures of adherence in the following ways: 1) Use more supportive, non-judgmental language and reassure families that the information is being utilized to help them better manage the child’s disease, 2) Assess adherence over a specific and reasonably short period of time (e.g., 1 week), 3) Provide anchors in the context of daily routines to promote better recall of adherence behaviors (e.g., treatments before or after school), 4) Conduct cognitive interviews with families to assess how they formulate their estimates of adherence, and 5) Have frequent discussions with healthcare providers to normalize the challenges associated with managing complex, chronic diseases and problem-solve the specific barriers encountered by that family [37]. One promising finding is that the diary data in this study, obtained in an unobtrusive manner, is a form of self-report that provided more accurate rates of adherence than more traditional paper-pencil self-report methods.

Although using a multi-method approach is often recommended in the literature [1], it should be acknowledged that it increases the complexity of both the analyses and interpretation. Further, these methods often utilize different time frames and yield different results, making it difficult to obtain a unitary rate of adherence. Given the infancy of adherence measurement in pediatric chronic illness, the multimethod approach is still probably the best one to use, despite its complexities [13]. Of the more objective measurement methods, diary data in comparison to electronic monitors offered the most comprehensive method for measuring all of the components of the treatment regimen. Electronic monitors are expensive and have limitations, ranging from technical difficulties (e.g., malfunctioning batteries) to being misplaced by patients. These problems result in both the loss of valuable data and expensive equipment.

Although this study presented an innovative method for measuring adherence, several limitations were noted. First, although the multi-method approach is ideal, as noted earlier, different measurement methods use different time
scales (e.g., continuous data for electronic monitors and 2- to 3-day period for diaries), making comparisons across methods more difficult to interpret. Second, prescribed treatment regimens for children with CF change frequently, making it difficult to measure adherence over time. For example, as children begin to experience symptoms of infection or significant wheezing, physicians may prescribe antibiotics or oral steroids for a brief period of time. Measuring adherence to these critical, but short-term medications is important, but often neglected in adherence research. Another limitation was determining the prescribed treatment regimen for patients due to poor documentation in medical charts. Without a prescribed treatment plan, it is nearly impossible to calculate rates of adherence for these patients. Finally, it is important to note the statistical and sample size limitations of the current study. Because each child had a slightly different treatment regimen, the sample sizes varied across measurement method. As a result, descriptive analyses were utilized instead of formal statistics in examining rates of adherence using the four measurement methods. Although small samples are a common problem in adherence research, the results of this study are quite similar to those of other studies [6,35].

In summary, the results of this study highlight the need to examine adherence by treatment component. Recent studies have also begun to examine barriers to adherence by treatment component to gain a better understanding of what makes treatment difficult for families of children with chronic illnesses [37]. Combined, these data will enable healthcare teams to provide effective individualized interventions to improve adherence behaviors.

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References


